

**“We got cancer”- A mixed methods study of quality of life and psychological distress in head and neck cancer patients and their families**

**Farah Shiraz**

**Submitted in partial fulfilment of the requirements of the Degree of Doctor of Philosophy**

**Centre for Psychiatry  
Wolfson Institute of Preventive Medicine  
Barts and The London School of Medicine and Dentistry  
Queen Mary University of London**

I, Farah Shiraz confirm that the research included within this thesis is my own work or that where it has been carried out in collaboration with, or supported by others, that this is duly acknowledged below and my contribution indicated. Previously published material is also acknowledged below.

I attest that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge break any UK law, infringe any third party's copyright or other Intellectual Property Right, or contain any confidential material.

I accept that the College has the right to use plagiarism detection software to check the electronic version of the thesis.

I confirm that this thesis has not been previously submitted for the award of a degree by this or any other university.

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without the prior written consent of the author.

Signature:

Date:

Details of collaboration and publications:

Shiraz, F., Rahtz, E., Bhui, K., Hutchison, I., & Korszun, A. (2014). Quality of life, psychological wellbeing and treatment needs of trauma and head and neck cancer patients. *British Journal of Oral and Maxillofacial Surgery*, 52(6), 513–517

# Acknowledgements

This project could have not been completed without the help of so many individuals.

First, I would like to start with thanking all the patients and families I had the pleasure of meeting and who agreed to take part in this study. Without them, this project would have not been possible and am truly humbled by their willingness to give up their time at one of the most difficult periods in their lives.

I would also like to thank saving faces for funding the study, particularly Iain Hutchison for his ongoing enthusiasm and support. Also, thank you to the Head and neck cancer clinical teams at Barts and UCLH, particularly Simon Whitley, Mike Dilkes, Leo Cheng, Peter Hardee, Amen Sibtain Nick Kalavrezos, Colin Liew, Luke Williams and Dawn Carnell for their in help in recruitment and follow up of patients. Also, I am extremely grateful to Mustansir Alibhai for his help in recruiting patients but also assisting with clinical data collection. Thank you to Karly Tang, Sujithaan Yoganathan, Fionnuala Daly, Ayesha Ahmedabdi for their help in data entry.

To my supervisors, Ania Korszun and Kam Bhui, I would like to thank them for their guidance and encouragement throughout the PhD. Thank you to Stephen Stansfield for welcoming me to the department, and all the staff at centre for psychiatry; Amarjit, Jane, Lisa Kass, Lisa Coward for all their help and support. I would also like to thank Mel Smuk and Joan Morris for their statistical input and being so generous with their time. Thank you to my office colleagues Neil, Emmy, Amanda and Ann- Marie for being continually supportive and making the office the perfect PhD environment.

None of this would have been possible without anyone I have already mentioned but I would like to finish by thanking my friends and family, particularly my mum who kept me well fed in the final stages. My friends, for putting up with me talking about head and neck cancer at every party, and wedding I've attended since 2011. Thank you to Noreen, Debi, and Charlotte, for keeping me smiling (and sane) particularly in the final stages, your words and encouragement got me through. And finally to my father who was the inspiration and drive for me to do this research.

Many thanks to you all

# Abstract

**Title:** “We got cancer”- A mixed methods study of quality of life and psychological distress in head and neck cancer patients and their families

**Background:** A diagnosis of cancer and its subsequent treatment can have a profound impact on the quality of a person’s life, as well as on the lives of their partners and family members. While the role of families as a source of support is generally recognised, very little is known about the effect that a partners’ or family members’ distress levels may have on Head and Neck Cancer (HNC) patients’ quality of life (QoL).

**Aims:** The aims of this thesis were; 1) to measure the levels of psychological distress of HNC patients and their partners and other family members; 2) explore the relationship between partner/family member psychological distress and patient QoL 3) to gain deeper understanding of the lived experiences of HNC couples, with specific focus on patients who had a partner with psychological distress before treatment.

**Method:** This mixed methods longitudinal study recruited 90 newly diagnosed HNC patients and 74 caregivers (partners n=50, family members n=24) which were followed over a period of 6-12 months. They completed the hospital and anxiety scale (HADS) and the WHO Quality of Life-BREF (WHOQOL-BREF) questionnaires before treatment and at 6 months following diagnosis. The qualitative phase of the study was completed 12 months following diagnosis, where a subsample of three HNC couples were purposively selected and interviewed about their experiences of HNC.

**Results:** There were three key findings within the present study. Firstly, psychological distress in caregivers, particularly partners was higher than in HNC patients. Secondly, HNC patients who had a caregiver with psychological distress showed lower QoL and finally, the qualitative study showed the negative impact of HNC on the patient-partner relationship.

**Conclusions:** What this study has shown is the importance of the caregiver’s role in HNC, and how their psychological functioning has an effect on the patient’s functioning. If partners or family members are to become active agents of help for the patient, it is proposed they should first be prepared psychologically for the task.

# Table of Contents

<b>Abstract.....</b>	<b>3</b>
<b>Overview of thesis chapters .....</b>	<b>12</b>
<b>Introduction to thesis.....</b>	<b>14</b>
<b>1 Literature review .....</b>	<b>15</b>
1.1 Head and neck cancer .....	16
1.1.1 How common is head and neck cancer and who gets it?.....	17
1.1.2 What are the risk factors for head and neck cancer?.....	19
1.1.3 How does head and neck cancer present? .....	20
1.1.4 Medical and surgical treatment .....	21
1.1.5 Prognosis.....	22
1.1.6 Summary of head and neck cancer .....	23
1.2 Head and Neck Cancer, and QoL.....	24
1.2.1 What is QoL? .....	24
1.2.2 Literature measuring HRQOL in HNC .....	25
1.2.3 World Health Organisation QoL measure- WHOQOL-BREF.....	28
1.2.4 Summary of HNC and QOL .....	30
1.3 Psychological distress and Head and Neck Cancer .....	31
1.3.1 Defining psychological distress in cancer.....	31
1.3.2 Depression disorder v. depressive symptoms .....	31
1.3.3 Measuring psychological distress in cancer .....	33
1.3.4 Psychological distress in HNC patients .....	33
1.3.5 Impact of psychological distress on Patient QoL .....	36
1.3.6 HNC specific factors contributing to psychological distress .....	36
1.4 Psychological impact of Cancer on Caregivers - Partners and Family members .....	39
1.4.1 Prevalence of psychological distress in caregivers .....	39
1.4.2 Why are caregivers showing higher psychological distress then patients?.....	40
1.4.3 Effects of cancer on caregivers .....	43
1.5 Conclusions .....	45
1.6 Overall literature review conclusions .....	46
1.7 Aims and Hypotheses.....	47
<b>2 Method .....</b>	<b>48</b>
2.1 Research Design.....	49
2.2 Ethics.....	49

2.2.1	Head and neck cancer clinics .....	49
2.2.2	Inclusion and exclusion criteria.....	49
2.2.3	Sample inclusion / exclusion criteria .....	50
2.3	Self-report Measures .....	51
2.3.1	WHOQOL-BREF.....	51
2.3.2	Hospital Anxiety and Depression Scale (HADS).....	52
2.4	Demographic and medical information .....	54
2.4.1	Socio-demographic .....	54
2.4.2	Clinical variables.....	54
2.4.3	Surgery specific variables .....	54
2.5	Procedure.....	55
2.5.1	Timing of Questionnaires .....	55
2.6	Statistical Analysis.....	60
<b>3</b>	<b>Results .....</b>	<b>61</b>
3.1	Quantitative Results.....	62
3.1.1	Subsample:.....	66
3.2	Prevalence of psychological distress in HNC patients, partners and Caregivers .....	69
3.2.1	Prevalence psychological distress in HNC patients before treatment.....	69
3.2.2	Patient Gender and psychological distress before treatment .....	69
3.2.3	Prevalence psychological distress in caregivers of HNC patients before treatment ....	70
3.2.4	Comparing prevalence of psychological distress between HNC patients and their partners before treatment.....	71
3.2.5	Comparing prevalence rates of psychological distress within caregivers .....	74
3.2.6	Prevalence levels of psychological distress in participants who completed HADS at two time points .....	75
3.2.7	Prevalence rates in HNC patients before treatment and 6-12 months following treatment.....	75
3.2.8	Prevalence of psychological distress in caregivers before treatment and 6-12 months following treatment .....	76
3.2.9	Prevalence of psychological distress in HNC Couples before treatment and 6-12 months following treatment.....	77
3.2.10	Summary of prevalence of psychological distress .....	79
3.3	The association of patient and caregiver psychological distress on HNC patients' QoL .....	80
3.3.1	Descriptive Analysis: Patient QoL and Psychological distress.....	80
3.3.2	Descriptive Analysis: Patient QoL and Caregiver Psychological distress .....	81

3.3.3	Testing the association between patient and caregiver psychological distress before treatment and patient QoL (Testing hypothesis i and ii) .....	82
3.4	Path analysis.....	87
3.5	Mediation Analysis:.....	88
3.6	Does psychological distress before treatment predict QoL 6-12 months following diagnosis? (Longitudinal analysis: testing hypothesis 3 and 4) .....	89
3.6.1	Descriptive analysis: Patient psychological before treatment and patient QoL 6-12 months following diagnosis. ....	89
3.6.2	Descriptive analysis: Caregiver (partner only) psychological distress before treatment and patient QoL 6-12 months following diagnosis. ....	92
3.7	Testing the association between patient psychological distress and caregiver psychological distress before treatment on patient QoL 6-12 months following diagnosis (Testing hypothesis iii and iv) 95	
3.8	Summary of patient and caregiver psychological distress on HNC patients' QoL.....	97
3.9	Role of socio-demographic and Clinical factors on patient QoL.....	99
3.9.1	Descriptive Analysis: Patient QoL and Socio demographic variables .....	100
3.9.2	Clinical variables and Quality of life .....	103
3.9.3	HNC patients QoL before treatment and 6-12 months following diagnosis .....	106
3.9.4	Changes in mean scores of patient QoL by clinical variables .....	106
3.10	Conclusions: Socio-demographic and Clinical factors on patient QoL.....	110
3.11	Overall summary of quantitative findings .....	111
3.11.1	Research aim 1: Summary of prevalence of psychological distress in patients and caregivers .....	111
3.11.2	Research aim 2: Patient and Caregiver psychological distress associated with patient QoL .....	111
3.11.3	Research aim 3: To explore the "lived experiences" of HNC patient-partner couples, where partners reported high levels of psychological distress before treatment (qualitative). 112	
<b>4.</b>	<b>Qualitative study .....</b>	<b>113</b>
4.1	Qualitative study Abstract .....	114
	<b>"We got cancer"- an interpretative phenomenological analysis of lived experience of head and neck cancer patients and their distressed partners .....</b>	<b>115</b>
4.2	Introduction: .....	115
4.3	Qualitative literature review.....	115
4.3.1	Summary of qualitative literature.....	117
4.4	Aims.....	118
4.5	Qualitative Methodology .....	118

4.5.1	What is Interpretative phenomenological analysis (IPA).....	118
4.5.2	Theoretical constructs of IPA.....	118
4.5.3	Why choose IPA?.....	119
4.6	Method .....	120
4.6.1	Participants .....	120
4.6.2	Sample.....	122
4.6.3	Summary of sample .....	122
4.7	Procedure.....	125
4.8	Ethical considerations .....	125
4.9	Interview schedule.....	125
4.9.1	The interview .....	126
4.9.2	Transcription .....	127
4.10	Analysis .....	127
4.11	Qualitative Results .....	128
4.12	Summary of themes:.....	129
4.13	Superordinate theme one: “We got Cancer” .....	130
4.13.1	Coping with the ‘bad news’.....	130
4.13.2	Being the ‘perfect’ cancer partner.....	133
4.13.3	‘Being the perfect cancer patient’ .....	135
4.13.4	Summary of “We got cancer” .....	137
4.14	Superordinate theme two: “It doesn’t shine as bright as it once did” .....	138
4.14.1	‘You don’t give a shit, so why should I?’ .....	138
4.14.2	‘I’m at the end of my tether’ .....	140
4.14.3	Communication and secrecy.....	142
4.14.4	Changes in intimacy .....	146
4.14.5	Summary of “it doesn’t shine as bright as it once did” .....	148
4.15	Superordinate theme three: What would have helped?.....	149
4.15.1	Willingness to accept emotional support .....	149
4.15.2	‘Fear of the unknown’ .....	151
4.15.3	What can we do? .....	152
4.15.4	“What would have helped summary” .....	154
4.16	Summary of Qualitative findings.....	155
4.17	Qualitative Discussion.....	158
4.17.1	Strengths of qualitative study .....	161



4.17.2	Limitations.....	162
4.17.3	Assessing validity.....	163
4.17.4	Implications for clinical practice?.....	165
4.18	Overall Qualitative Conclusions .....	166
<b>5</b>	<b>General discussion.....</b>	<b>167</b>
5.1	Aims and Findings .....	168
5.2	Prevalence of psychological distress in patients and caregivers .....	168
5.2.1	Why is the prevalence of psychological distress higher in caregivers than in HNC patients? .....	169
5.3	Association between patient and caregiver psychological distress and patient QoL.....	170
5.4	Methodological evaluation .....	174
5.5	Data Analysis.....	176
5.6	Measures.....	176
5.6.1	HADS .....	176
5.6.2	WHOQOL-BREF.....	177
5.7	Reflection .....	178
5.8	Future developments in treatment of HNC patients.....	181
<b>6</b>	<b>Final conclusions .....</b>	<b>183</b>
<b>7</b>	<b>References .....</b>	<b>184</b>
<b>8</b>	<b>Appendices:.....</b>	<b>195</b>
8.1	BJOMS Publication .....	196
8.2	Patient and Caregiver, information sheet, Consent form and sample questionnaires .....	203
8.2.1	Patient information sheet.....	204
8.2.2	Patient Consent form.....	209
8.2.3	Caregiver information sheet .....	211
8.2.4	Caregiver consent form.....	215
8.2.5	Example of wellbeing questionnaire which included the HADS, WHOQOL-BREF and Demographics. ....	217
<b>8.3</b>	<b>Qualitative Study appendices .....</b>	<b>223</b>
8.3.1	Step by step IPA analysis.....	223

## Tables

Table 1 Incidence of HNC in UK 2012, with predicted rates for 2015. ....	17
Table 2 “Red flag” symptoms and signs of head and neck cancer .....	21
Table 3 Summary of HRQOL findings in HNC patients.....	25
Table 4 ICD and DSM-IV criteria for depression .....	32
Table 5 Prevalence of psychological distress in HNC patients.....	34
Table 6 Transactional model of stress and coping framework .....	42
Table 7 Physical, Emotional, Social and Burden experienced by partners and family members of cancer patients.....	44
Table 8 Patients inclusion and exclusion criteria for recruitment .....	50
Table 9 Caregiver inclusion and exclusion criteria for recruitment.....	51
Table 10 Socio-demographics of HNC patients (n=90) and Caregivers (n=74) who completed questionnaires before treatment (time point 1) .....	64
Table 11 Clinical information for patient sample who completed time point 1 (N=90).....	65
Table 12 Clinical Variables of HNC patients in who completed both time points (n=59) and non - respondents (n=31).....	67
Table 13 Socio-demographics of HNC patients (n=59) and Caregivers (40) who completed questionnaires at both time points (before treatment and 6-12 months following diagnosis).....	68
Table 14 Prevalence (%) of symptoms of depression, anxiety and total psychological distress before treatment.....	69
Table 15 Odds ratio of psychological distress between patients and partners.....	72
Table 16 Compares prevalence psychological distress in HNC patients who completed HADS before treatment and 6-12 months post treatment (n=59).....	75
Table 17 Prevalence of psychological distress in Caregivers before treatment and 6-12 months following treatment .....	76
Table 18 mean scores of patient QoL by their level of depression and anxiety symptoms (n=90).....	80
Table 19 Before treatment: Mean and SD scores of patient QoL by level of depression and anxiety symptoms caregivers .....	81
Table 20 univariate statistical associations between psychological factors and patient quality of life (outcome).....	83
Table 21 Adjusted $\beta$ model of patient and caregiver depression and QoL domains.....	85
Table 22 shows the unadjusted and adjusted percentage change [95% CI] in physical QoL for patient and caregiver depression (adjusted for patient age and gender). .....	86
Table 23 Showing the association between depression before treatment (time point 1) and quality of life domains 6-12 months following diagnosis (time point 2), n=59. ....	95
Table 24: Showing the association between depression in HNC couples and quality of life 6-12 months following diagnosis, n=30. ....	96
Table 25 Socio-demographics and HNC patients’ Quality of life before treatment (n=90) Mean and SD of WHOQOL-BREF domains .....	100
Table 26 univariate linear regression model of statistically significant socio-demographic variables and patient QoL before treatment .....	101
Table 27 Clinical variables and HNC patients’ Quality of life: Mean and SD of WHOQOL-BREF domains before treatment .....	103

Table 28 shows the mean, median and SD of changes in patients scores before treatment and 6-12 months post diagnosis: (N=59) .....	106
Table 29 Descriptive statistics (N, Mean and standard deviation) showing HNC patient QoL by clinical variables over two time points (n=60) .....	107
Table 30 Participant demographics and clinical details including scores of psychological distress ...	124
Table 31 interview schedule topic guide .....	126
Table 32 Master themes and subthemes from IPA analysis.....	129
Table 33: General methods recruitment challenges .....	178
Table 34 Six stages of IPA analysis .....	224
Table 35: Step 2 initial note taking, extract from case study 2.....	225
Table 36: Step 3: Developing emergent themes.....	226
Table 37: STEP 4: Searching for connections cross emergent themesTable 37 Searching for connections across themes “it doesn’t shine as bright as it once did” .....	227
Table 38 Master table of themes including description of each theme and subtheme.....	231

## Figures

Figure 1 Head and neck cancer regions .....	16
Figure 2 Predicted incidence rates of HNC by Gender (2015) .....	18
Figure 3 WHOQOL-BREF: Diagram showing each facet that makes up the four domains of QoL of WHOQOL-BREF questionnaire(Skevington, Lotfy, & O’Connell, 2004, p. 307) .....	29
Figure 4: Leventhal self-regulation model (1984).....	38
Figure 5 Four QoL domains of WHOQOL-BREF questionnaire .....	52
Figure 6 Hospital anxiety and Depression Scale: Subscale and Items .....	53
Figure 7 consort diagram of participant recruitment .....	56
Figure 8 Step by step process of participant recruitment .....	57
Figure 9 Questionnaires completed by HNC patients at Time point 1 and Time point 2 .....	58
Figure 10 Questionnaires completed by Caregivers of HNC patients before treatment (time point 1) and 6-12 months following treatment (time point 2). .....	59
Figure 11 Caregiver sample n=74.....	63
Figure 12 Male and Female HNC patients showing high symptoms of depression, anxiety and total psychological distress before treatment (n=90). .....	70
Figure 13 Prevalence of high symptoms of depression, anxiety and total psychological distress before treatment in patients (n=90) and caregiver sample (n=74) .....	71
Figure 14 Prevalence of psychological distress in HNC patients and their Partners before treatment73	
Figure 15 Prevalence of psychological distress in partners of HNC patients compare d to family members of HNC patients.....	74
Figure 16 Changes over time in the % prevalence of high HADS scores in HNC couples (n=30).....	78
Figure 17 Path analysis diagram showing the associations between patient depression, caregiver depression and patient physical QoL.....	87
Figure 18 Standardised regression coefficients for the relationship between patient depression and patient physical quality of life as mediated by caregiver depression.....	88

Figure 19 changes over time in PHYSICAL QoL in patients with high depression compared with patients with low depression scores. ....	90
Figure 20 changes over time in PSYCHOLOGICAL QoL in patients with high depression scores before treatment.....	90
Figure 21 changes over time in SOCIAL RELATIONSHIPS in patients with high depression scores before treatment .....	91
Figure 22 changes over time in ENVIRONMENT QoL in patients with high depression scores before treatment.....	91
Figure 23 changes over time in patients PHYSICAL QOL by PARTNER depression scores before treatment.....	92
Figure 24 changes over time in patients PSYCHOLOGICAL QOL by PARTNER depression scores before treatment.....	93
Figure 25 changes over time in patients SOCIAL RELATIONSHIPS by PARTNER depression scores before treatment .....	94
Figure 26 changes over time in patients ENVIRONMENT QOL by PARTNER depression scores before treatment.....	94
Figure 27 Clinical Variables and Patient QoL before treatment: Site of Cancer .....	104
Figure 28 Mean scores of stage of cancer and patients QoL before treatment (n=90) .....	105
Figure 29: Eligible participants for Qualitative recruitment .....	121
Figure 30: An Exploratory model showing the impact of HNC on patients and their partners.....	156



## Overview of thesis chapters

### **Chapter 1: Literature review**

Chapter one presents an overview of Head and neck cancer (HNC), followed by an introduction to quality of life (QoL) and how it is currently measured within the HNC field. This chapter also introduces the current literature that has examined psychological distress in cancer patients, including the most up to date literature which has examined psychological distress in HNC patients. This chapter also presents the literature that has examined the impact of cancer on caregivers (family members and partners). The aim of this chapter is to introduce the rationale for the hypotheses and methodology.

## **Chapter 2: Methods**

Chapter two introduces the sample, research design, study protocol including the data collection procedures, and details of the clinics patients were recruited from. It also presents the measures used to collect data and the statistical analyses that were used to analyse the data.

## **Chapter 3: Results**

Chapter three presents the quantitative findings of this thesis. It begins by introducing the dataset, followed by results showing the prevalence of psychological distress in patients and their caregivers, and findings related to the proposed hypothesis.

## **Chapter 4: Qualitative study**

This chapter is specifically focused on the qualitative component of this thesis and includes; a review of the current qualitative literature within HNC, an introduction to the qualitative method used in the study and details how participants were selected to take part. The chapter also presents an overview of each participant that was interviewed, and presents how the interview data was recorded and analysed. The results of the analysis are presented, followed by a discussion of the key findings including an evaluation of the qualitative methodology.

## **Chapter 5: Overall Discussion**

This final chapter discusses the overall conclusions that can be drawn from the quantitative and the qualitative results of this study. A summary of the key findings are presented and how these relate to the original aims of the thesis. The methods are also critically discussed with suggestions to possible improvements. Finally, a discussion of the clinical significance of the results with reference to future proposed clinical interventions for patients and their caregivers are reported.

## Introduction to thesis

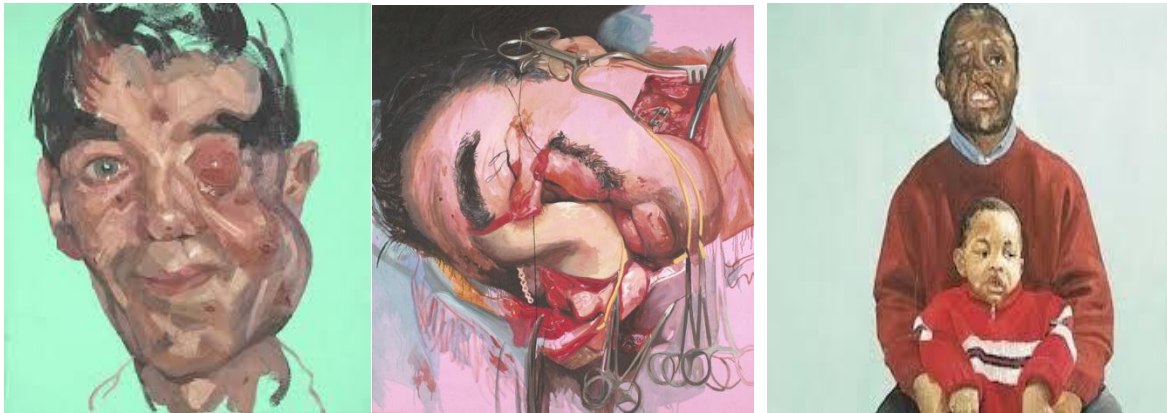
*“To have and to hold, from this day forward, for better, for worse, for richer, for poorer, in sickness and in health, to love and to cherish, till death do us part, and here I pledge you my faithfulness”*

The real power of these words may not be fully appreciated until a traumatic event, like cancer, brings a deeper meaning to these vows and challenges a couple’s relationship. When an individual is diagnosed with cancer, the partner is usually counted upon to become the primary helper. The well partner is expected to offer emotional support, adapt to the lifestyle changes brought about by the illness and be sensitive to the needs of the patient. These are high expectations that many partners want to meet, but may not be fully capable of doing so.

The overall aim of this thesis is to provide a multi-dimensional insight into head and neck cancer (HNC) patient’s quality of life (QoL), which is currently lacking in the literature. The aim is to go beyond the traditional concept of QoL which currently focuses primarily on the measurement of symptoms and disability - commonly referred to as health related QoL (HRQOL).

I aim to highlight and introduce the broader impact of HNC on the QoL of patients such as social relationships, psychological impact, environmental factors and how the effect of cancer on family and partners can have a negative impact on patients.

This will be achieved using a mixed methods approach, where quantitative measures and qualitative interviews will be utilised to examine the impact of HNC on patients QoL. This project introduces a holistic method to examining QoL in HNC patients, defining QoL as a state of physical, mental and social wellbeing, not just the absence of disease and ill-health.



## 1 Literature review

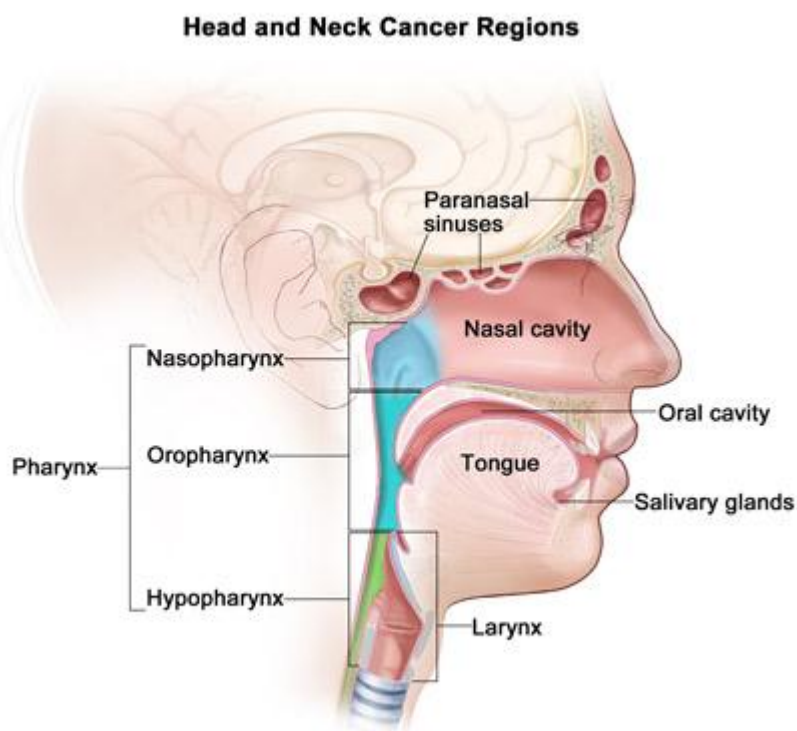
I begin this chapter by presenting an overview of Head and neck cancer (HNC), followed by the current quality of life literature within this field. I will also introduce the prevalence of psychological distress in cancer patients, including the most up to date literature which has examined psychological distress in HNC patients. Finally I will present the literature that has examined the impact of cancer on caregivers (family members and partners). The aim of this chapter is to introduce the rationale for the hypotheses and methodology. The review is limited to areas relevant to the thesis title. However, where only limited data exist on HNC, results from heterogeneous cancer groups are also included.



## 1.1 Head and neck cancer

Head and neck cancer include malignancies that arise on the lips and in the mouth, pharynx (including the nasopharynx, oropharynx and hypopharynx), larynx, salivary glands, and paranasal sinuses (see Figure 1). Cancers at different sites have different course and variable histopathological types, although squamous cell carcinoma (SCC) is by far the most common (Mehanna, De Boer, & Morton, 2008). The anatomical sites affected are important for functions such as speech, swallowing, taste and smell, so the cancers and their treatment may have considerable functional sequelae with subsequent impairment of quality of life (QoL). Decisions about treatment are usually complex, and treating clinicians must balance efficacy of treatment and likelihood of survival with potential functional and QoL outcomes. Patients and their carers will often also need considerable support during and after treatment (Hodges & Humphris, 2009).

**Figure 1 Head and neck cancer regions**



1

<sup>1</sup> Image and extracted from <http://www.cancer.gov/cancertopics/factsheet/Sites-Types/head-and-neck>

### 1.1.1 How common is head and neck cancer and who gets it?

In 2012, the World Health Organisation (WHO) estimated that there were approximately 750,000 new cases of head and neck cancer and approximately 300,000 deaths each year worldwide (Ferlay et al., 2014). In the UK, there were just over 9000 new HNC cases (larynx, lip and oral cavity, nasopharynx and other oropharynx), with the most common sites being the oral cavity (3,137 cases a year). Table 1 reports the incidence of HNC in 2012, with predicted rates of incidence for 2015 (GLOBOCAN 2012, WHO)

**Table 1 Incidence of HNC in UK 2012, with predicted rates for 2015.**

	HNC Cancer (larynx, lip and oral cavity, nasopharynx and Other oropharynx)			
Year	Estimated number of new cancers (all ages)	Male	Female	Both sexes
2012		6811	2885	9696
	ages < 65	3619	1374	4993
	ages >= 65	3192	1511	4703
<sup>2</sup> 2015		7132	2992	10124
	ages < 65	3659	1391	5050
	ages >= 65	3473	1601	5074
	Demographic change	321	107	428
	ages < 65	40	17	57
	ages >= 65	281	90	371
	GLOBOCAN 2012 (IARC), WHO			

<sup>2</sup>The table and figures were created using the GLOBOCAN 2012, cancer incidence and mortality cancer register <http://globocan.iarc.fr>

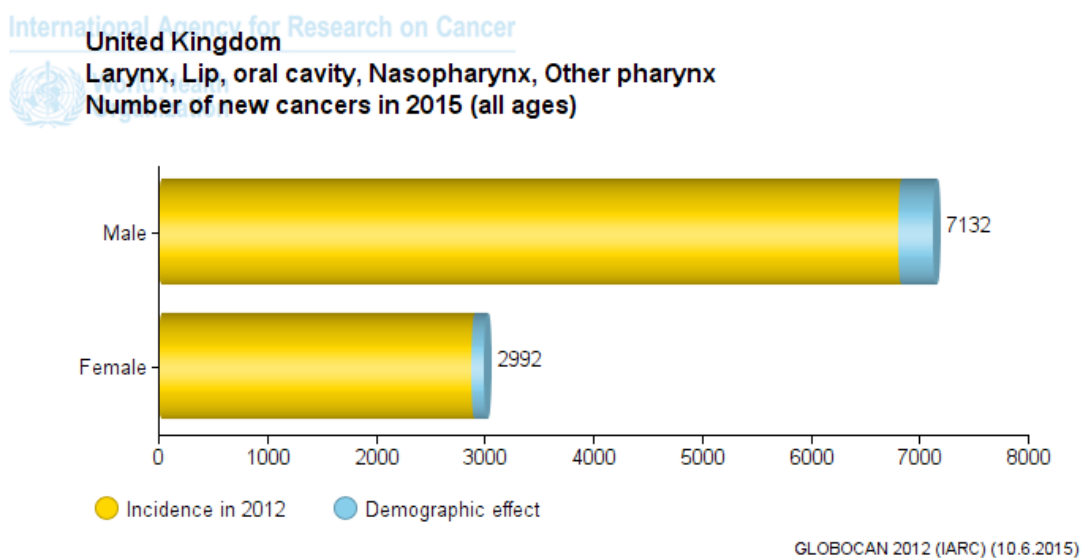
GLOBOCAN uses population forecasts from the United Nations, World Population prospects, the 2012 revision. Numbers are computed using age-specific rates and corresponding populations for 10 age-groups.

The male to female ratio reported by large epidemiological studies and national cancer registries varies but generally is from 2:1 to 4:1 depending on the site of the disease (WHO, 2008). However, within the oral cavity which is the most common within the UK, around 67% are diagnosed in men with 33% in women, giving a male: female ratio of around 2:1 (Ferlay et al., 2014).

Figure 2 shows the predicted incidence rate for 2015 in males and females.

The incidence of HNC has plateaued in many parts of the world but sub-types, such as oral and oropharyngeal cancer, continue to increase, both in the UK and worldwide.

**Figure 2 Predicted incidence rates of HNC by Gender (2015)**



Several retrospective analyses from patients recruited in randomised trials as well as retrospective studies have shown recent changes in the epidemiology and pathogenesis of head and neck cancers related to the human papillomavirus, (HPV), especially oropharyngeal carcinoma (Duvvuri & Myers, 2009), for example, the UK has seen a doubling in the incidence of oropharyngeal cancer from 1/100 000 population to 2.3/100 000 in just over a decade (Oxford Cancer Intelligence Unit, 2010). This significant increase in HPV associated HNC cancers may explain the increase in predicted rates reported in Table 1 and

Figure 2. HPV associated cancers tend to occur in people who are younger than the average person with HNC, and have an overall better response to treatment and prognosis (Pulte & Brenner, 2010).

## **1.1.2 What are the risk factors for head and neck cancer?**

### **1.1.2.1 Tobacco and Alcohol**

The major risk factors include; tobacco (smoking), smokeless tobacco (chewing, powdered, inhaled) areca nut consumption (itself a carcinogen) and alcohol (Purdue et al., 2009)

Tobacco has been shown to significantly increase the risk of cancer of the mouth, with a particularly high incidence in South Asia (India, Pakistan, Bangladesh), where tobacco, areca and slaked lime are held in the mouth as the betel quid or 'paan'(Conway et al., 2009). Smoking is more strongly associated with laryngeal cancer and alcohol consumption with cancers of the pharynx and oral cavity. In general, smokers are 10-times more likely to get HNC compared to never-smokers (Argiris, Karamouzis, Raben, & Ferris, 2008; Conway et al., 2009) but this is as high as 27 times in oral squamous cell carcinomas and 12 times in laryngeal SCC (Argiris et al., 2008).

Heavy alcohol consumption is also an independent risk factor and alcohol and tobacco can synergistically interact to increase risk. Purdue and colleagues (2009) pooled data from 15 case-control studies of HNC (9,107 cases, 14,219 controls) and showed that non-smokers who have three or more alcoholic drinks (beer or spirits) a day had double the risk (odds ratio 2.04, 95% confidence interval 1.29 to 3.21) of developing the disease compared with non-drinkers (Purdue et al., 2009).

### **1.1.2.2 Genetic factors**

Most people who smoke and drink do not develop HNC. The International Head and Neck Cancer Epidemiology Consortium (INHANCE) carried out pooled analyses of epidemiological studies that examined risks associated with the disease. This work confirmed the role of genetic predisposition that had been suggested by small studies. Their findings showed a family history of head and neck cancer in a first degree relative was associated with a 1.7 fold (1.2 to 2.3) increased risk of developing the disease (Conway et al., 2009).

### **1.1.2.3 Viral infection**

As highlighted earlier, HPV has attracted significant attention in the last decade, with recent observational studies showing this virus as a strong risk factor for the development of HNC, especially oropharyngeal cancer. A multinational observational study that compared 5642 cases of HNC with 6069 controls found the risk of developing oropharyngeal carcinoma was associated with; a history of six or more lifetime sexual partners, four or more lifetime oral sex partners and earlier age of first sexual intercourse. Patients are generally younger (usually 40-50 years old) and often do not report the usual risk factors of smoking or high alcohol intake and often will present with a small primary tumour and large neck nodes (Pulte & Brenner, 2010).

#### **1.1.2.4 Other risk factors**

Some evidence also points to a role of occupational exposure, poor dental hygiene and dietary factors such as low fruit and vegetable intake (Argiris et al., 2008; Conway et al., 2009).

#### **1.1.3 How does head and neck cancer present?**

Patients with HNC present with a variety of symptoms, depending on the function of the site where they originate. Laryngeal cancers commonly present with hoarseness, whereas pharyngeal cancers often present late with dysphagia or sore throat. Patients with early disease stand a better chance of cure or increased survival. However one of the major issues associated with HNC is that in the early stages, it may be asymptomatic, meaning patients are more likely to present with more advanced disease stage (Hiten, 2012).

Table 2 identifies “Red flag” signs and symptoms that practice guidelines consider warranting urgent referral and consultation with a specialist head and neck clinician. UK guidelines specify that urgent referral should mean that patients are seen within two weeks.

<sup>3</sup>Table 2 “Red flag” symptoms and signs of head and neck cancer

Symptoms
Sore throat
Hoarseness
Stridor
Difficulty in swallowing
Lump in neck
Unilateral ear pain
Signs
Red or white patch in the mouth
Oral ulceration, swelling, or loose tooth
Lateral neck mass
Rapidly growing thyroid mass
Cranial nerve palsy
Orbital mass
Unilateral ear effusion

(Scottish Intercollegiate Guidelines Network (SIGN) & Network, 2006, pp. 6–8)

#### 1.1.4 Medical and surgical treatment

The treatment plan for an individual patient depends on a number of factors, including the exact location of the tumour, the stage of the cancer, and patient age and general health. Treatment modalities can include surgery, radiation therapy, chemotherapy, targeted therapy, or a combination of treatments (Jacobi, Van Der Molen, Huisken, Van Rossum, & Hilgers, 2010).

For anatomical sub-sites such as the oral cavity, salivary glands and sinuses, surgery is often the first line of treatment, with radiotherapy given post-operatively to optimise tumour control (Bonner et al., 2010). Although treatment varies by sub-site, the goal of organ preservation is always important because crucial functions such as speech and swallowing are often at risk (Jacobi et al., 2010; Rogers et al., 2003). The negative impact upon these functions may be as important as the cancer itself in terms of impact on QoL.

---

<sup>3</sup> “Red flag symptoms have been extracted from the Scottish Intercollegiate Guidelines Network (SIGN) & Network, 2006(Scottish Intercollegiate Guidelines Network (SIGN) & Network, 2006)

#### **1.1.4.1 Side effects of treatment**

**Radiotherapy:** The systematic clinical investigation of organ-preserving radiotherapy and chemo radiotherapy regimens suggested that these regimens could produce overall survival results as good as surgical resection for patients with loco regionally advanced squamous-cell cancer of the head and neck (Bonner et al., 2010). Despite these advances, treatment side effects are often significant and life changing. These can include; substantial or permanent reduction in salivary production leading to a chronic dry mouth (xerostomia), swallowing difficulties (dysphagia), and altered or diminished taste (dysgeusia). Also, radiation-related swelling and fibrosis can cause airway problems resulting in tracheostomy dependence (Chen et al., 2012). The interaction of certain factors, such as chemotherapy, may amplify adverse effects of treatment and persist for long durations if chemotherapy is delivered concurrently with radiation (Epstein, Robertson, & Emerton, 2001; Magné et al., 2001).

**Surgery:** Advances in surgical treatment and reconstructive techniques have enabled enormous improvements in functional and cosmetic outcomes (Wehage & Fansa, 2011). However, surgery still imposes its own long- term problems. Profound alterations in QoL often result from undesirable cosmetic outcomes related to the surgical removal of cancer and organ tissue (e.g. eyes, nose, larynx, tongue and facial skin, mandible) and reconstruction with regional or free-flaps, resultant scarring of the head, neck and donor sites, and chronic tracheostomy or tracheostomy dependence (Rogers et al., 2003; Wehage & Fansa, 2011). Facial disfigurement can lead to embarrassment and social avoidance, thereby compromising patients QoL (Minako et al., 2010). Furthermore, reconstructive options include the harvest of tissue from distant sites such as the forearm or the leg, which may further limit function and impact negatively on QoL (Rogers et al., 2003).

#### **1.1.5 Prognosis**

Despite various therapeutic interventions, including surgery, radiotherapy, and chemotherapy, the 5-year survival rate for this HNC has improved only marginally during the past two decades (Leoncini et al., 2015). For patients with disease confined to the head and neck, there are two major and distinct patterns of treatment failures after definitive therapy: recurrence of primary disease (local, regional or distant) and development of second primary cancer. The 5-year survival rate after second primary cancer diagnosis is about 8% if the malignancy is outside the head and neck area, and increased to 30% if the second primary cancer is an HNC. The 5 year survival expectation differs among HNC sites. In a recent study Leoncini and colleagues (2015) found five-year overall survival was 62% for HNC cases, 55% for oral cavity, 53% for oropharynx, 41% for hypopharynx, and 71% for

larynx. About 40 to 60% of HNC patients developed recurrences and around 20% of HNCs develop second primary cancer, both being associated with poorer survival.

In the UK, a recent regional audit presented a one year and three year survival analysis for oral cavity cancer (Oxford Cancer Intelligence Unit, 2010). The 1 year relative survival for patients diagnosed between 2004 and 2011 with oral cavity cancer in England and Wales remained stable at 80% for men and 81% for women in 2011. The 3 year relative survival has significantly improved for men, rising from 58% in 2004 to 2006 to 66% in 2008 to 2010. Over the same time 3 year relative survival also increased for women, from 64% in 2004 to 2006 to 68% in 2008 to 2010 (Oxford Cancer Intelligence Unit, 2010).

#### **1.1.6 Summary of head and neck cancer**

Head and neck cancer presents unique difficulties when compared to other cancers. The face has an integral role in social and emotional expression and communication, and changes in its anatomy or function can have potentially devastating consequences. The main treatment modalities for HNC are surgery, radiotherapy and chemotherapy, and these may be used in combination. These treatments, often extensive, can result in unpleasant side-effects and sequelae. These include extensive soreness and dryness of the mouth and neck, (leading to difficulty with swallowing and speech), limitation in social (and sexual) activities, and feelings of isolation (Mehanna, De Boer, & Morton, 2008). For those patients undergoing surgical treatments there is the additional burden of visible and potentially extensive facial and neck disfigurement, which can be difficult to conceal.

Although the main aim of treatment of any cancer is to prolong life, maintaining and ensuring QoL of patients is as significant. The epidemiology and presentation of HNC appears to be changing, with patients of certain HNC cancers being younger with better survival outcomes. This puts QoL more in the forefront than ever, as individuals undergoing extensive treatment may be faced with the long term effects for longer periods. Therefore, ensuring QoL becomes a significant issue.



## 1.2 Head and Neck Cancer, and QoL

Over the past 30 years, QoL has become a respected construct for evaluating the effectiveness of treatment in healthcare. This is evidenced not only by the significant increase in associated literature, but also by the increased sophistication in its measurement and the increase in the number of QoL questionnaires. Oncology has particularly welcomed it as an essential outcome measure, with treatment considerations often incorporating not only prognosis, but also impact upon patient QoL.

### 1.2.1 What is QoL?

In research, the difficulty lies in the need to define QoL when evaluating health care outcomes, particularly when making judgements and comparisons across disciplines and the recommendations become based on QoL.

The literature contains a bewildering array of definitions, with centrality around health status, physical functioning and symptoms. In mainstream psychology, QoL is defined as a *“conscious cognitive judgment of satisfaction with one's life”*(Pavot, 1993), whereas within medical research the term *health related QoL* (HRQOL) is commonly used which focuses on symptoms, illness and treatment and often neglects the broader constructs such as standard of living, social relationships, psychological impact, and environmental factors.

The World Health Organization (WHO) defines QoL as;

***“Individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the persons’ physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment”***

(The WHOQOL Group, 1998, p. 3)<sup>4</sup>

The significance of this definition is it highlights the subjective concept of QoL, which, as WHO suggests, is embedded in cultural, social and environmental context. The quote clearly indicates a different model of measuring healthcare outcomes, however, the current QoL and HNC literature is

---

<sup>4</sup> Definition extracted- World Health Organization: Measuring QoL, (1997).

still embedded within a medical model of health care, where functional outcomes and clinical measures such as survival and physical functioning take precedence.

Morton, (1995) published a seminal paper highlighting ‘the evolution of QoL in HNC’ (Morton, 1995) and suggested that QoL is frequently referred to and used in HNC, but it is not clearly defined. Similarly, Gotay and Moore believed HNC would benefit from a multidimensional QoL approach, due to the “multitude of its impact of treatment and long term impact on individuals lives post treatment and beyond” (Gotay and Moore; 1992; as cited in Morton. 1995, p. 1029)

*‘While research in QoL is a challenging area, in many ways head and neck cancer is ideally suited to such an endeavour’*, Gotay and Moore (1992; as cited in Morton 1995, p. 1029)

### 1.2.2 Literature measuring HRQOL in HNC

Table 3 summarises 18 studies from 2000-2015 that represent a summary of key findings within the HNC and HRQoL literature.

**Table 3 Summary of HRQOL findings in HNC patients.**

First Authors, year.	Aims of research	Summary of results and principle findings	HRQOL measure
Van Nieuwenhuizen, Buffart, Brug, René Leemans, & Verdonck-de Leeuw, (2015)	Systematic review of and survival in patients HNC, adjusted for important clinical, demographic and lifestyle-related factors (n=19).	Strong evidence for a positive association between pre-treatment physical functioning and survival and between change in global QoL from pre-treatment to 6months after treatment and survival.  Several inconsistent findings, with insufficient evidence for an association with survival of other HRQoL domains, including role, emotional, cognitive and social functioning, mental health and well-being.	review
Bilal, Doss, Cella, & Rogers, (2014)	The study aimed to identify potential socio-demographic and clinical prognostic value of HRQoL in head and neck cancer patients in a developing country	Treatment status, tumour stage and tumour site had the strongest negative impact on patients HRQoL,  Treatment type, marital status, employment status and age were moderately associated with HRQoL.  Weak associated factors of HRQoL with a small effect size included tumour size and type, gender, education level and ethnicity.	<sup>5</sup> (FACT-H&N)
Funk, Karnell, & Christensen, (2012)	HRQOL reported by 5-year head and neck cancer survivors and factors that predicted these long-term scores.	Those who are functioning poorly 1 year after diagnosis were still reporting poor QoL 5 years post treatment. Eating problems, persistent pain were good predictors.	Overall QoL (QOL).
Osthus, Aarstad, Olofsson, & Aarstad, (2011)	To examine the survival prediction of head and neck HRQoL scores among successfully treated and cognitive functioning HNC patients	“feeling ill”, “sexuality”, “open mouth”, “swallowing”, and “pain” specifically predicted survival.	EORTC QLQ- H&N35
Johansson, Rydén, & Finizia, (2011)	HRQOL and survival in patients treated for laryngeal cancer.	Tumour site and stage showed no effect on adjustment response and HRQOL.	EORTC QLQ-C30 + H&N35)

<sup>5</sup> FACT - The Functional Assessment of Cancer Therapy -Head and Neck

Jacobi, Van De Molen, Huiskens, Van Rossum & Hilgersl., (2010)	The effects on voice and speech of advanced head and neck cancer and its treatment by means of chemo radiotherapy (CRT).	Overall, the studies indicated that voice and speech degenerated during CRT, improved again 12 months after treatment and exceeded pre-treatment levels after 1 year or longer. (no baseline measure)	Various outcome measures
Vartanian & Kowalski, (2009)	To evaluate the acceptance of major surgical procedures and QoL among long-term survivors of advanced head and neck cancer	Vast majority of patients considered a radical surgical procedure an acceptable treatment and reported a good QoL. Most patients (91.2%) reported that they would undergo the same treatment if they had it to do again, and 95.6% reported that they would not like to exchange their present outcome for another treatment option with a lower chance of cure but with a possibly improved QoL.	University of Washington QoL Questionnaire (UW-QoL)
Van Der Schroeff, Derks, Hordijk, & De Leeuw, (2007)	HRQOL in HNC patients	No significant differences in survival or overall QOL between older and younger head and neck cancer patients.	EORTC QLQ-C30 and H&N35
García-Peris et al., (2007)	Prevalence of dysphagia in head and neck cancer patients treated with surgery and radiotherapy or chemo-radiotherapy	Dysphagia negatively affects HNC QoL.	Self-report QoL
(Van Der Schroeff et al., 2007)	HRQOL in HNC patients aged 75+.	The survival rate after 3-6 years for younger patients was 36%, as compared to 31% in the older patient group.  Higher tumour stages, more co-morbidity and non-standard treatment showed to be independent prognostic factors for mortality.  No significant differences in survival or overall QOL between older and younger head and neck cancer patients six years following diagnosis.	EORTC QLQ-C30 and H&N35
Chandu, Smith, & Rogers, (2006)	Clinical and socio-demographics factors associated with HRQOL.	Long-term HRQOL of HNC patients seems good with HRQOL at 1 year being equivalent to long-term HRQOL.	review
Mehanna & Morton, (2006)	To assess whether pre-treatment and post-treatment QoL (QOL) is associated with long-term survival in patients with head and neck cancer (over 10 years).	At 10 years, before treatment, patients with low QOL had no significantly increased odds of death. In contrast, after treatment, patients with low QOL at 1 year had significantly increased odds of death even after adjustment for covariates.	Auckland QOL questionnaire before treatment and 12 months
Rogers et al., (2006)	A cross-sectional postal survey was undertaken of patients treated for oral/oropharyngeal squamous cell carcinoma by primary surgery compared to national reference data.	Patients under 60 years of age fared significantly worse than expected for their age but this was not so for older patients.	<sup>6</sup> UW-QoL v4) and the <sup>7</sup> EuroQoL EQ-5D.
El-Deiry et al., (2005)	To compare the long-term, health-related quality-of-life outcomes in patients with advanced head and neck cancer (HNC) treated with surgery and postoperative radiation therapy (SRT) or concurrent chemotherapy and radiation therapy (CRT)	As nonsurgical means of treating HNC have become more aggressive and surgical techniques have become more focused on function preservation and rehabilitation, the overall health-related QoL resulting from these different approaches is similar.	Head and neck cancer-specific health-related QoL from the Head and Neck Cancer Inventory.
Duffy et al., (2002)	The relationship between smoking, alcohol intake, depressive symptoms and QoL in HNC	Smoking was negatively associated with five scales of the SF-36V including Physical Functioning, General Health, Vitality, Social Functioning, and Role-Emotional Health.	SF-36V
Hammerlid & Taft, (2001)	To examine HRQOL of HNC cancer survivors compared with general population norms (Swedish population).	No difference Age and gender with general population, except on the role-physical functioning scale.  Treatment-related side-effects and disease-specific problems (e.g., swallowing, local pain and dry mouth) significantly worse than norm values.  Female HNC patients generally scored better than the norms on both the SF-36 and the EORTC QLQ-C30  Male patients scored significantly worse on most SF-36 scales.	the SF-36 Health Survey (Short Form 36)  EORTC QLQ-C30 and QLQ-H&N35

<sup>6</sup> University of Washington QoL Questionnaire Version 4-UW-QoLv4

<sup>7</sup> EuroQoL EQ-5D.

		<p>Patients over 65 years more often scored worse than the norm than did patients &lt;65.</p> <p>Clinically relevant differences were found on the majority of SF-36 scales in comparison of tumour sites,</p> <p>Patients with small (stage I+II) versus advanced (stage III+IV) tumours revealed few differences.</p> <p>Three years after diagnosis H&amp;N cancer patients still suffer significant functional limitations/problems related to their disease and its treatment but these problems do not generally affect their overall HRQL. Tumour stage no longer differentiates HRQL at 3 years; however, factors related to the patients' age, gender and location of the tumour appear to have bearing on their reported health status.</p>	
De Graeff et al., (2000)	long-term changes of QoL and mood in patients HNC treated with surgery and/or radiotherapy	<p>There was limited deterioration of physical and role functioning and of many head and neck symptoms at 6 months, with improvement thereafter.</p> <p>After 36 months only physical functioning, taste/ smell, dry mouth, and sticky saliva were significantly worse, compared with baseline.</p> <p>Females, higher cancer stage, and combination treatment were associated with more symptoms and worse functioning.</p> <p>Treatment for head and neck cancer results in short-term morbidity, most of which resolves within 1 year.</p>	<sup>8</sup> EORTC & HN35
Weymuller et al., (2000)	To undertake a QOL analysis of head and neck cancer, a disease-specific QOL tool, the University of Washington Quality-of-Life (UW-QOL) questionnaire,	<p>The results of this study demonstrated that the shoulder domain question of the UW-QOL questionnaire was able to discriminate among selective neck dissection, modified radical neck dissection, and radical neck dissection. Similar analysis of other domains (speech, swallowing, etc.) will be much more complex, since the surgical interventions, such as composite resection, are not as well defined as the variations of neck dissection.</p> <p>When patients with advanced oropharyngeal cancer were asked how their health had changed since prior to tumour identification, those who were treated with surgery perceived that their health was better, but those who were treated with chemo radiation perceived that their health was worse.</p>	UW-QOL

Table 3 highlights two main issues of QoL literature in HNC. Firstly, a variety of instruments are being used to measure HRQoL, which predominantly focus on the physical and functional outcomes of patients. This is evidently of significant importance; however it is only presenting a one dimensional view of HNC patients' QoL. Secondly, several inconsistencies exist across the literature, particularly the association between demographic and clinical factors. For example, some studies suggest younger patients show worse QoL (Rogers, Bijaya, Goru, Lowe, & Humphris, 2006) and others suggesting minimal differences (Hammerlid, Bjordal, Ahlner-Elmqvist, Jannert, Kaasa, & Sullivan 1997; Hammerlid & Taft, 2001). Hammerlid and colleagues, (2001) showed patients with stage 1 and stage 2 disease compared to stage 3 and 4 tumours revealed few differences in their HRQoL scores (Hammerlid & Taft, 2001) whereas Bilal et al (2014) showed tumour stage to be strongly associated with patients' QoL, where later stage disease was associated with worse QoL

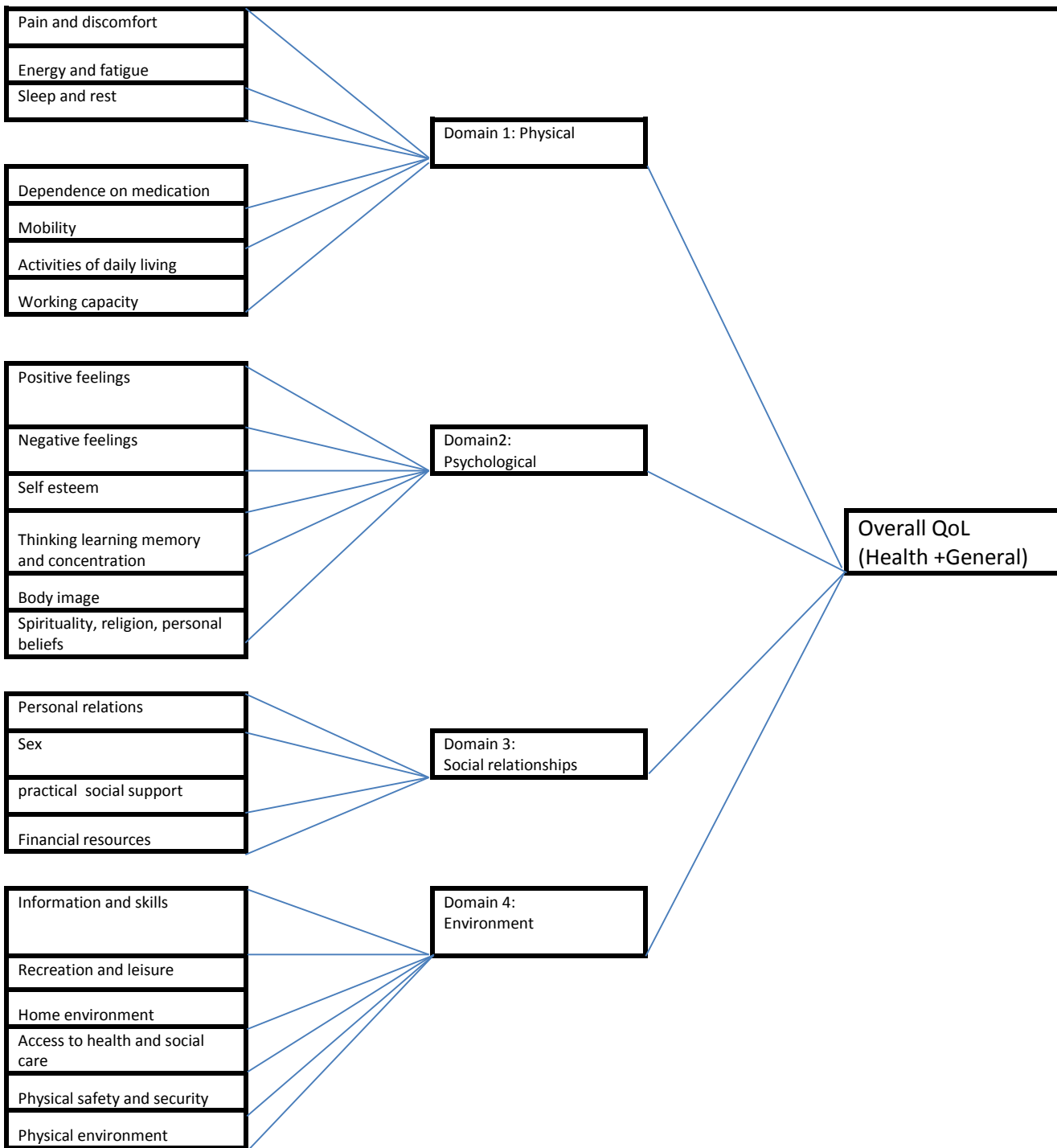
<sup>8</sup> EORTC- European Organization for Research and Treatment of Cancer

(Bilal et al., 2014). What is evident from the review of the literature is the need for researchers and clinicians to shift beliefs that only physical factors such as tumour stage, type of surgery, extent of cancer and number of physical side effects will impact patients QoL. Measures of disease alone are insufficient ways of measuring an individual's QoL, particularly within HNC. There is a pressing need to expand research on the clinical and social usefulness of current functional and symptom related measures.

### **1.2.3 World Health Organisation QoL measure- WHOQOL-BREF**

The world health organisation (WHO) developed a QoL instrument which aims to capture the multi-dimensional domains of QoL and goes beyond functional and symptom related constructs. It was developed by the WHO group in 15 international field centres in an attempt to develop a QoL assessment that would be cross culturally valid and also provide a measure of individuals QoL from a multi-dimensional perspective (Skevington, & Lotfy, 2004). It has been specifically developed to go beyond HRQOL and provides less focus on specific functional impairments and allows an insight into wider constructs of individuals QoL. (Figure 3)

**Figure 3 WHOQOL-BREF: Diagram showing each facet that makes up the four domains of QoL of WHOQOL-BREF questionnaire(Skevington, Lotfy, & O’Connell, 2004, p. 307)**



At the time of this review, to our knowledge only four studies have been published using the WHOQOL-BREF within the HNC population. However, these four studies had all been conducted by the same research group in Zurich within one sample of HNC patients. In these studies, Zwahlen and colleagues (2008) found high levels of QoL in all four domains. They reported little differences were shown between a healthy, age- matched population (Zwahlen et al., 2008; Jenewein et al., 2008, Drabe, Zwahlen, & Büchi, 2008) and the HNC sample.

One explanation for this high QoL may be due to the individuals' expectations and experiences of health and illness. Carr et al (2001) suggested that an individual's perception of QoL may be based more on their expectations and experiences of health, rather than the disease itself. If the expectations do not match the experience of health, the level of QoL will be low. Conversely, someone who has adapted his expectations to the change in his health due to a severe illness might experience a significant improvement of QoL (Carr, Gibson, & Robinson, 2001). QoL may become more influenced by perceptions of the illness and expectations of treatment than the actual illness itself. This would suggest that the psychological experience of the cancer might have a greater impact on a patient's QoL than the physical ordeal.

#### **1.2.4 Summary of HNC and QOL**

There is no consensus on the definition of QoL with definitions ranging from those with holistic emphasis on the social, emotional, and physical well-being of patients after treatment to those that describe the impact on a person's health (HRQOL). The WHOQOL-BREF provides a more comprehensive measure of treatment outcome than conventional measures that have been used with HNC. It allows individuals to summarise the judgments people make to describe their experiences of health and illness. This is what distinguishes the WHOQOL-BREF measure from the measure of disability such as the EORTC, FACT-G and UWQOL that ask predominantly about functional and symptom related facets. As Carr and colleagues (Carr et al., 2001) suggested; people assess their QoL by comparing their expectations with their experience which may account for the reason why patients with severe disease such as HNC may report good QoL. Primarily focusing on QoL instruments may be detrimental for this reason and inclusion of additional measurements, particularly a measure of psychological distress, may allow a deeper insight into the impact of cancer on an individual's well-being.

## 1.3 Psychological distress and Head and Neck Cancer

### 1.3.1 Defining psychological distress in cancer

Despite its importance, “psychological distress” is a general and ill-defined construct that includes a wide variety of different components and manifestations. In specific reference to cancer, the National Comprehensive Cancer Network defined psychological distress as:

***“An unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis.”***

**(National Comprehensive Cancer Network, 1999, p. 113)**

As the above description indicates, some degree of distress is normal. From time to time, most patients with cancer will have brief episodes of sad or anxious mood, loss of interest in activities, sleep problems, thoughts of hopelessness and helplessness, or worries about potential catastrophe. These are normal reactions to cancer, and often they assist in the process of adjustment. The real challenge is distinguishing a ‘normal’ reaction to cancer from an individual who is experiencing psychological distress.

### 1.3.2 Depression disorder v. depressive symptoms

Depressive disorder (DD) refers to a clinically diagnosed condition often preceded by a clinical interview based upon diagnostic criteria for depressive disorders from the diagnostic statistical manual (DSM; American Psychiatric Association, 2013) or international classification of disorders (ICD-10) see Table 4. A DD is a condition that is characterised by recurrent episodes of depressed mood and disturbed cognitive function

Depressive symptoms are common, transient and experienced by most people in their lifetime, especially in response to a stressor. Symptoms are often measured using self-report instruments such as the hospital depression and anxiety scale (HADS) which is frequently used within the healthcare setting (Zigmond & Snaith, 1983). These questionnaires are very useful in that they give an indication of how many symptoms are present at the time of completing the questionnaire. The questionnaires are brief and provide a useful tool in a clinical setting by drawing attention to patients who may be suffering from DD. For example, in the HADS depression subscale of the questionnaire, if a patient scored 7 to 10 (out of 14) they have a sufficient number of depressive



symptoms to be considered as suffering from depression (Peveler, Carson, & Rodin, 2002; Zigmond & Snaith, 1983).

It is important to note that self-reported questionnaires for depression are not designed to yield a discrete diagnosis of depression. They are constructed to measure depression as a single dimension of psychopathology, assessing symptoms associated with a potential depressive episode. These instruments are often measuring depressed mood rather than depression as a clinical diagnosis. However there is significant evidence that recurrent or persistent mild, subclinical symptoms are an important precursor to a potential depressive episode (Katz, Kopek, Waldron, Devins, & Tomlinson, 2004; Mitchell, Meader, & Symonds, 2010; Snaith, 2003).

**Table 4 ICD and DSM-IV criteria for depression**

ICD-10	DSM-IV
Lowering of mood, reduction of energy and decrease in activity.	Five (or more) of the following symptoms have been present during the same 2 week period and represent a change from a previous functioning; at least one of the symptoms is either; depressed mood or loss of interest or pleasure.
The lowered mood varies little from day to day and is unresponsive to circumstances.	Depressed mood most of the day, nearly every day
Capacity for enjoyment, interest and concentration is reduced and marked tiredness after even minimum effort is common.	Marked or diminished interest in all, or almost all, activities most of the day, nearly every day.
Disturbed sleep.	Significant weight loss when not dieting or weight gain or decrease in appetite nearly every day.
Self-esteem and self-confidence are almost always reduced and even in the mild form, some ideas of guilt or worthlessness are often present.	Insomnia or hypersomnia nearly every day
May be accompanied by: Early waking in the morning; several hours before usual time	Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)
Depression worst in the morning	Fatigue or loss of energy nearly every day
Marked psychomotor retardation	Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day
Agitation	Diminished ability to think or concentrate, or indecisiveness nearly every day
Loss of appetite, weight loss	Recurrent thoughts of death, recurrent suicidal ideation, plan or attempt.
Loss of libido	
Depending on the number and severity of symptoms, a depressive episode may be specified as mild, moderate or severe	

### **1.3.3 Measuring psychological distress in cancer**

Clinically significant depressive symptoms occur 2-3 times more frequently in people affected with cancer compared to the general population (Peveler et al., 2002). While general QoL measures will often contain domains for emotional and social well-being they are often not able to detect clinical levels of psychological distress. Thus, when screening for prevalence of psychological distress, a measure that is able to detect high depressive symptoms compared to 'normal' cancer related distress is essential.

#### **1.3.3.1 Hospital Depression and Anxiety Scale (HADS)**

The HADS (Zigmond & Snaith, 1983) is one of the most commonly used questionnaires for identifying psychological distress in oncology patients (Katz et al., 2004; Mitchell, Ferguson, Gill, Paul, & Symonds, 2013; Rogers et al., 2006). It is a 14 item self-assessment scale which has two factors, anxiety (HADS-A) and depression (HADS-D). Scores are constructed by summation, whereby increasing scores indicate increasing burden. There is a lack of consensus about what the optimal cut-off score should be for the HADS when it is used as a screening test to detect cases of minor and major depression. Cut-off scores recommended in the literature have ranged from a low of 7 (Razavi et al., 1990) to a high of 11 (Clarke et al., 1993). Authors of the instrument recommend the optimal cut off point to be  $\geq 8$  for the identification of high symptoms of depression, which is most commonly reported. A global score for psychological distress may also be calculated, by adding the depression and anxiety scores together and the optimal screening score of 15, described by Kugaya et al (Kugaya, Akechi, Okuyama, & Nakano, 2000) and Mitchell et al (Mitchell, Meader, & Symonds, 2010). In an international review examining the experiences with HADS in different clinical settings, Hermann (1997) found high acceptability amongst patients with some studies reporting 100% response rates. It has also shown high reliability with internal consistencies (Cronbach alphas) of the English versions between 0.80 to 0.93, which means the instrument is reliably measuring symptoms of depression and anxiety in medically ill patients. It does, however, not allow one to make definite diagnoses and gives a dimensional rather than categorical representation of mood.

#### **1.3.4 Psychological distress in HNC patients**

As previously highlighted, the 5-year survival rate for some HNC tumour sites is now greater than 50%. As a result, HNC patients' QoL and psychological adjustment to treatment are increasingly important. Zabora and colleagues (2001) examined 4496 people with various malignancies. The site-specific results of this study indicated that HNC was among the six types of cancer with the highest mean score for depression when measured within 90 days of diagnosis. This may be for

several reasons, including; the observable physical disfigurement following treatment, disruption in communication ability and impairment in overall functioning which may increase the likelihood of psychological reactions. Also, patients with HNC tumours may be more likely than those with cancer in other sites to have histories of drinking, smoking, or using other substances to cope with stress.

<sup>9</sup> **Table 5** presents a summary of eleven studies from 1997-2014 that have utilised the HADS questionnaire to measure psychological distress in HNC patients.

**Table 5 Prevalence of psychological distress in HNC patients**

First Authors, year.	Country	Prevalence of depression	HADS CUT OFF	Treatment, and Time point	Summary of results and principle findings
Chen & Chang, (2004)	Taiwan	25%	≥11	(Chemotherapy (76%) Not reported (24%)	Increased depressed; insomnia, pain,
Hutton & Williams, (2001)	UK	22%	≥8	After treatment (surgery or surgery and adjuvant 8 months or longer).	Depression decreased with age
Hammerlid et al., (1997)	Sweden	20% (before treatment) 15% (3 months) 14% (6 months) 13% (12 months)	≥8	Diagnosis to 12 months  Radiation or brachytherapy (% not reported)	Highest depression 2-3 months following treatment
Hammerlid, Mercke, Sullivan, & Westin, (1998)	Sweden	23% (before treatment)  26% (1 months)  13% (3 months)  14% (after treatment)  24% (12 months)	≥11	Before and after treatment.  Radiation (68%) Chemo+ radiation (20%) Laryngectomy and radiation (12%)	Patients with large tumours at diagnosis and 12 months more frequently depressed than patients with small tumours,
Kelly, Paleri, Downs, & Shah, (2007)	UK	43% (before treatment) 32% (during treatment) 24%	Not reported	Radiation or chemotherapy (100%)	Patients experienced deterioration in QoL and increase in depression scores over the course of the treatment

<sup>9</sup> Studies were extracted from Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, (2009) systematic review examining the prevalence of and correlate of depression among patients with HNC- however only studies using the HADS questionnaire were extracted. Recent studies have also been added to the review table.

		(following treatment)			
Kugaya, Akechi, Okuyama, et al., (2000)	Japan	17%	≥15	After treatment (not reported)	Depression was associated with education, living alone, advanced cancer stage and alcohol abuse.
Pandey et al., (2007)	India	10%	≥8	Time of treatment Surgery (32%) Radiation (33%) Multi-modality 35	Depression was correlated with emotional distress Social distress Anxiety. Depression was also correlated with activity of daily living.
Rose & Yates, (2001)	Australia	10% (before treatment) 41% (6 weeks following) 30% (one month post treatment)	≥8	Radiation (100%)	No significant change in depression between 6 weeks and one month
Rogers, Bijaya, Goru, Lowe, & Humphris, (2006)	UK	11%	≥11	Surgery (69%) Surgery and adjuvant (32%)	cross-sectional survey, a notable minority of patients were anxious or depressed after primary surgery with or without adjuvant radiotherapy for oral and oropharyngeal squamous cell carcinoma
Shiraz et al 2014	UK	39%	≥8	Not specified	Patients with high scores on the HADS reported poorer QoL, and 40% of those with high levels of psychological distress were willing to consider psychological support.
Verdonck-de Leeuw, I M Erenstein, Van der Linden, Kuik, de Bree, & Leemans, (2007)	Netherlands	27%	≥12	After treatment; Parotidectomy or radiation (39%) Surgery and radiation (39%) Chemotherapy and radiation (22%)	Higher depression was associated with presence of feeding tube, fewer social contacts, passive coping style, and non-expression of emotions.

Table 5 shows a review of HADS in HNC patients and shows prevalence ranging from 10-43%, both nationally and internationally. Scores ≥8 appear to be the most commonly reported cut off scores. However prevalence rates appear to vary according to the treatment and the time point at which the patient completes the questionnaire.

<sup>10</sup>A recent study examining the prevalence of psychological distress in HNC patients was conducted by Shiraz et al 2014 who found 37% of HNC patients presented with high depressive symptoms on

<sup>10</sup> This paper was the pilot study for the thesis and was published in the British Journal of Oral and Maxillofacial Surgery 2014 see appendix 8.1 for copy of the publication.

Shiraz, F., Rahtz, E., Bhui, K., Hutchison, I., & Korszun, A. (2014). Quality of life, psychological wellbeing and treatment needs of trauma and head and neck cancer patients. *British Journal of Oral and Maxillofacial Surgery*, 52(6), 513–517

the HADS questionnaire, and 44% showed elevated symptoms of anxiety. Patients with high depression and anxiety levels also reported lower quality of life. Forty per cent of those with high levels of psychological distress indicated a need for more support in coping emotionally with their condition (Shiraz, Rahtz, Bhui, Hutchison, & Korszun, 2014)

Psychological distress in HNC is essential to study as comorbid illnesses can complicate treatment and may lead to poor adherence to treatment recommendations thus leading to poorer QoL. The prevalence of depression in HNC cancer varies significantly by assessment method (i.e., self-report measures vs. diagnostic interview), but indicates that approximately 15 to 50% of patients suffer some degree of depression at any given point across the disease trajectory.

### **1.3.5 Impact of psychological distress on Patient QoL**

It's only in the last few years that healthcare providers involved in HNC have begun to examine the potential role psychological distress may have on a patient's QoL. Howren and colleagues (2010) found that depressive symptoms at diagnosis and before treatment were associated with poorer HRQOL one year later. This was prevalent even after adjusting for baseline HRQOL as well as age, gender, marital status, disease site and stage, alcohol and tobacco use, and physical comorbidities. Similarly, in a cohort of laryngeal patients, Johansson et al (2011) also found an association between increased anxiety and depressive symptoms and lower HRQOL (Johansson et al., 2011). Hammerlid et al (2001) found the long term impact of psychological distress with patients with depressive symptoms at diagnosis still reporting lower QoL 3 years post diagnosis. These findings have significant implications as depression is a treatable condition and early intervention could help reduce future deterioration in patients QoL.

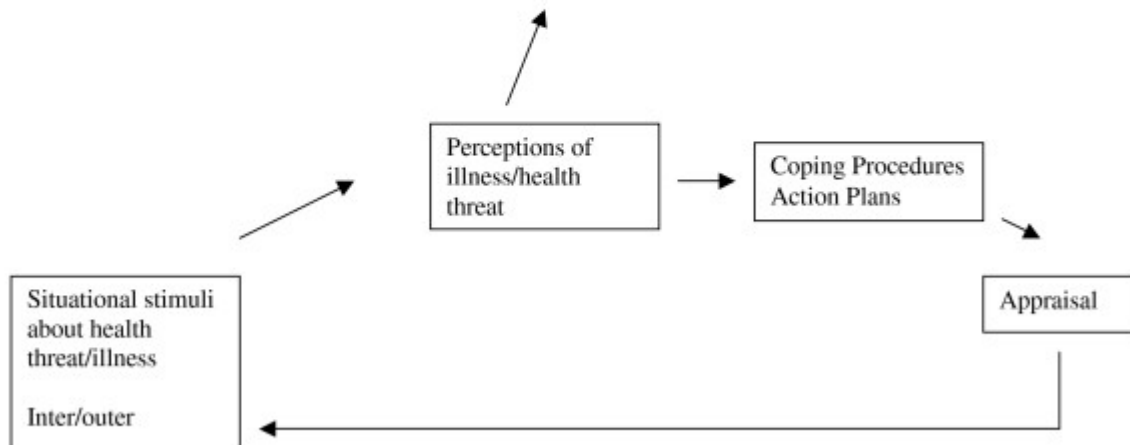
### **1.3.6 HNC specific factors contributing to psychological distress**

Several factors specific to HNC have been associated with increased psychological distress in HNC patients. Dysfunction as a result of treatment may increase psychological distress and therefore have a major impact on patients QoL. Researchers have noted that the impairments in voice, speech, and swallowing caused by radiation therapy can negatively impact overall QoL and social functioning, above the impairments produced by surgery (Epstein et al., 2001). Also, post-treatment disfigurement and dysfunction are significant problems for many HNC patients. Patients may have visible scarring and structural changes due to surgical removal of bone and tissue; may have neck stoma after laryngectomies; or may experience swelling that distorts appearance. However, there has been mixed evidence related to post-treatment disfigurement increased

depression. Katz et al (2000) reviewed six studies addressing disfigurement specifically in HNC patients; four of the six studies showed no relation of objective measures of disfigurement to aspects of QOL(Katz, Irish, Devins, Rodin, & Gullane, 2000). On the other hand, although the degree of objective disfigurement may not be associated with QOL, it may still limit specific areas like social functioning (Dropkin, 1999). Certain individual factors interact with disfigurement to produce distress and there are subgroups of HNC patients who cope less effectively with disfigurement. For example, a person whose identity has always been strongly based on appearance or on communication ability may be much more likely than someone whose identity is not, to have greater distress at lower levels of disfigurement (Hagedoorn & Molleman, 2006). This therefore highlights an individual's perceptions about the disfigurement rather than the actual disfigurement that may be contributed to the increased levels of psychological distress.

The way individuals appraise their illness may be a vital indicator in explaining why some patients will experience poorer quality of life (QoL) and elevated levels of psychological distress compared with others. Leventhal's (1984, Leventhal, Brissette, & Leventhal, 2003) Self-Regulatory Model (SRM) suggests that when an individual is confronted with an illness or condition, they will attempt to assign meaning by accessing their perceptions about the illness. The self-regulation model of illness is made up of five components that guide an individual's illness perceptions and coping efforts: 1) identity: the label or name given to the condition and the symptoms that goes with it, 2) cause: the individualistic ideas about perceived cause of the condition, 3) time-line: the predictive belief about how long the condition will last, 4) consequences: individual belief about consequences of illness, 5) control/curability: the beliefs about whether the condition can be cured and kept under control (see Figure 4). Upon receiving a diagnosis of cancer, patients will create a mental representation of why they think they developed the cancer, gather knowledge about what they need to do to make themselves better and how they can self-regulate their emotional response. Some research suggests that individuals who perceive the cause of their cancer as within their control are more likely to change the behaviours that they believe contributed to their disease (Rabin & Pinto, 2006). A novel feature of the model is that it highlights how people regulate their coping responses both to illness danger (what is the health threat and what can I do about it) and to the person's regulation of controlling their emotions by engaging in behaviours to reduce the emotional impact (how do I feel, and what can I do to make myself feel better). The model predicts that the impact of a problem will be mediated by a person's cognitions and these will influence their emotional responses, coping behaviours and appraisals.

Identity (label)	Timeline	Consequences	Cause	Control
Symptoms	Expected duration	Impact on life functioning	External (e.g. infection)	Preventable
Names			Internal (e.g. genes)	Curable Controllable



**Figure 4: Leventhal self-regulation model (1984)**

Scharloo and colleagues,(2005) tested the self-regulation model and found that patients who perceived fewer symptoms, had less belief in illness and/or symptoms as cyclical in nature, a less strong emotional response to illness and less belief in their own behaviour causing the illness were associated with better functioning (Scharloo et al., 2005). Similarly, Foley et al,(2006) found cancer patients who perceived their cancer as a ‘positive’ experience had the highest QoL compared to those who resented cancer reporting increased psychological distress (Foley et al., 2006).

The literature examining psychological distress and QoL is still in its early stages, and further studies are required to assess the role psychological distress has on individuals’ QoL but also the impact of cancer on the wider network.

## **1.4 Psychological impact of Cancer on Caregivers - Partners and Family members**

When an individual is diagnosed with cancer, there is a social and cultural expectation for partners or family members to become the providers of practical and emotional support. Most caregivers cope well with the role with some studies showing certain individuals are able to gain positive experiences following cancer, reporting more closeness in relationships and personal strength (Ruf, Büchi, Moergeli, Zwahlen, & Jenewein, 2009). However an important minority become highly distressed and we still know very little about the consequences of cancer patients having a highly distressed partner or family member.

### **1.4.1 Prevalence of psychological distress in caregivers**

Following cancer diagnosis, families, particularly the partner, are among the most important resources for patients coping with cancer and cancer-induced life changes. Too often, the responsibility for complex care resides with spouse caregivers in particular, without regard for their resource or skills to provide the care. As caregiving increases, partners may experience a collection of physical, mental and social consequences that may exceed those of their ill partner.

Braun et al (2007) assessed the prevalence of psychological distress among advanced cancer patients (lung and GI) and their spouses (101 couples of patients and caregivers). Forty per cent of the spouse caregivers reported clinical levels of depression, compared to 20% reported in their ill partners. They also found patients who had a partner who reported low symptoms of psychological distress did better physically and emotionally (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007). The cross-sectional nature of the study limits our ability to determine causal relationships however highlights that the elevated levels of psychological distress in partners can have a negative impact on the patient.

The few studies that have examined prevalence of psychological distress in HNC are showing similar results. Vickery et al (2003) examined levels of psychological distress in HNC patients and their partners. Forty percent of partners compared to Fourteen per cent of patients were reporting clinical levels of anxiety. Levels of anxiety were higher in partners of patients who had received surgery and radiotherapy compared to radiotherapy alone. Interestingly, there was no difference between patients and their partners' levels of depressive symptoms, both reported prevalence of 11% (Vickery, Latchford, Hewison, Bellew, & Feber, 2003). It should be noted, however, that the psychological distress was measured at one time point only and it is likely that the process of psychological distress is not a static entity and is changeable across time. Hodges et al, (2005) examined the prevalence of anxiety and depressive symptoms at 3 and 6 months following



diagnosis in a cohort of HNC patients and carers (86 partners, 13 non partners). They found, 3 months following diagnosis patients and their caregivers were showing similar levels of depressive symptoms (14% and 13% in carers). However, caregivers were reporting significantly higher levels of anxiety; 21% in patients and 37% in caregivers (Hodges, Humphris, & Macfarlane, 2005). These findings suggest that caregivers are reporting significantly higher symptoms of anxiety for up to 6 months following diagnosis. Zwahlen et al (2008) examined the psychiatric morbidity in successfully treated oral cavity squamous cell cancer survivors (mean 3 years since surgery). Results showed 39% of wives compared to 16% of patients reported increased levels of psychological distress. These findings highlight that in a proportion of caregivers are finding difficulty in adjusting to their partner's diagnosis for up to three years following treatment.

These studies emphasise the increased levels of psychological distress amongst partners of cancer patients. There have been very few studies that have examined the prevalence of psychological problems among non-partners. What evidence there is suggests that non-partner carers can also develop high levels of psychological distress. Bowman and colleagues (2006) found that family members appraised the cancer experience as more stressful than did cancer patients themselves. They appeared to be less able to let go of the diagnosis and treatment phase of the disease and continued to have a negative appraisal of the overall cancer experience (Bowman, Rose, & Deimling, 2006). Kissane and colleagues (1994) examined families of patients receiving palliative care and found that 35% of spouses and 28% children were showing clinically relevant symptoms of depression (Kissane et al., 1994). Edwards and Clarke, (2004) examined levels of psychological distress amongst colorectal, breast and prostate relatives. They found patients' illness characteristics i.e. cancer type, physical functioning, type of treatment appear to be risk factors for patients' psychological distress but not for relatives' depression and anxiety. Almost 13% of patients compared to 21% of relatives reported clinically relevant symptoms of depression (Edwards & Clarke, 2004).

#### **1.4.2 Why are caregivers showing higher psychological distress than patients?**

There is some evidence that women are generally more distressed than their male counterparts, regardless of their role as a patient or partner (Hagedoorn, Kreicbergs, & Appel, 2011; Hagedoorn, Sanderman, Bolks, Tuinstra, 2008; Ybema, Kuijer, Hagedoorn, & Buunk, 2002). One possible explanation for this gender phenomenon could be that women's emotional life is more affected by their partners' well-being. Women's roles, particularly in couples and families, might commit them to being nurturing and, therefore, more reactive to stressors in significant others (Pitceathly & Maguire, 2003). Apart from gender, a number of explanations have been presented for the increased levels of distress in partners compared to patients. The experience of illness and

treatment is clearly different for a partner. They themselves are not facing the threat of death or suffering but are faced with the prospect of losing or caring for their partner. Such a prospect may induce feelings of helplessness, as they are unable to take a direct role in fighting the cancer (Pitceathly, Maguire, Haddad, & Fletcher, 2005). This may also be applicable in family members (Vickery et al., 2003). The prevalence studies show a prolonged effect of increased distress. Bigatti et al (2001) suggested psychological distress in partners may become prolonged because partners disregard their own problems in order to focus exclusively on patients' needs. (Bigatti, Wagner, Lydon-Lam, Steiner, & Miller, 2011). This may have consequences on a partner's health, which could also result in negative consequences for a patient with cancer. Also, stressors with which couples are confronted with may be quite different depending on the role of the patient within the relationship. If the patient is the financial supporter, the illness may be associated with forced retirement and financial strains, but If the patient is the primary housekeeper the social relationships may be more likely to change (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Ybema et al., 2002).

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1987) provides a framework for evaluating the processes of coping with stressful events and provides an explanation as to why some partner's may experience higher psychological distress than the patient. Table 6 summarises the key constructs of the Transaction Model of Stress and Coping. According to this model, partner' s may be appraising patient's cancer more negatively, perceiving little control over the outcome and therefore suffer with increased feelings of helplessness in addition to negative thoughts about losing their partner. Partners who experience elevated levels of psychological distress will find it more difficult to adopt positive coping strategies therefore choosing to engage in maladaptive coping behaviours which not only has a negative effect on their own wellbeing but potentially affect the social support provided to the patient.

**Table 6 Transactional model of stress and coping framework**

<b><i>Concept</i></b>	<b><i>Definition</i></b>
Primary Appraisal	Evaluation of the significance of a stressor or threatening event.
Secondary Appraisal	Evaluation of the controllability of the stressor and a person's coping resources.
<b>Coping Behaviours</b>	Actual strategies used to mediate primary and secondary appraisals.
<i>Problem management</i>	Strategies directed at changing a stressful situation.
<i>Emotional regulation</i>	Strategies aimed at changing the way one thinks or feels about a stressful situation.
Meaning-based coping	Coping processes that induce positive emotion, which in turn sustains the coping process by allowing re-enactment of problem- or emotion focused coping.
Outcomes of coping	Emotional well-being, functional status, health behaviours.
Dispositional coping styles	Generalized ways of behaving that can affect a person's emotional or functional reaction to a stressor; relatively stable across time and situations.
<i>Optimism</i>	Tendency to have generalized positive expectancies for outcomes.
<i>Information Seeking</i>	Attentional styles that are vigilant (monitoring) versus those that involve avoidance (blunting)
(Glanz, Rimer, & Viswanath, 2008, pp. 214–215)	

Significant evidence highlights the positive effects of social support on a patient's wellbeing (Cohen & Wills, 1985; Lutgendorf et al., 2005; Minako et al., 2010). Several hypotheses have been proposed for this positive association. Berkman and Glass, (2000) suggested social support has a positive impact on individuals due to meeting basic human needs for companionship, intimacy, a sense of belonging, and reassurance of one's worth as a person, supportive ties may enhance wellbeing and health, regardless of stress levels (Berkman, Glass, Brissette, & Seeman, 2000). A second

hypothesis is proposed by Thoits, (1995) who suggested an individual's social support network may help them reinterpret events or problems in a more positive and constructive light. This "buffering effect" is the underlying mechanism to enhance individuals coping responses when experiencing a stressor such as cancer. Research involving people going through major life transitions such as cancer has shown how social support from partner and family influence the coping process and buffer the effects of the stressor on health (Cohen & Wills, 1985; Hagedoorn & Kuijer, 2000; Lutgendorf et al., 2005). A study by Bigatti in 2011 showed that partners who perceived low social support had increased psychological distress and ineffective coping strategies (Bigatti et al., 2011).

This therefore proposes several implications for the quality of social support a partner or caregiver may provide when experiencing increased level of psychological distress. The effects of negative social support have not been studied within HNC, however, a recent study by Manne 1997, identified patients who perceived negative responses from their partners reported increased psychological distress and lower QoL (Manne, Taylor, Dougherty, & Kemeny, 1997; Manne, Ostroff, Winkel, & Grana, 2005).

### **1.4.3 Effects of cancer on caregivers**

Stenberg et al (2010) recently conducted a systematic review which examined the effects of caring for a patient with cancer (Stenberg, Ruland, & Miaskowski, 2010). The findings were based on 192 studies published between 1990-2008 which reported a range of problems reported by both family and partner caregivers.

Table 7 draws attention to the wide array of problems experienced by caregivers, which go beyond providing emotional and practical support to patients. Partners and family members are reporting physical health problems as well as reporting isolation, loneliness and loss of intimacy in relationships (Stenberg et al., 2010).

**<sup>11</sup>Table 7 Physical, Emotional, Social and Burden experienced by partners and family members of cancer patients**

Physical Health problems	Emotional problems and reaction	Social problems	Burden related to responsibilities and impact on daily life
Pain	Anxiety	Financial difficulties	Direct care for patient
Back pain	Anxiety for own health	Change in employment status	Emotional support
Leg pain	Not wanting to leave patient alone	Giving up work	Accompanying patient to appointments
Sleep problems	Worry	Role strain	Filling out forms
Loss of energy	Depression	Balancing multiple roles	Make decisions
Loss of weight	Fear of recurrence	Less marital satisfaction	Monitor activities of the patient
Tired	Hopelessness	Spousal role problems	Provide medical or nursing treatments
Muscle tension	Scared about surgery and risks	Isolation	Report symptoms progress
Fatigue	Feelings of inadequacy	Loneliness	Cannot practice hobbies
Headache	Easily irritated	Loss of intimacy	Disrupted schedule
Poor sleep quality	Panic	Regret and feelings of loss of connectedness	Loss of independence
Loss of physical strength	Self-doubt	Difficult to get help	Restricted social life

The review by Stenberg and colleagues (2010) gives an overview into the complex range of challenges faced for caregivers of cancer patients and summarises the vast spectrum of difficulties that have been reported. In summary, the most frequently reported problems were emotional (e.g. anxiety, depression and fear) and social problems (e.g. financial difficulties, role strain, isolation).

<sup>11</sup> Table has been constructed from extractions from a systematic review conducted by Stenberg, Ruland & Miaskowski who conducted a systematic review on the effects of caring for a patient with cancer. Extracted from Stenberg et al 2010, pg. 1015-1017

## **1.5 Conclusions**

Cancer and its treatment precipitates profound changes in the family system, including disruptions in daily household routines, financial and emotional strain, and role changes engendered by a wide array of complex caregiving responsibilities (Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004). The similarity in levels of depression and anxiety between patients, partners and family members suggest that common factors impact on the whole family and suggests that individual events reverberate throughout the whole family system. However, not all partners and family member are reporting elevated levels of psychological distress, and in some cases some couple are able to reflect on the positive experiences of cancer.

It is important that professionals involved in the on-going care of cancer patients and their families are aware of the increasing demands made on caregivers and the specific problems they perceive in caregiving. Family and partners are the key social support systems during the cancer trajectory, and according to the “buffer hypothesis” (Cohen & Wills, 1985) act as an anti-stressor reducing the negative impact of the disease. If caregivers are increasingly distressed, this social support system may become more detrimental than positive.

## 1.6 Overall literature review conclusions

Head and neck cancers were traditionally associated with older men who smoke and consume alcohol, however the epidemiology and presentation of HNC appears to be changing, with patients with certain HNC cancers being younger with better survival outcomes. This puts QoL more in the forefront, as individuals undergoing extensive treatment may be faced with the long term effects for longer periods. Therefore, ensuring QoL becomes a significant issue.

Traditional QoL measures in HNC (*i.e.*, EORTC-QLQ, FACT-G, UWQOL) are useful for measuring functional outcomes in HNC patients but do not give the global impact of HNC and patients' perception of overall life satisfaction. Therefore, there is a need to assess QoL from a multidimensional construct which will allow us to bridge boundaries between disciplines and supplement an alternative perspective to HNC patients' QoL, which is currently lacking in the literature.

The current literature is also showing that increased psychological distress is associated with poorer QoL. Further research is required to examine the impact of psychological distress on HNC patients' physical, social relationships, lifestyle and environmental factors.

There have been inconsistencies in the prevalence of psychological distress in HNC patients, potentially due to the different methods of assessing depressive symptomatology and different time points reported. Thus there is a need for further studies to measure the prevalence before and following treatment to examine if HNC patients levels of psychological distress increases over time.

There have been very few studies that have looked at levels of psychological distress (anxiety and depression) in partners and family members of HNC patients, particularly within the UK. Thus further examination examining the prevalence of psychological distress amongst partners and family members of HNC patients is required. There is a significant need to identify which factors contribute to patients' and caregivers' psychological distress, particularly if high psychological distress in caregivers has a negative impact on the patient's QoL and psychological wellbeing.

## 1.7 Aims and Hypotheses

The main aims of this study were:

1. To measure the prevalence of psychological distress (symptoms of anxiety and depression) in HNC patients, and caregivers (partners and family members) at two- time points; before treatment and 6-12 months following treatment.
2. To examine the association of patient and caregiver psychological distress on HNC patients' QoL and to test the following hypotheses;
  - I. Before treatment, HNC patients who have high levels of psychological distress (symptoms of depression and anxiety) have poorer QoL
  - II. Patients whose partners and family members have high levels of psychological distress (anxiety and depression) have poorer QoL.
  - III. HNC patients with high depression and anxiety before treatment will show poorer quality of life 6-12 months following diagnosis
  - IV. HNC patients with partners who show high levels of distress have poorer QoL 6-12 months following diagnosis
3. To explore the "lived experiences" of HNC patient-partner couples, where partners reported high levels of psychological distress before treatment (qualitative)

The associations between other possible explanatory factors on patient QoL, i.e. Socio-demographic variables and clinical related variables such as treatment, stage of disease, and cancer site were also investigated.





## 2 Method

This chapter introduces the study protocol including the data collection procedures, details of the clinics patients were recruited from, the measures used to collect data and the statistical analyses that were used to analyse the data. The methodology for the qualitative phase of this thesis is detailed in chapter 4. The participants who took part in the quantitative and qualitative phases of the study were recruited from the clinics and procedures detailed in this chapter.

## **2.1 Research Design**

A mixed methods prospective study was used to answer the proposed research aims. (See chapter 4 for qualitative methods).

## **2.2 Ethics**

Ethics approval was obtained from the NRES Committee London, Camberwell St Giles -. REC reference:12/LO/0351

### **2.2.1 Head and neck cancer clinics**

The study participants were drawn from HNC patients and their caregivers' (partner or family member of HNC patient) who were treated for HNC between July 2012 and January 2014.

Participants were recruited from outpatient clinics at the Macmillan Cancer Centre, University College London Hospital (UCLH) and St Bartholomew's Hospital. Both clinics are multidisciplinary consisting of maxillofacial surgeons, ear nose and throat surgeons, speech therapists, dieticians, oncologists and cancer nurse specialists.

### **2.2.2 Inclusion and exclusion criteria**

Participants were identified and assessed for eligibility at the weekly multidisciplinary (MDT) meetings at each site, where newly referred and existing patients are reviewed. The clinical care team identified suitable patients based on the specified eligibility criteria (see Table 8). The inclusion criteria for patients were: aged 18 and over (no upper age limit specified), a biopsy confirmed primary tumour of the Head and neck, and a treatment plan of curative intent. Due to small numbers of new patients, recurrent HNC cancer patients were also included in this study. Patients were not eligible for the project if they were undergoing palliative treatment, English was not their first language or if consultants felt that a patient's participation was inappropriate.

See Table 8 and Table 9 for detailed patient and caregiver inclusion and exclusion criteria.

Caregivers were selected through patient’s nomination and for the purpose of this study; a caregiver is defined as;

- i) Partner or spouse of patient,
- ii) Relative or family member of patient,

Caregivers were only approached to participate following the permission from the patient. HNC patients who did not have a partner or family member were still included in the study sample.

### 2.2.3 Sample inclusion / exclusion criteria

**Table 8 Patients inclusion and exclusion criteria for recruitment**

<b>Patients Inclusion criteria</b>	<b>Patients Exclusion Criteria</b>
All patients were required to have a primary diagnosis of HNC.	Patients receiving being treated palliative / end of life treatment,
Newly diagnosed or recurrent primary HNC	Head and Neck Cancer not patients primary cancer e.g. Skin excluded
Curative treatment intent (all treatment types included)	Patients treated neurologically- e.g., brain Cancer
Aged 18 or over (no upper age limit)	Inability to read, write or speak English  Questionnaires are only available in English, and the researchers are only able to seek consent, administer questionnaires and conduct interviews in English.
Fluency in English	Cognitive impairment where patients may be unable to give informed consent, or understand the questionnaires and interviews.
	Patients with active psychosis or severe mental illness which may affect capacity to consent

**Table 9 Caregiver inclusion and exclusion criteria for recruitment**

Caregiver Inclusion criteria	Exclusion criteria
Partners of patients must be a co-resident, and have been living with the patient for at least 6 months.	Inability to speak, read or write English
Immediate relative as specified by patient	Cognitive impairment where patients may be unable to give informed consent, or understand the questionnaires and interviews.
Aged 18 or over (no upper age limit)	Patients with active psychosis or severe mental illness which may affect capacity to consent
Fluency in English	Primary diagnosis of Cancer

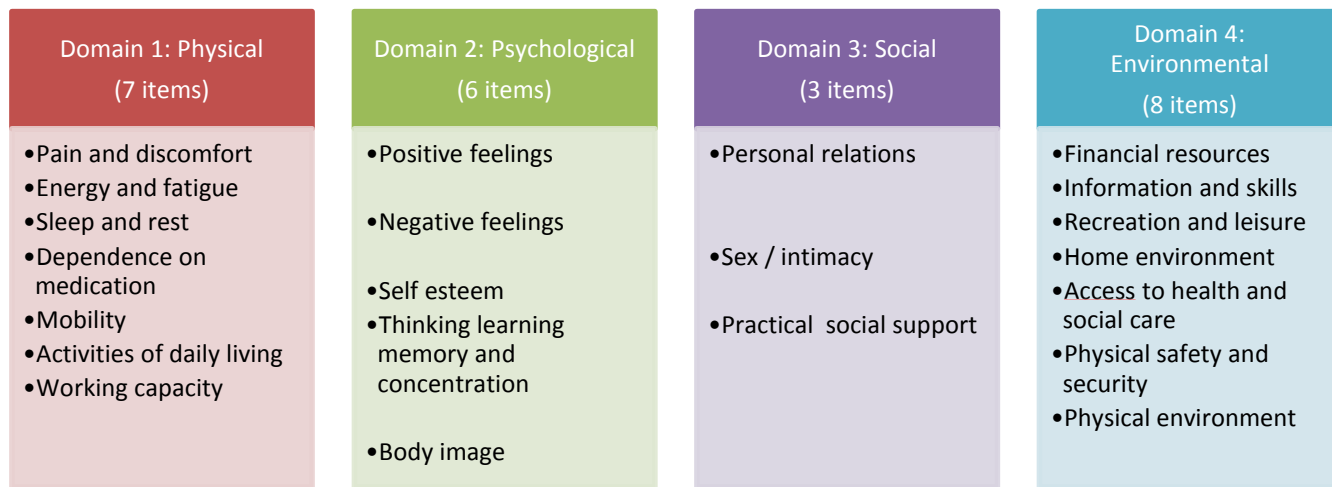
## **2.3 Self-report Measures**

The following questionnaires were administered to both patients and caregivers, before treatment and 6-12 months post diagnosis.

### **2.3.1 WHOQOL-BREF**

The WHOQOL-BREF consists of 26 items providing scores for four domains related to QoL: physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items). Ratings range from 1 (very poor) to 5 (very good). Figure 5 shows each item covered within each QOL domain.

**Figure 5 Four QoL domains of WHOQOL-BREF questionnaire**



### 2.3.1.1 Scoring and interpretation of WHOQOL-BREF

All items are rated on a 5-point scale assessing intensity, capacity, frequency or evaluation (satisfaction). Following reversal of negative items, domain scores are summed and transformed into percentile scores (scale range: 0–100). The higher the score, better the quality of life.

The WHOQOL- BREF is used as a continuous scale and is not recommended to be categorised.

### 2.3.2 Hospital Anxiety and Depression Scale (HADS)

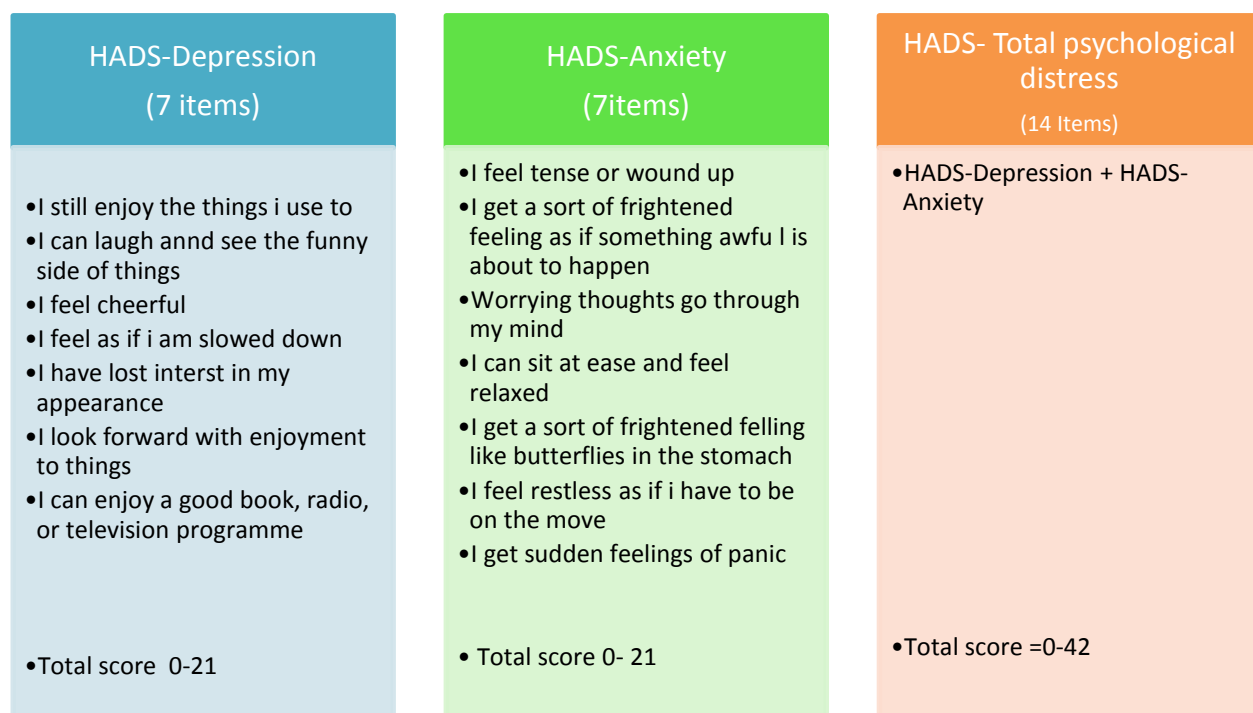
The HADS was selected to identify patients and caregivers with high levels of psychological distress (anxiety and depressive symptoms).

#### 2.3.2.1 Scoring and interpretation of HADS

HADS is a 14-item self-assessment scale with two subscales; anxiety and depression. Each item on the HADS has a Likert response scale rated from 0 to 3. Answers range from 0-21. Scores for anxiety and depression are summed with increasing scores indicating increasing symptoms. As recommended by the <sup>12</sup>authors, scores of  $\geq 8$  indicate possible anxiety or depression. An overall distress score (HADS-T) can also be summed by adding scores of HADS-Depression and HADS-Anxiety subscale. A cut off score of  $\geq 15$  for HADS-T indicates elevated psychological distress.

<sup>12</sup> (Zigmond & Snaith, 1983)

**Figure 6 Hospital anxiety and Depression Scale: Subscale and Items**



**Figure 6** shows each subscale and item on the HADS questionnaire (see appendix 8.2 for patient and caregiver questionnaire, consent form and information sheet)

## 2.4 Demographic and medical information

### 2.4.1 Socio-demographic

The socio-demographic variables collected from all participants included;

- Age
- Gender
- Education level
- Marital status
- Ethnicity
- Religion
- Current Employment status

### 2.4.2 Clinical variables

The following clinical variables were also collected by the researcher. To ensure accurate coding of clinical variables, in particular staging, all clinical variables were coded with the assistance of an oral maxillofacial registrar and the patients treating consultant.

- Treatment
- First or Cancer recurrence (First cancer v. recurrence)
- <sup>13</sup>Cancer staging (early loco-regionally advanced)
- Tumour type (SCC V. Non SCC)
- Site of tumour (oral cavity v oropharynx v other sites including nasopharynx, larynx, salivary gland and unknown primary)
- Tumour Node Metastases (TNM)

### 2.4.3 Surgery specific variables

The following variables were also collected from patients who underwent surgery.

- Did patient undergo a tracheostomy? (yes v no)
- Was patient in ITU following treatment? (yes v no)
- Did patient undergo a free flap reconstruction? (yes v no)
- Did patient have a nasogastric tube? (yes v no)

---

<sup>13</sup> The Cancer staging was performed in accordance with the AJCC staging system for head and neck cancer.  
\*Descher, D.G. & Day, T, (2008) American joint committee on Cancer (AJCC), Early stage disease: Stage I, II  
Locoregionally advanced: Stage III or IV.

## **2.5 Procedure**

All patients and caregivers were recruited from University College London Hospital (UCLH) or St Bartholomew's Hospital East London. Patients were identified at weekly multidisciplinary meetings and assessed for eligibility by a HNC clinician. Recruitment of participants took place at the weekly outpatient Head and neck cancer clinic. Patients were invited to join the study after confirmation of their diagnosis and treatment plan. The researcher was always introduced to the patient by their treating clinician. The patient was given information about the study and given the choice to consent at the clinic or take the information sheets and questionnaires home and return in the freepost envelope. Caregivers were recruited after permission from the patient was given for them to be involved in the study. Written informed consent was obtained from patients and their caregivers individually.

Figure 7, presents a consort diagram, reporting the total participants approached and number who consented and took part in the study. See Figure 8, for a step by step process of patient and caregiver recruitment

### **2.5.1 Timing of Questionnaires**

#### **2.5.1.1 Time point 1 (before treatment)**

Time point 1 was defined as the period before treatment commenced. All participants were recruited within 0 – 3 weeks. Only questionnaires that were completed before treatment (time point 1) were included in time point 1 analysis.

#### **2.5.1.2 Time point 2 (6-12 months following diagnosis)**

Only participants who completed questionnaires before treatment were eligible to take part in time point 2.

At both time points participants were provided with freepost envelopes to return their questionnaires. Participants were also informed that they might be selected for an interview 12 months following diagnosis (qualitative study, see chapter4).

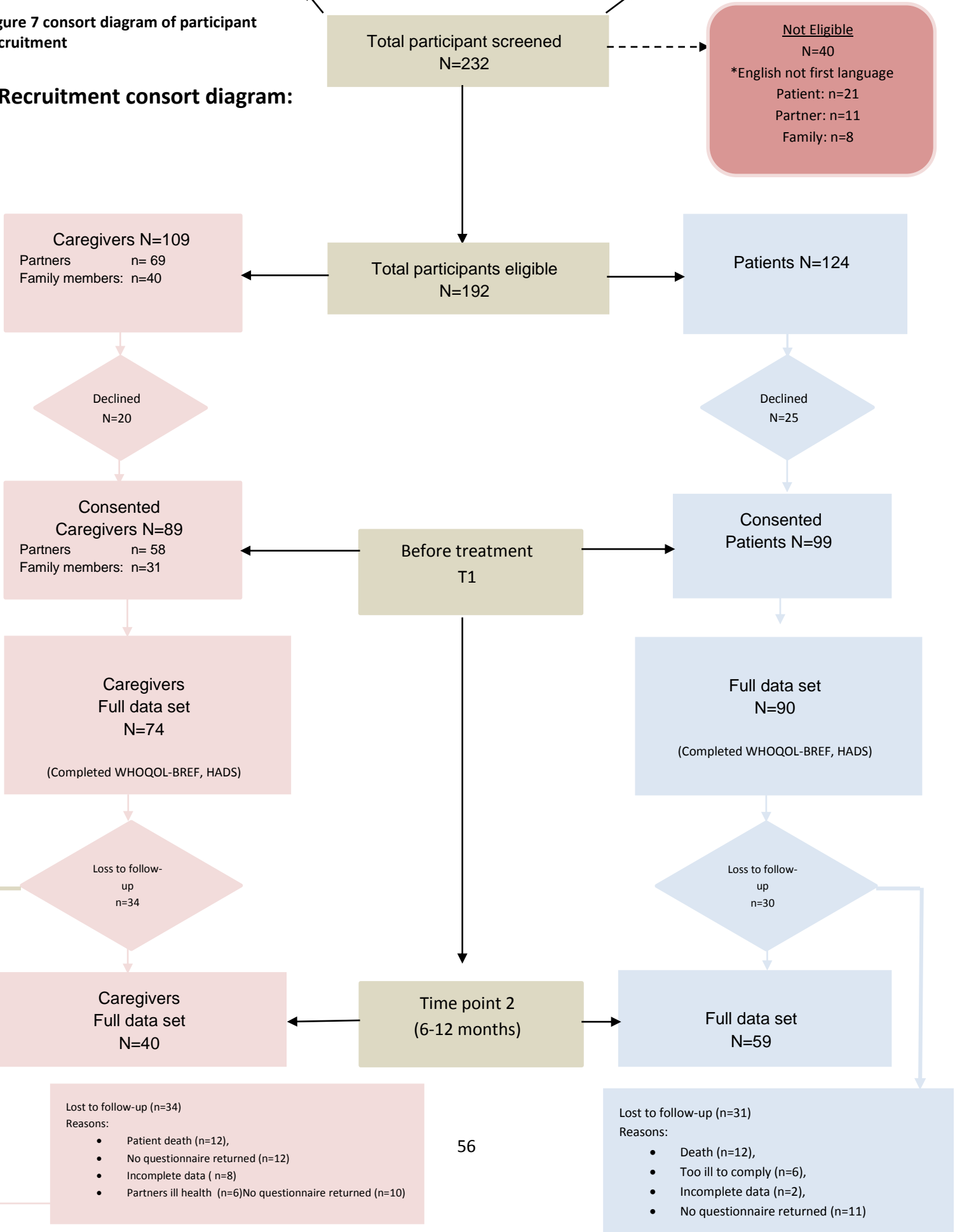
Figure 9, and Figure 10 show the completion of questionnaires by HNC patients and their caregivers at each time points.



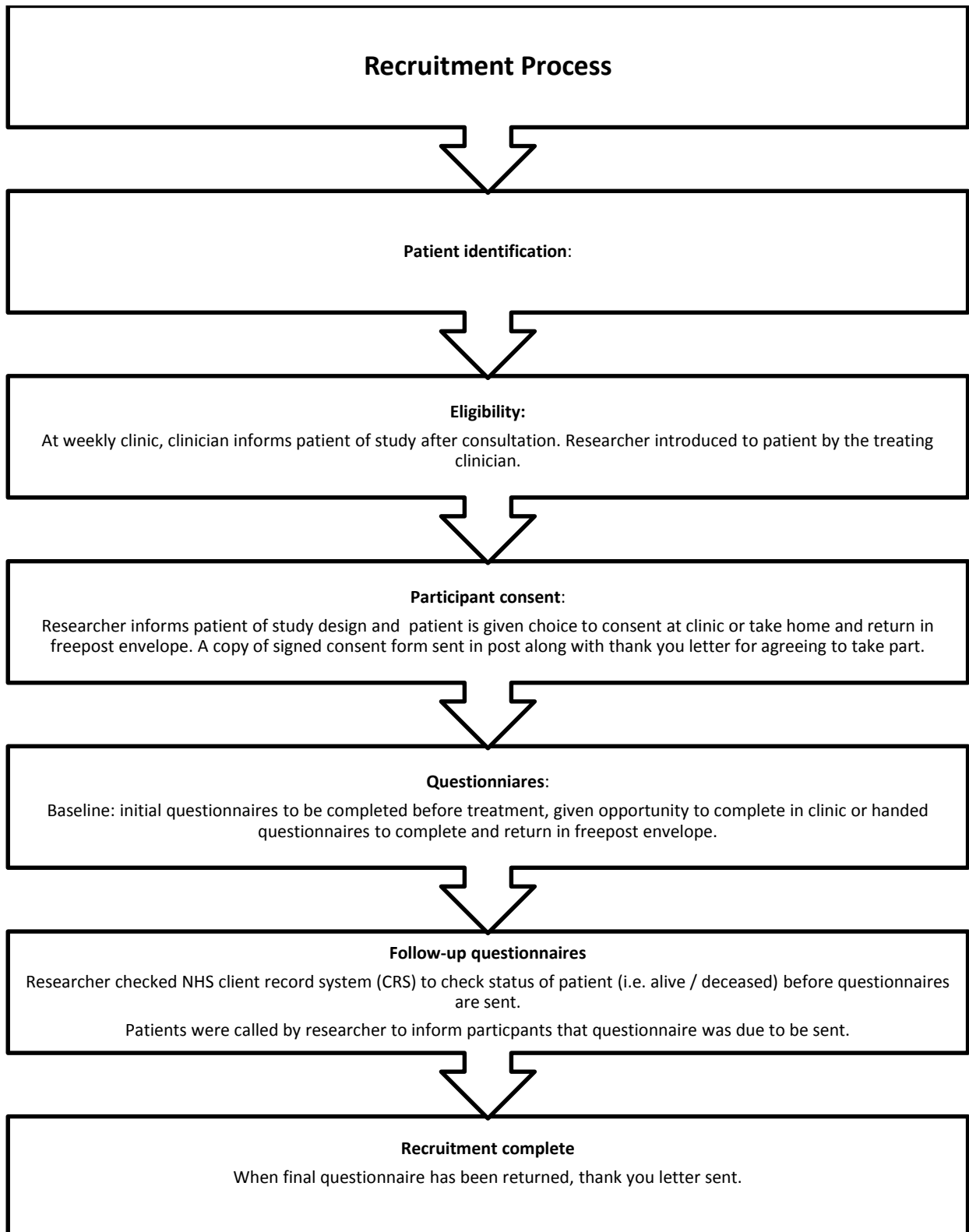


**Figure 7** consort diagram of participant recruitment

**Recruitment consort diagram:**



**Figure 8 Step by step process of participant recruitment**



**Figure 9 Questionnaires completed by HNC patients at Time point 1 and Time point 2**

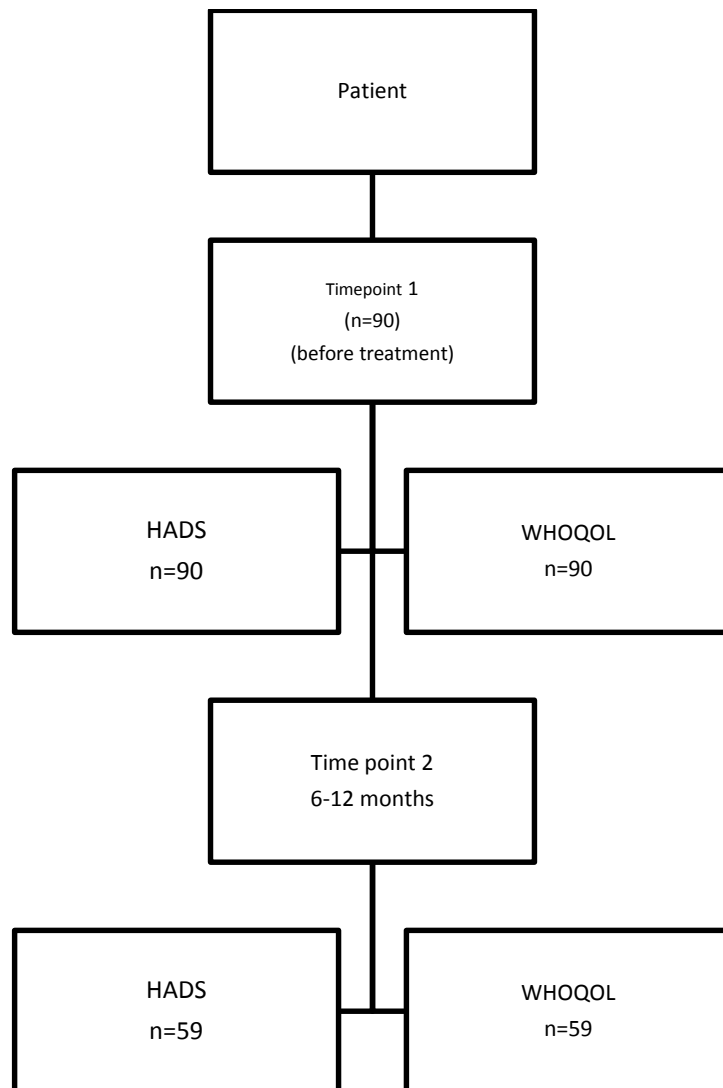


Diagram shows the number of HNC patients who completed the HADS and WHOQOL-BREF questionnaires before treatment (time point 1) and 6-12 months following treatment (time point 2).

**Figure 10 Questionnaires completed by Caregivers of HNC patients before treatment (time point 1) and 6-12 months following treatment (time point 2).**

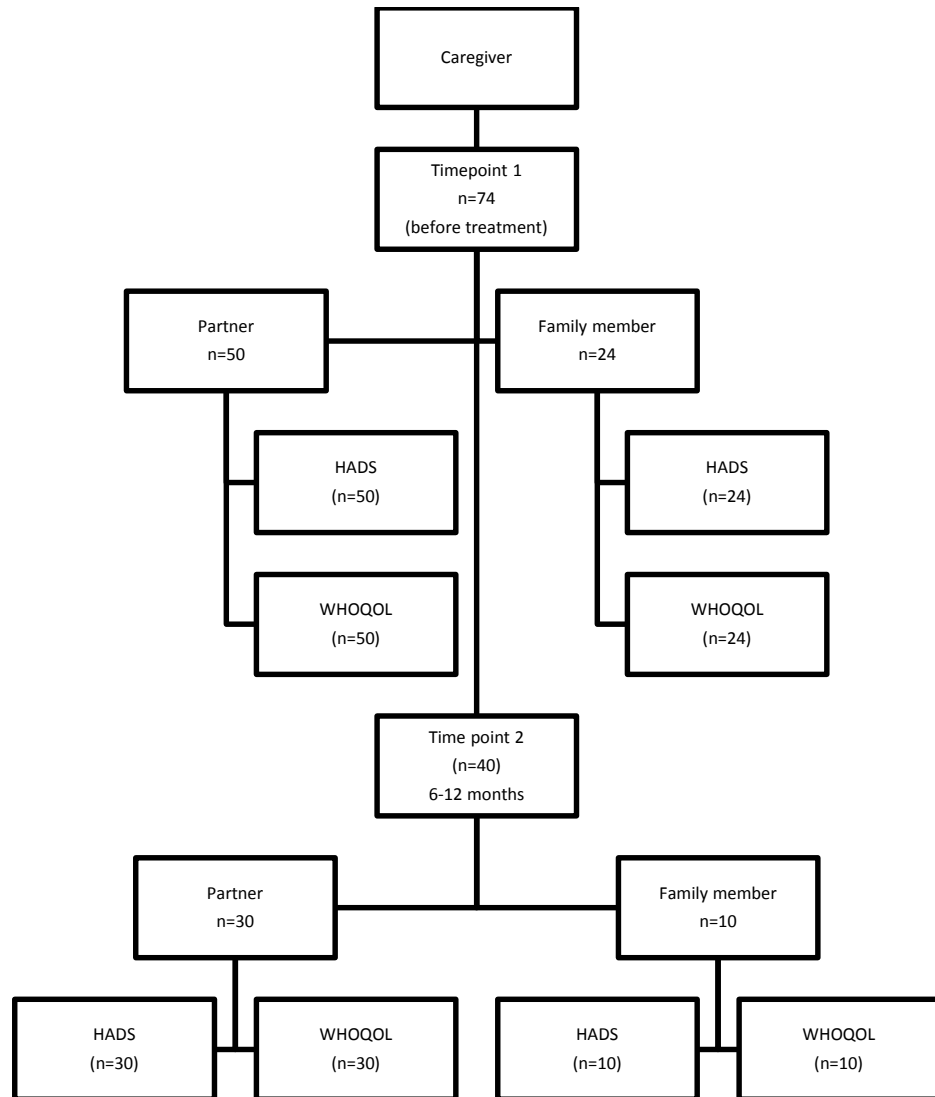


Diagram shows the number of partners and family members who completed the HADS and WHOQOL-BREF questionnaires before treatment and 6-12 months following treatment

## 2.6 Statistical Analysis

To ensure accuracy of statistical analysis and coding of data, double data entry was undertaken. All data was coded and analysed using <sup>14</sup>STATA 12.0.

The mean scores and standard deviations of all self-report measures were examined. Median scores were also derived due to the non-normal distribution of data within both self-report measures. T-tests were applied for planned comparisons of means, however due to the non-normal distribution of data, non-parametric statistics such as the Wilcoxon- matched paired test and Mann-Whitney U test were used to compare median scores across groups (i.e. comparing patients and partners levels of distress). The chi square and Fisher's exact tests were conducted to examine the representativeness of follow up participants

To undertake parametric linear and multivariate regression analysis the four dimensions of WHOQOL-BREF were normalised when used as the outcome (Cohen,Cohen,West, & Aiken., 2002). The transformation was achieved using the STATA zero-skewness log function *Inskew0*. The transformation to make the data approximate the normal distribution, allows for parametric regression to be fitted.

Regression modelling was undertaken to test the hypothesis. Univariate analysis examined the significant associations between predictor variables and outcome. A stepwise modelling approach was performed, where each psychological factor that was significantly associated to 0.05 levels was entered into a multivariate model. The aims of the model were to investigate which psychological factors were most strongly associated with patient QoL. The same data modelling was undertaken when examining the association between clinical and socio-demographic factors and patient QoL.

A path analysis was conducted to provide estimates of the magnitude and significance of the hypothesised causal connections between patient depression, caregiver depression and patient physical quality of life. A mediation analysis further examined the statistical associations identified in the path analysis.

---

<sup>14</sup> StataCorp. 2011. *Stata Statistical Software: Release 12*. College Station, TX: StataCorp LP.



### 3 Results

This chapter presents the quantitative findings from this thesis. It begins by introducing the dataset, followed by:

1. Results showing the prevalence of psychological distress in patients and their caregivers (Research aim 1 of the thesis)
2. Testing the hypothesis that psychological distress is associated with patient QoL (hypothesis i and iv)
3. Testing the hypothesis that caregiver psychological distress is associated with patient QoL (hypothesis ii and iv)
4. Exploring the associations between other explanatory factors of QoL; socio demographics and clinical factors

The findings of each research aim are summarised, with overall discussion of key findings in chapter five. The qualitative results (research aim 3) are presented in chapter four.

### 3.1 Quantitative Results

A total of 124 HNC patients were eligible to take part in the study. In total, 90 patients completed HADS and WHOQOL-BREF before treatment (65 male and 25 female patients) see Table 10 and Table 11 for patient demographics and clinical information. The age of the total sample ranged between the ages 27 to 94 years, with patients being predominantly White British, male with mean age of 64. Sixty-six per cent were married or living with a partner. The clinical variables of the patient sample showed the majority were newly diagnosed (85%), with 46% having a diagnosis of cancer of the oral cavity.

A total of 109 caregivers (partners n=69 and family members n=40) were approached to take part in the study. Twenty declined participation, with 11 caregivers (55%) citing the experience of undertaking research too stressful at the present time. Nine chose not to return questionnaires before treatment without any reason given. A total 74 caregivers (partner n=50, family members n=24) completed the HADS and WHOQOL-BREF questionnaire before treatment, (female=59 and male =15). This sample was predominantly White British, female, with a mean age 56.

Table 10 shows the socio-demographics of caregivers. Figure 11 presents the number of caregivers recruited before treatment with a breakdown of their relationship to HNC patient.

Figure 11 Caregiver sample n=74

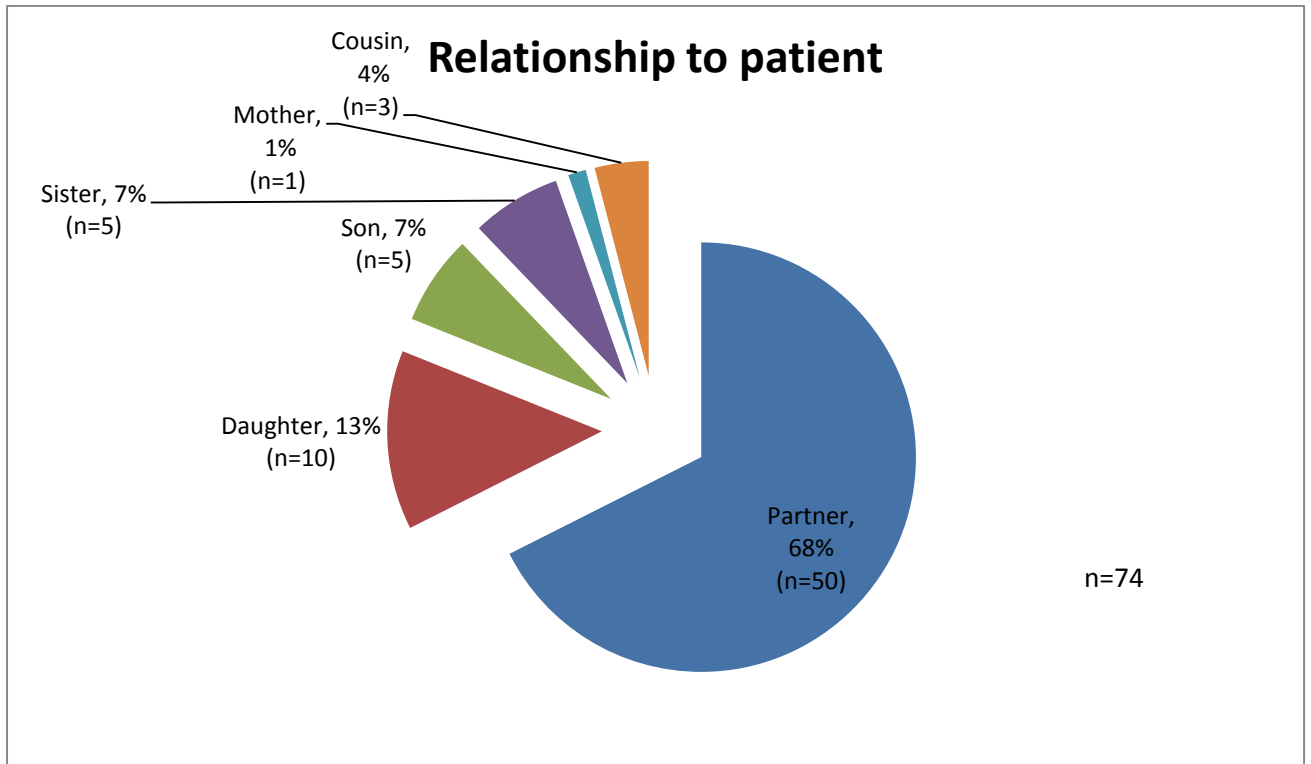


Figure 11 shows the number of caregivers recruited by relationship HNC patient



**Table 10 Socio-demographics of HNC patients (n=90) and Caregivers (n=74) who completed questionnaires before treatment (time point 1)**

	Patient N=90		Caregiver N=74	
	M (SD)		M(SD)	
Age	64(13)		56(12)	
Age grp		(%)		%
18-59	32	35.6	42	56.8
60-74	38	42.2	22	29.7
75-95	20	22.2	9	12.2
Missing	0	0	1	1.4
Gender				
Male	65	72.2	15	20.3
Female	25	27.8	59	79.7
Marital status				
Married/ living with partner	59	65.6	62	83.8
Single	18	20.0	7	9.5
Divorced/widowed	13	14.4	4	5.4
Education				
None	42	46.7	22	29.7
G.C.S.E/equivalent	26	28.9	26	35.1
Higher Education	22	24.4	24	32.4
Missing	0	0	2	2.7
Ethnicity				
White British/White other	75	83.3	62	83.8
Black British/Black other	5	5.6	1	1.4
Asian British/Asian other	8	8.9	7	9.5
Other	2	2.2	3	4.1
Missing	0	0	1	1.4
Employment				
Full time / Part time	28	31.1	37	50.0
Unemployed	21	23.3	15	20.3
Retired	38	42.2	21	28.4
Not specified	3	3.3	0	0.0
Missing	0	0	1	1.4
Religion				
No religion	24	26.7	27	36.5
Religion specified	66	73.3	47	63.5

Table 10 shows the socio demographics of all participants (patients n=90, and caregivers n=74) who completed questionnaires before treatment (time point 1).

**Table 11 Clinical information for patient sample who completed time point 1 (N=90)**

Patient Sample		(N=90)
Clinical variables		
Cancer	N	%
First Cancer	77	85.6
Recurrence	13	14.4
Site		
Oral cavity	41	45.6
Oropharynx	23	25.6
Nasopharynx	3	3.3
Larynx	10	11.1
Salivary gland	6	6.7
Unknown primary	7	7.8
SCC		
Yes	78	86.7
No	12	13.3
Stage		
Early(stage I-II)	31	34.4
Loco regionally advanced disease (stage III-IV)	56	62.2
Missing	3	3.3
T classification		
X	9	10.0
1	26	28.9
2	21	23.3
3	5	5.6
4	29	32.2
Treatment		
Surgery alone	40	44.4
Surgery +Adjuvant treatment	37	41.1
Radiotherapy only	4	4.4
Chemo+ Radiotherapy	9	10.0

Table 11 shows the clinical details of all patients who completed questionnaires before treatment (n=90).

### 3.1.1 Subsample:

Table 12 and Table 13 present the clinical and socio-demographic information of a subset the total sample of participants who completed the questionnaires at both time points, i.e. before treatment and 6-12 months following treatment.

**HNC patients:** From the 90 patients who completed questionnaires before treatment, 59 completed the questionnaires at both time points (before treatment and 6-12 months following diagnosis). This represented a 67% response rate. There were no statistically significant differences between socio-demographics of patients who completed both time points compared to the 31 non respondents ( $p>0.05$ ). However, 83% of the 31 non respondents had been diagnosed with <sup>15</sup>loco-regionally advanced disease, and were less likely to take part at time point 2 (see Table 12 which shows the clinical variables of patients who completed questionnaires at both time points) However, the sample at time point 2 was still equally proportioned in terms of stage of cancer (early stage  $n=26$ , loco-regionally advanced  $n=31$ ) thus not significantly biased to early stage patients. The main reasons for patient attrition included; patient death  $n=12$ , patient ill health  $n=10$ , patient withdrew  $n=2$ , lost to follow  $n=7$ .

**Caregivers:** From the 74 caregivers who completed questionnaires before treatment, forty (Partners  $n=30$ , family members  $n=10$ ) completed questionnaires at both time points, representing a 54% ( $n=34$ ) response rate. There were no statistically significant differences between socio demographics of caregivers who completed both time points compared to the 34 non respondents ( $p>0.05$ ). The main reasons for caregiver attrition included; patient death ( $n=12$ ), partners ill health ( $n=6$ ), incomplete questionnaire data ( $n=8$ ), and loss to follow up where no questionnaire was returned ( $n=12$ )

---

<sup>15</sup> Stage of disease was coded by based on the American joint committee on Cancer (AJCC), Early stage disease: Stage I, II Locoregionally advanced: Stage III or IV guidelines. These were coded by a HNC maxillofacial registrar to ensure clinical accuracy (Descher, D.G. & Day, T, 2008) .

**Table 12 Clinical Variables of HNC patients in who completed both time points (n=59) and non - respondents (n=31)**

Clinical variables	(n=59)		Non respondents (n=31)		<i>p</i> <sup>16</sup> - value
		%		%	
<b>Cancer</b>					<b>0.04</b>
First Cancer	49	83.1	<b>28</b>	90.3	
Recurrence	11	18.6	<b>3</b>	9.7	
<b>Site</b>					<b>0.54</b>
Oral cavity	27	45.8	<b>15</b>	48.4	
Oropharynx	16	27.1	<b>7</b>	22.6	
Nasopharynx	2	3.4	<b>1</b>	3.2	
Larynx	8	13.6	<b>2</b>	6.5	
Salivary gland	3	5.1	<b>3</b>	9.7	
Unknown primary	4	6.8	<b>3</b>	9.7	
<b>Stage</b>					<b>0.01</b>
Early(stage I-II)	26	44.1	<b>6</b>	19.4	
Loco regionally advanced disease (stage III-IV)	31	52.5	<b>25</b>	80.6	
<b>T classification</b>					<b>0.13</b>
X	5	8.5	<b>1</b>	3.2	
1	21	35.6	<b>5</b>	16.1	
2	16	27.1	<b>5</b>	16.1	
3	2	3.4	<b>3</b>	9.7	
4	16	27.1	<b>14</b>	45.2	
<b>Treatment</b>					<b>0.92</b>
Surgery alone	26	44.1	<b>15</b>	48.4	
Surgery +adjuvant treatment	25	42.4	<b>12</b>	38.7	
Radiotherapy only	3	5.1	<b>1</b>	3.2	
Chemo+ radiotherapy	6	10.2	<b>3</b>	9.7	

Table 12 shows the clinical variable for the subset of patients who completed questionnaires at both time points.

<sup>16</sup> Fisher's exact to examine the association between those that responded compared to non-respondents.

**Table 13 Socio-demographics of HNC patients (n=59) and Caregivers (40) who completed questionnaires at both time points (before treatment and 6-12 months following diagnosis).**

	Patient N=59		Caregiver N=40	
Age grp		%		%
18-59	25	42.4	22	55.0
60-74	26	44.1	13	32.5
75-95	8	13.6	5	12.5
Gender				
Male	43	72.9	6	15.0
Female	16	27.1	34	85.0
Marital status				
Married/ living with partner	37	62.7	34	85.0
Single	16	27.1	4	10.0
Divorced/widowed	6	10.2	2	5.0
Education				
None	25	42.4	10	25.0
G.C.S.E/equivalent	17	28.8	13	32.5
Higher Education	17	28.8	16	40.0
Missing data	0	0.0	1	2.5
Ethnicity				
White British/White other	51	86.4	37	92.5
Black British/Black other	3	5.1	1	2.5
Asian British/Asian other	4	6.8	2	5.0
Other	1	1.7	0	0.0
Employment				
Full time / part time	21	35.6	21	52.5
Unemployed	16	27.1	6	15.0
Retired	20	33.9	12	30.0
Not specified	2	3.4	1	2.5
Religion				
No religion	22	37.3	16	40.0
religion specified	37	62.7	24	60.0

Table 13 shows socio-demographic details of patients and caregivers who completed study at both time points, before treatment and 6-12 months following treatment.

## 3.2 Prevalence of psychological distress in HNC patients, partners and Caregivers

We begin with the analysis of prevalence rates in the 90 patients and 74 caregivers who completed HADS questionnaire before treatment (Table 10 for socio-demographics and Table 11 clinical information on this participant sample).

### 3.2.1 Prevalence psychological distress in HNC patients before treatment

Table 14 shows the prevalence rates of depression, anxiety and total psychological distress symptoms in HNC patients before treatment. Scores of 8 or above were taken to indicate high symptoms of anxiety or depression (Zigmond & Snaith, 1983). The prevalence rates of patients with high symptoms (scores of 8 or above) of psychological distress before treatment ranged between 20% and 41%.

**Table 14 Prevalence (%) of symptoms of depression, anxiety and total psychological distress before treatment**

	HNC patients N=90		
	<sup>17</sup> Cut off score	N	%
HADS-Depression	≥ 8	18	20
	0-7	72	80
HADS-Anxiety	≥ 8	37	41
	0-7	53	59
HADS-Total psychological distress	≥ 15	29	32
	0-14	61	68

### 3.2.2 Patient Gender and psychological distress before treatment

Before treatment, female HNC patients (n=25) showed significantly higher symptoms of anxiety;  $\chi^2 (1, ) = 10.33, p= 0.001$ ) and total psychological distress;  $\chi^2 (1, ) = 6.19, p= 0.013$  when compared to

male patients. There was no statistical difference between depressive symptoms ( $p>0.05$ ). Figure 12 shows the proportion (%) of male and female patients with high symptoms of depression, anxiety and total psychological distress before treatment

**Figure 12 Male and Female HNC patients showing high symptoms of depression, anxiety and total psychological distress before treatment (n=90).**

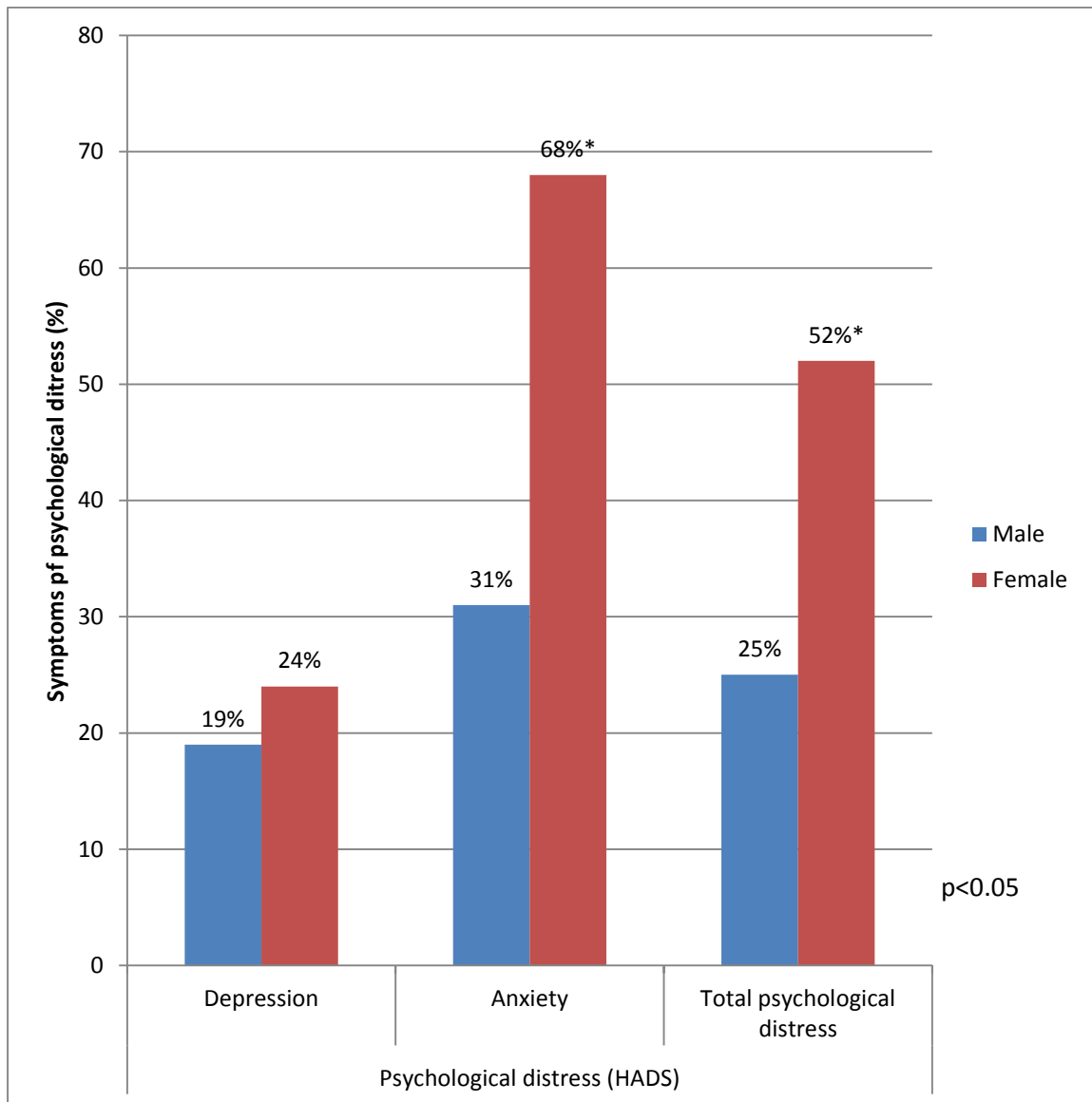
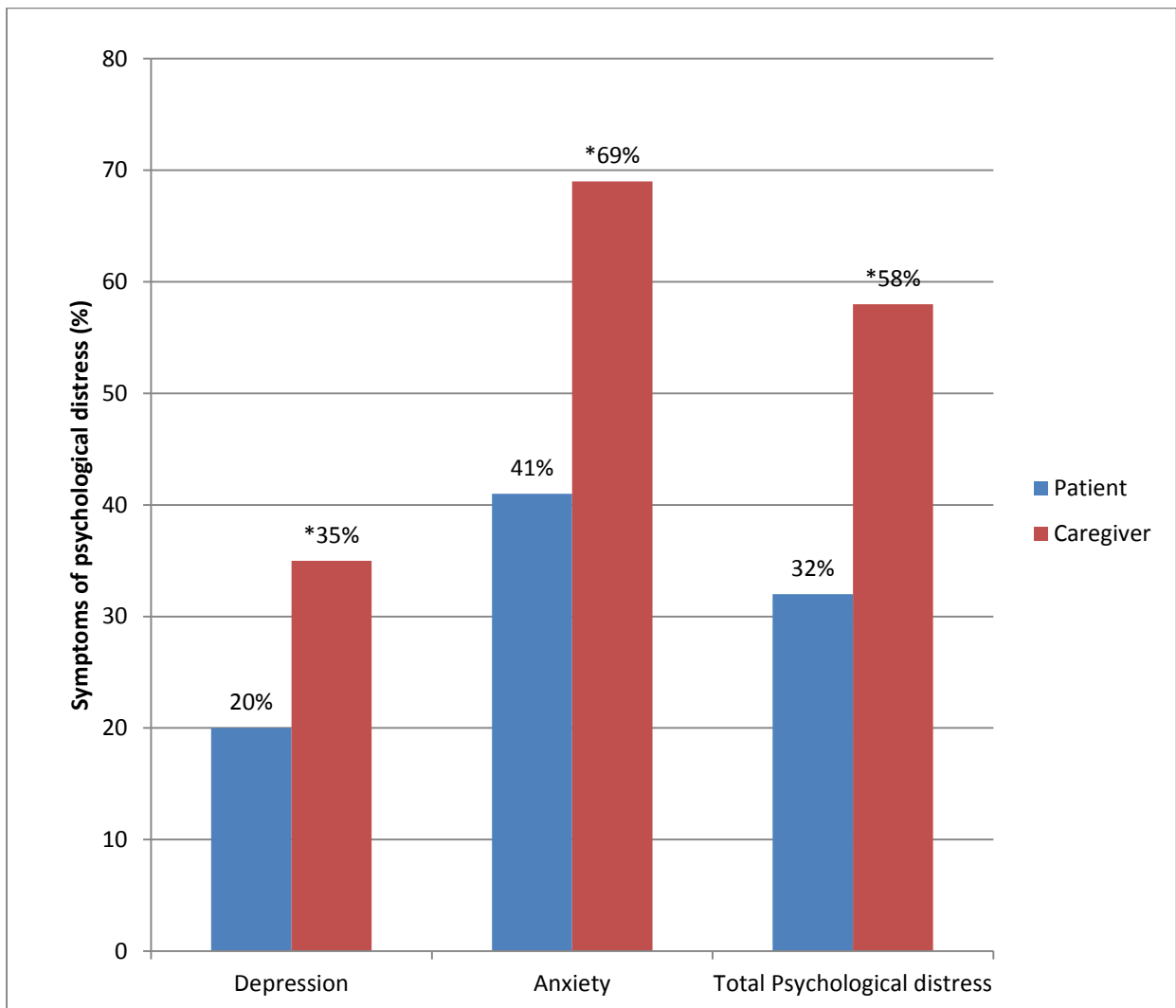


Figure 12 shows female patients are reporting elevated symptoms of depression, anxiety and total psychological distress; however there was no statistical significance between depressive symptoms and gender of patient.

### 3.2.3 Prevalence psychological distress in caregivers of HNC patients before treatment

Figure 13 shows the prevalence rates of <sup>18</sup>high levels of psychological distress between patients and caregivers before treatment. Caregivers showed significantly higher depression, anxiety and total psychological distress. These differences were statistically significant ( $p < 0.05$ )<sup>19</sup>

**Figure 13 Prevalence of high symptoms of depression, anxiety and total psychological distress before treatment in patients (n=90) and caregiver sample (n=74)**



### 3.2.4 Comparing prevalence of psychological distress between HNC patients and their partners before treatment

<sup>18</sup> Cut off scores 8 and above for depression and anxiety, 15 and above for total psychological distress

<sup>19</sup> Chi squared test showed a statistically significant difference in prevalence between patient and caregiver psychological distress.



Further analysis compared levels of psychological distress HNC couples (n= 50). The odds ratio for partner distress was 3.80 with a 95% confidence interval of 1.48-9.75. This suggests before treatment, partners' were nearly 4 times more likely to report higher symptoms of depression than HNC patients. This was statistically significant at the .05 level. The odds ratio values for anxiety and total psychological distress are shown in Table 15 where partners of HNC patients showed significantly higher proportion of psychological distress (depression, anxiety and total psychological) than HNC patients.

Table 15 Odds ratio of psychological distress between patients and partners

	Partner OR N=50	
	<sup>20</sup> OR [95% CI]	P-value
Depression	3.80 [1.48-9.75]	0.005
Anxiety	4.26[1.83-9.97]	0.001
Total psychological distress	4.53[1.95-10.51]	0.001

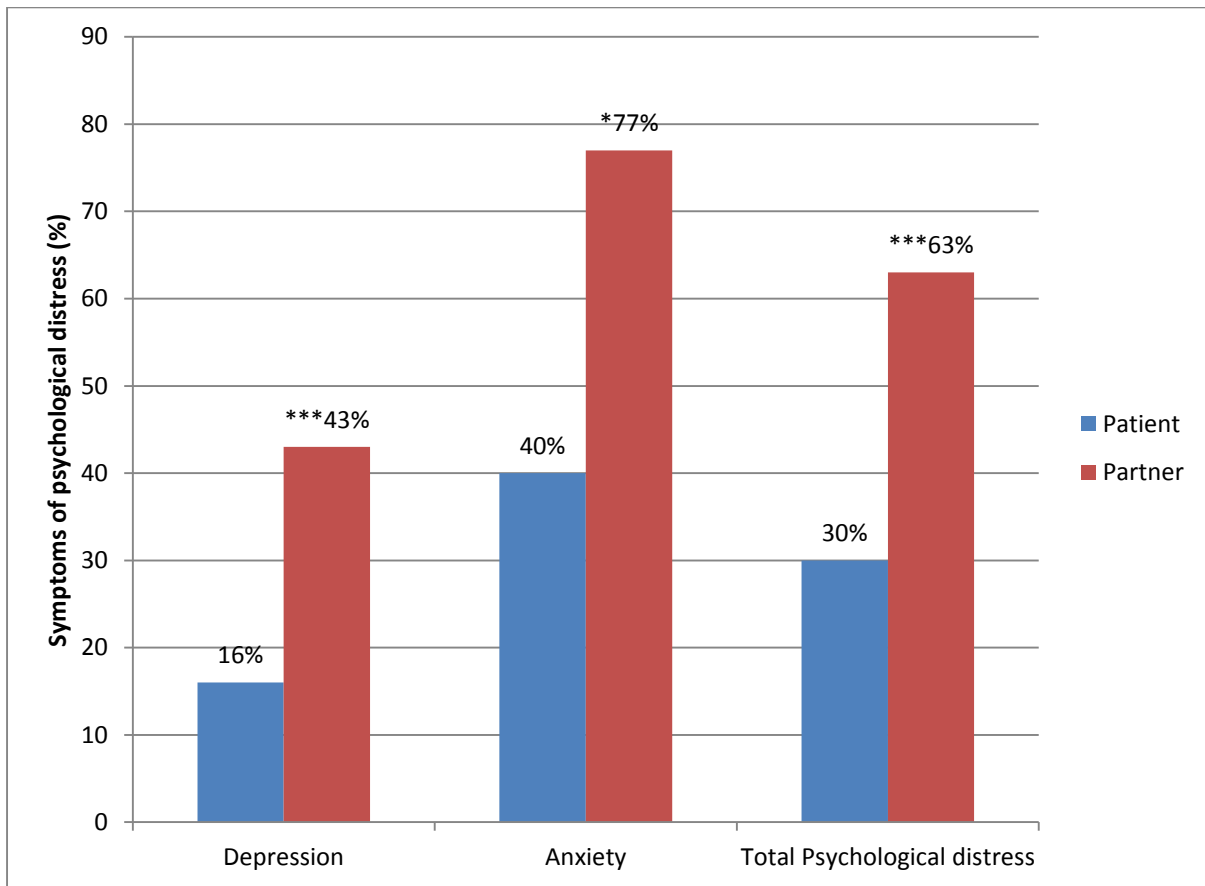
Table 15 shows before treatment partners are showing significantly higher odds of showing elevated symptoms of depression, anxiety and total psychological distress than HNC patient.

Figure 14 shows the levels of psychological distress before treatment in patients ranged between 16% and 30% compared to 43% and 77% in their partner's (n=50). These differences were statistically significant, suggesting partners are reported higher depression, anxiety and total psychological distress before treatment. When examining the prevalence rates of high levels of anxiety and depressive symptoms in HNC couples; patients who experienced high symptoms of depression (8 out of 50= 16% of total sample), 98% (7 out of the 8 patients) also had a partner who had high symptoms of depression ( $p>0.005$ ). Also, from the 40% of patients (20 /50) who experienced high symptoms of anxiety, 85% (17 out of 20) also had a partner with elevated levels of anxiety ( $p>0.05$ ).

---

<sup>20</sup> HNC Patients reference group.

Figure 14 Prevalence of psychological distress in HNC patients and their Partners before treatment



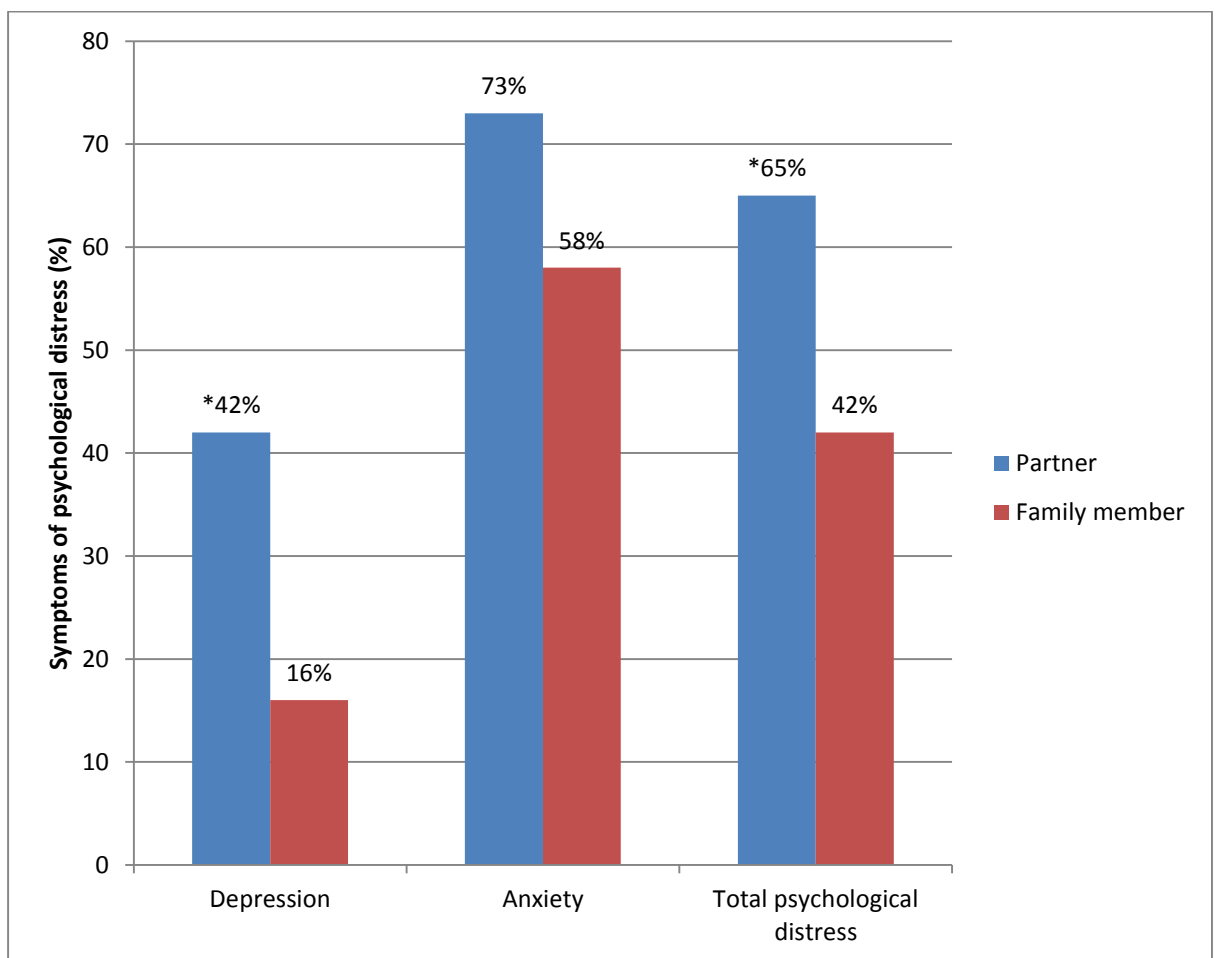
\*  $P \leq 0.05$  \*\*  $P \leq 0.01$  \*\*\*  $P \leq 0.001$

Figure 14 shows before treatment, partners are showing statistically higher symptoms of depression, anxiety and total psychological distress when compared to HNC patient.

### 3.2.5 Comparing prevalence rates of psychological distress within caregivers

A sub group analysis examining the difference in prevalence levels between partners (n=50) and family member's (n=24) was also undertaken. Results showed that before treatment partners were more likely to report elevated symptoms of depression, anxiety and total psychological distress than other family members.

**Figure 15** Prevalence of psychological distress in partners of HNC patients compared to family members of HNC patients



\* P ≤ 0.05

Figure 15 shows partners of HNC patients are showing higher symptoms of depression and total psychological distress than family members of HNC patients. The difference in prevalence levels were statistically significant <sup>21</sup>(p<0.05). There was no statistical difference between levels of anxiety; both partner and family members are showing high symptoms before treatment.

<sup>21</sup> Fisher's exact test

### 3.2.6 Prevalence levels of psychological distress in participants who completed HADS at two time points

#### 3.2.7 Prevalence rates in HNC patients before treatment and 6-12 months following treatment

Fifty-nine HNC patients (43 male, 16 female) completed the HADS questionnaire, before treatment and 6-12 months following diagnosis. Seventy-three per cent (n=43) of this sample were male with a mean age of 62 (SD 11.9, range 29-82). See Table 13, for socio-demographics of patients and Table 12 for clinical details.

Table 16 shows a longitudinal assessment of HNC patients with clinically high levels of depression, anxiety and total psychological distress; before treatment and 6-12 months following diagnosis. Similar to the cross sectional analysis, patients prevalence rates of psychological distress before treatment ranged between 17% to 27%, however 6-12 months following diagnosis prevalence rates ranged between 25% and 32%. There was no significant differences between gender and levels of psychological distress 6-12 months diagnosis ( $p>0.05$ ).

**Table 16 Compares prevalence psychological distress in HNC patients who completed HADS before treatment and 6-12 months post treatment (n=59)**

N=59	HADS Before treatment			HADS 6-12 months	
	<sup>22</sup> Cut off score	n	%	n	%
HADS-Depression	<b>≥ 8</b>	<b>10</b>	<b>17</b>	<b>16</b>	<b>27</b>
	0-7	49	83	43	73
HADS-Anxiety	<b>≥ 8</b>	<b>24</b>	<b>41</b>	<b>19</b>	<b>32</b>
	0-7	35	59	40	68
HADS-Total psychological distress	<b>≥ 15</b>	<b>16</b>	<b>27</b>	<b>15</b>	<b>25</b>
	0-14	43	73	44	75

Table 16 shows an increase in depressive symptoms, with a small decrease in anxiety and psychological distress 6-12 months following treatment.

<sup>22</sup> HADS cut off scores as recommended by <sup>22</sup>Zigmond and Snaith; where HNC patients have been grouped according to their scores on the HADS questionnaire. Scores 0-7 is within 'normal range' with scores 8 and above relating to a possible mood disorder. The total psychological distress indicates scores 15 above suggesting high levels of total psychological distress.

### 3.2.8 Prevalence of psychological distress in caregivers before treatment and 6-12 months following treatment

A total of 40 caregivers (30 partners, 10 family members) completed the HADS questionnaire at both time points (before treatment and 6-12 months following diagnosis). The majority of the sample was female (n=34, male; n=6), with mean age of 58 (SD 12.5, range 31-85).

(See Table 13 for socio-demographics of caregivers who completed HADS before treatment and 6-12 months following treatment).

**Table 17 Prevalence of psychological distress in Caregivers before treatment and 6-12 months following treatment**

Caregivers N=40	HADS				
	Before treatment			6-12 months	
	Cut off score	n	%	n	%
HADS-Depression	≥ 8	15	38	11	28
	0-7	25	63	29	73
HADS-Anxiety	≥ 8	30	75	24	60
	0-7	10	25	16	40
HADS-Total psychological distress	≥ 15	23	58	18	45
	0-14	17	43	22	55

Table 17 shows a longitudinal assessment of caregivers with clinically high levels of depression, anxiety and total psychological distress; before treatment and 6-12 months following diagnosis. Similar to the cross sectional analysis, caregivers prevalence rates of psychological distress before treatment ranged between 38% and 58%. These high prevalence rates continued 6-12 months following diagnosis, with prevalence rates ranging between 28% and 60%. Longitudinal analysis showed caregiver's reported higher symptoms of depression and anxiety than patients before treatment and 6-12 months following diagnosis. These findings also highlight symptoms of psychological distress are not just transient reactions that occur following diagnosis. For a

proportion of caregivers, elevated symptoms continue 6 to 12 months, particularly symptoms of anxiety

### **3.2.9 Prevalence of psychological distress in HNC Couples before treatment and 6-12 months following treatment**

Figure 16 shows longitudinal assessment of prevalence rates in HNC patients and their partners (n=30). Graph showed partners' of HNC patients reported higher prevalence of depression, anxiety and total psychological distress before treatment and 6 to 12 months following treatment. These differences were statistically significant ( $p < 0.05$ ). Although, HNC partner's levels of distress decreased slightly over time, it still remained higher than patients. At 6-12 months, prevalence levels of psychological distress ranged between 31% and 66%, compared to 20% and 23% in HNC patients.

Figure 16 Changes over time in the % prevalence of high HADS scores in HNC couples (n=30)

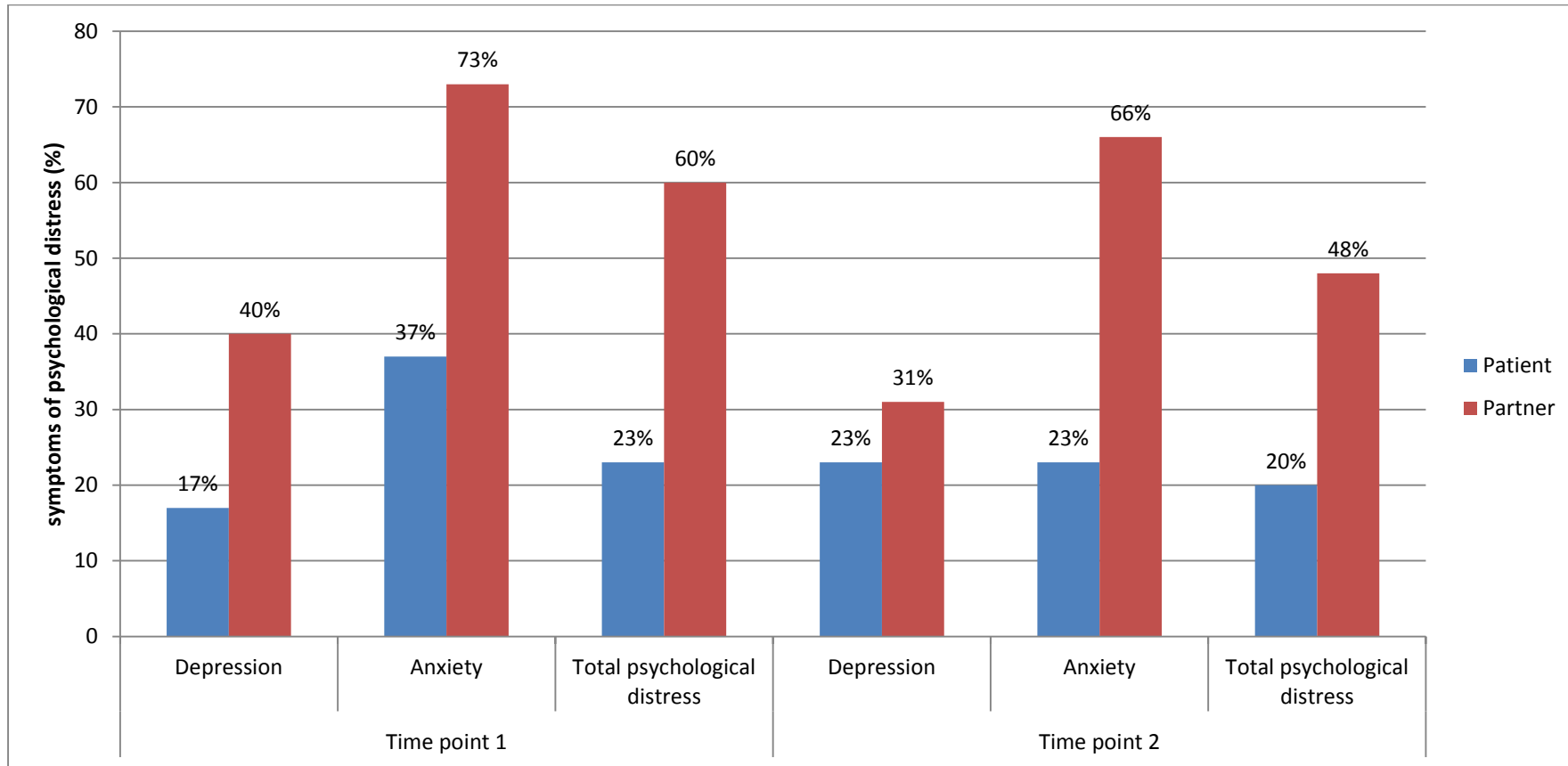


Figure 16 shows the difference in prevalence of psychological distress between HNC patients, and their partners. Partners of HNC patients are showing higher levels of psychological distress than HNC patient before treatment (time point 1) which continues 6-12 months following diagnosis (time point 2).

### **3.2.10 Summary of prevalence of psychological distress**

HNC cancer patients reported high symptoms of psychological distress, before treatment and 6-12 months following treatment. However, caregivers particularly the partner of the HNC patients is showing significantly higher symptoms of depression and anxiety than HNC patients at both time points. Partners are also showing significantly higher levels of psychological distress, when compared to family members. This highlight the different emotional experience partners may experience when compared to family members.



### 3.3 The association of patient and caregiver psychological distress on HNC patients' QoL

#### 3.3.1 Descriptive Analysis: Patient QoL and Psychological distress

Descriptive analysis showed before treatment, HNC patients with elevated symptoms of depression and anxiety reported lower mean QoL scores.

**Table 18 mean scores of patient QoL by their level of depression and anxiety symptoms (n=90)**

		HNC patient psychological distress			
		<sup>23</sup> Depression			
		Low (n=72)		High (n=18)	
Patient Quality of life	WHOQOL-BREF Domains	Mean	SD	Mean	Std. Dev.
	Physical	71.42	(19.34)	<b>44.39</b>	<b>(25.14)</b>
	Psychological	68.94	(13.62)	<b>51.11</b>	<b>(14.00)</b>
	Social relationships	78.75	(17.07)	<b>58.39</b>	<b>(22.78)</b>
	Environment	78.72	(15.06)	<b>58.50</b>	<b>(18.52)</b>
		<sup>24</sup> Anxiety			
		Low (n=53)		High (n=37)	
	Physical	71.96	(20.64)	<b>57.49</b>	<b>(24.21)</b>
	Psychological	66.58	(14.03)	<b>63.65</b>	<b>(17.20)</b>
	Social relationships	78.23	(19.39)	<b>69.59</b>	<b>(19.94)</b>
	Environment	77.62	(16.66)	<b>70.46</b>	<b>(18.45)</b>

Table 18 showed patients with high symptoms of depression and anxiety showed considerably lower mean scores within all four QoL domains, particularly physical QoL, when compared to patients with low symptoms of depression anxiety.

<sup>23</sup> Depression: Patient Low depression: HADS-D:≤ 8; High depression : HADS-D≥8

<sup>24</sup> Anxiety: Patient low anxiety: HADS-A ≤8; patient high anxiety: HADS≥8

### 3.3.2 Descriptive Analysis: Patient QoL and Caregiver Psychological distress

Similarly, Table 19 showed HNC patients with a caregiver reporting high symptoms of depression or anxiety, also showed lower mean scores in the physical, psychological, social relationship and environment QoL domains (before treatment). This difference is particularly evident when compared to patients who had a caregiver showing low symptoms of anxiety and depression. Scores were particularly lower within the social relationships domains, suggesting the impact on patient's personal relationships, perceived social support and intimacy. High depressive scores in caregivers showed a greater decline in patients QoL when compared to high anxiety scores.

<b>Table 19 Before treatment: Mean and SD scores of patient QoL by level of depression and anxiety symptoms caregivers</b>						
			<b>Caregiver psychological distress N=74</b>			
			<b><sup>25</sup>Depression</b>			
Patient Quality of life			<b>Low (n=72)</b>		<b>High (n=18)</b>	
	WHOQOL Domain		Mean	SD	Mean	Std. Dev.
	Physical		73.24	17.25	<b>57.83</b>	<b>24.28</b>
	Psychological		68.33	14.08	<b>61.54</b>	<b>11.16</b>
	Social relationships		80.72	14.97	<b>67.75</b>	<b>24.02</b>
	Environmental		80.35	13.94	<b>68.88</b>	<b>19.77</b>
			<b><sup>26</sup>Anxiety</b>			
			<b>Low (n=53)</b>		<b>High (n=37)</b>	
	Physical		72.82	14.16	<b>65.73</b>	<b>23.39</b>
	Psychological		68.27	14.32	<b>64.96</b>	<b>13.08</b>
	Social relationships		80.41	14.97	<b>74.38</b>	<b>21.01</b>
	Environmental		79.73	14.97	<b>74.90</b>	<b>17.72</b>

<sup>25</sup> Depression: Patient Low depression: HADS-D:≤ 8; High depression : HADS-D≥8

<sup>26</sup> Anxiety: Patient low anxiety: HADS-A ≤8; patient High anxiety: HADS≥8

### **3.3.3 Testing the association between patient and caregiver psychological distress before treatment and patient QoL (Testing hypothesis i and ii)**

A univariate regression analysis was undertaken to construct a statistical model to predict the impact of each of the following <sup>27</sup>psychological factors: 1) Patient anxiety (HADS-A), 2) Patient depression (HADS-D), 3) Patient total psychological distress(HADS-T) 4) caregiver anxiety (HADS-A) 5) Caregiver depression (HADS-D) 6) caregiver total psychological distress HADS-T on the four <sup>28</sup>WHOQOL-BREF domains: physical, psychological, social relationships and environment: (outcome measures). A stepwise modelling approach was performed, where each psychological factor that was significantly associated (0.05 levels) with each QoL domain, was entered into a multivariate model. The aim of the model was to identify psychological factors that were most strongly associated with patient QoL before treatment.

#### **3.3.3.1 Univariate Model examining the association between patient psychological distress, caregiver psychological distress and patient QoL**

Table 20 shows the univariate analysis of the statistically significant associations between psychological factors and patient quality of life.

The findings of the univariate analysis showed there was a statistically significant association between patients with high symptoms of depression, anxiety and total psychological distress before treatment and their physical quality of life, suggested an impact of psychological distress on patients QoL. This association was still present, when adjusted for patient gender and age. This association was also shown in the psychological, social relationships and environment domains ( $p < 0.05$ ). Patient anxiety was also statistically associated with physical, social relationships and

---

<sup>27</sup> Psychological factors measured by cut off scores of the Hospital depression and anxiety scale : Anxiety :HADS-A, Depression HADS-D, Total psychological distress

<sup>28</sup> The WHOQOL -Bref domains were log transformed to allow a linear regression model to be fitted to the data. When the scale was transformed due to the negative skew of the data, the scale was transformed and converted the negative beta coefficients to represent a positive change i.e. negative coefficient shows better quality of life. Thus the direction of change in the transformed variables are represented by negative coefficient meaning a positive change and a positive coefficient meaning a decrease in quality of life scores. To make the transformed beta coefficients clinically meaningful the coefficients were back transformed to represent a percentage change. This percentage change allowed interpreting the effect of the variable on the outcome variable and is a standard procedure when transforming variables.

environment domain, however there was no association between patient anxiety and the psychological domain of WHOQOL-BREF ( $p > 0.05$ ).

Also univariate analysis showed a statistically significant association between patients QoL and Caregiver depression. This suggests patients who had a caregiver reporting high symptoms of depression before treatment, were reporting significantly lower QoL.

Table 20 shows HNC patients are reporting 35% lower scores within the physical quality of life domain [ $\beta = 35$ , CI95% 21-46,  $P < 0.01$ ] when they had a caregiver who had high symptoms of depression before treatment. Caregiver depression was also significantly associated with patients psychological, social relationship and environment QoL domains ( $p < 0.01$ ). There was no association between caregiver anxiety and patients QoL ( $P > 0.05$ ).

**Table 20 univariate statistical associations between psychological factors and patient quality of life (outcome)**

WHOQOL-BREF domain	N	Predictor variables:	<sup>29</sup> Percentage Change [95%CI]	p value
<b>Physical</b>				
	90	Patient Depression	35 [21-46]	0.01
	90	Patient Anxiety	22 [9-34]	0.01
	90	Patient Total Psychological Distress	36 [26-45]	0.01
	74	Caregiver Depression	22 [8-35]	0.01
<b>Psychological</b>				
	90	Patient Depression	27 [17-36]	0.01
	90	Caregiver Depression	13 [2-23]	0.02
	74	Caregiver Total Psychological Distress	10 [1-21]	0.06
<b>Social Relationships</b>				
	90	Patient Depression	27 [14-38]	0.01
	90	Patient Anxiety	15 [1-26]	0.03
	74	Caregiver Depression	18 [4-30]	0.02
	74	Caregiver Total Psychological Distress	15 [0-27]	0.05
<b>Environmental</b>				
	90	Patient Depression	32 [20-43]	0.01
	90	Patient Total Psychological Distress	30 [20-39]	0.01
	90	Patient Anxiety	14 [0-26]	0.05
	74	Caregiver Depression	20 [5-32]	0.01

<sup>29</sup>Percentage change represents the back transformed regression coefficient:

### **3.3.3.2 Multivariate model examining the association of patient depression and caregiver depression, on patient QoL (adjusted for age and gender).**

The multivariate analysis included the variables that were significantly associated with patients low QoL from the univariate analysis shown in Table 20. Due to small sample size, multivariate analysis was limited to the number of variables that could be entered into the model. Therefore, patient depression and caregiver depression were entered in the same model. The results showed caregiver depression was still significantly associated with patients physical QoL [<sup>30</sup>B% 17, 95% CI 1-31,  $P=0.04$ ]. This suggested caregiver depression is showing an independent association with patients physical QoL, even when patient depression is within the same model (Table 21). However, there was no statistical significant association between caregiver depression and patients (psychological, social and environmental domain) before treatment when patient depression was added to the model. ( $p>0.05$ ). This may be due to small sample size, reducing the statistical power of the model.

---

<sup>30</sup> B% represents percentage change

**Table 21 Adjusted  $\beta$ % model of patient and caregiver depression and QoL domains**

<b>WHOQOL-BREF domain</b>			
	Predictor variables:	Percentage Change [95%CI]	p-value
<b>Physical</b> n=74			
	*Patient Depression	20 [0-36]	0.05
	*Caregiver Depression	17 [1-31]	0.04
<b>Psychological</b> n=74			
	*Patient Depression	19 [6-31]	0.01
	Caregiver Depression	7 [-5-18]	0.23
<b>Social relationships</b> n=74			
	Patient Depression	15 [-6-32]	0.14
	Caregiver Depression	14 [-3-28]	0.09
<b>Environmental</b> n=74			
	*Patient Depression	26 [7-41]	0.01
	Caregiver Depression	12 [-5-26]	0.15

\*Statistically significant associations

Table 21 shows the multivariate model found patient depression and caregiver depression had an independent association with patient QoL before treatment. However, the table showed, both factors (patient and caregiver depression) remain significant when tested within the same model. There was no significant association between caregiver depression and the psychological, social relationships and environment domain ( $p > 0.05$ ).

Table 22 showed the final model, comparing the univariate model (unadjusted model) percentage change scores with multivariate model percentage change scores (adjusted model).

**Table 22 shows the unadjusted and adjusted percentage change [95% CI] in physical QoL for patient and caregiver depression (adjusted for patient age and gender).**

WHOQOL-BREF	Predictor variables	Percentage Change [95%CI]		Percentage Change [95%CI]	
		Unadjusted	p-value	<b>Adjusted</b>	p-value
Physical: n=74	Patient depression	35 [21-46]	<b>0.01</b>	<b>20 [0-36]</b>	0.05*
	Caregiver depression	22 [8-35]	<b>0.01</b>	<b>17 [1-31]</b>	0.04*

Table 22 shows patients depression contributes the most significantly to patients physical QoL (20 per cent change in QoL) however multivariate analysis found caregiver depression has an independent association thus contributing to this association. These associations were still present when adjusted for patient age.

To assess this association further, a pathway and mediation analysis was undertaken. This aimed to assess the amount of variance caregiver depression contributed to patient physical quality of life and establish direction of effect.

### 3.4 Path analysis

A path analysis was conducted to provide estimates of the magnitude and significance of the hypothesised causal connections between patient depression, caregiver depression and patient physical quality of life. The path diagram in figure 16 shows the standardised  $\beta$  coefficients between these associations on the <sup>31</sup>log transformed scale.

**Figure 17 Path analysis diagram showing the associations between patient depression, caregiver depression and patient physical QoL**

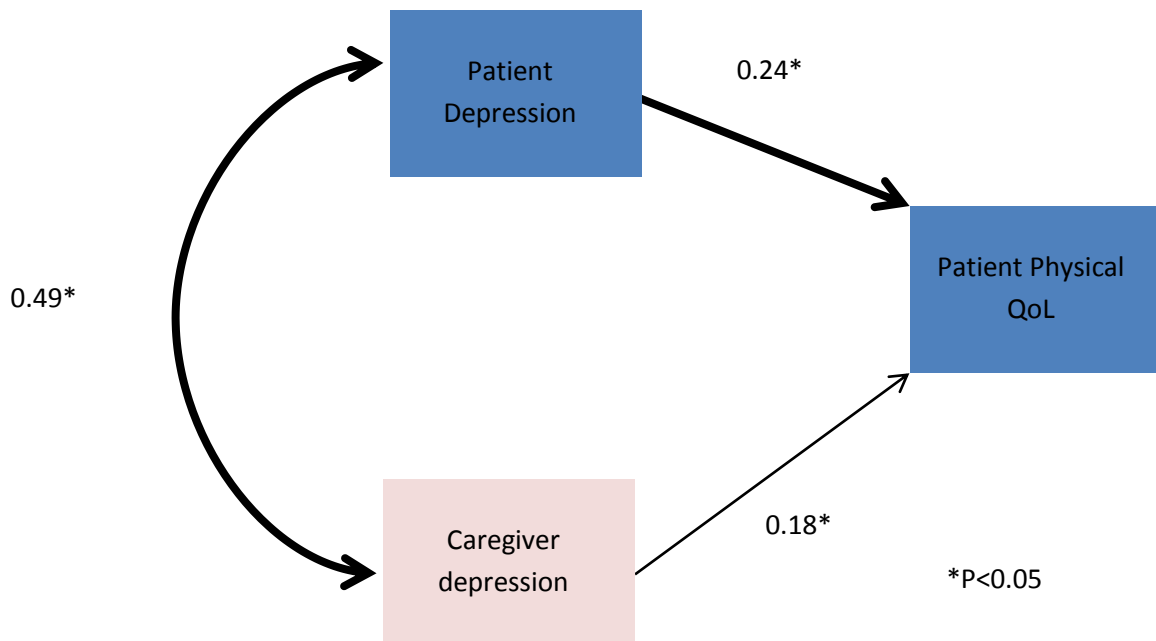


Figure 17 shows a path analysis diagram with standardised parameters ( $p<0.05$ ). Arrows represent the direction of the significant associations. Width of arrows varies according to strength of association to aid interpretation.

Path analysis showed a strong correlation between patient and caregiver depression, and an independent significant association between caregiver depression and patient physical quality of life and an independent significant association between patient depression and patient physical quality of life. To examine these associations further, a mediation analysis was conducted.

<sup>31</sup> The WHOQOL- bref was log transformed, when the scale was log transformed due to the negative skew of the original WHOQOL-BREF domains, the scale was transformed and converted the negative coefficients to represent a positive change i.e. negative coefficient shows better quality of life. Thus the direction of change in the transformed variables represent the following; negative coefficient meaning a positive change i.e. better quality of life, and a positive coefficient meaning a decrease in quality of life scores.



### 3.5 Mediation Analysis:

A mediation analysis was conducted in <sup>32</sup>STATA 12 using the <sup>33</sup>medeff command.

Results of the mediation analysis show the standardized indirect effect was 0.26 [95% CI 0.15-0.75], this indirect effect was statistically significant  $p < 0.10$ . This suggests that 26% of the total effect of patient depression and patient physical QoL was mediated by caregiver depression (Figure 18).

**Figure 18 Standardised regression coefficients for the relationship between patient depression and patient physical quality of life as mediated by caregiver depression**

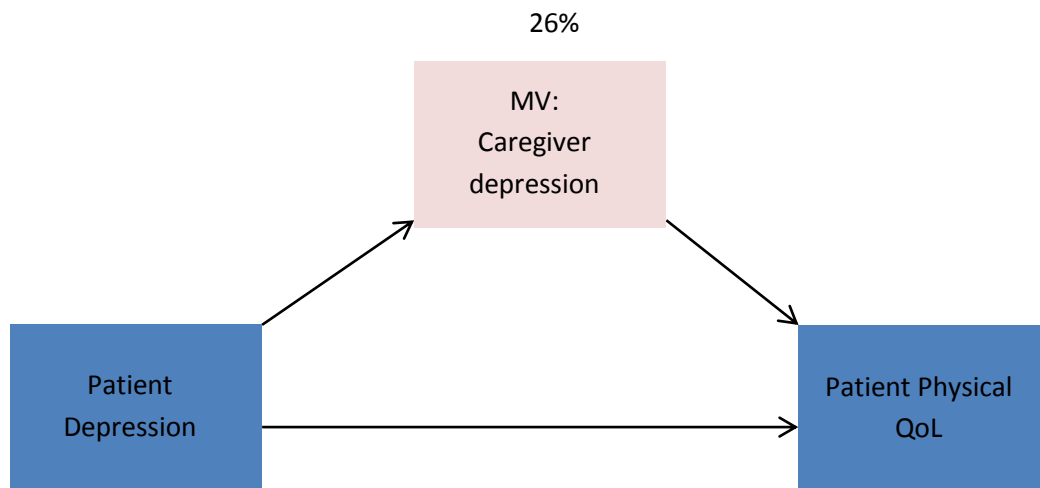


Figure 18 illustrates the relationship between patient depression and patient physical QoL was mediated by caregiver depression.

The mediation analysis suggested that before treatment, if patients have a caregiver with depression in addition to their own depression- they are more likely to report lower physical QoL(before treatment) compared to patients who do not have a distressed caregiver.

<sup>32</sup> StataCorp. 2011. *Stata Statistical Software: Release 12*. College Station, TX: StataCorp LP.

<sup>33</sup> medeff is the command for estimating mediation effects for a variety of data types. For a continuous mediator variable and a continuous outcome variable, the results will be identical to the usual Baron and Kenny method. The command can however, accommodate other data types, including binary outcomes and mediators, and calculate the correct estimates.

### **3.6 Does psychological distress before treatment predict QoL 6-12 months following diagnosis? (Longitudinal analysis: testing hypothesis 3 and 4)**

A descriptive analysis looked at the patterns across mean scores, followed by a regression analysis to test the association between psychological distress before treatment and patient QoL 6-12 months following diagnosis.

#### **3.6.1 Descriptive analysis: Patient psychological before treatment and patient QoL 6-12 months following diagnosis.**

HNC patients who reported <sup>34</sup>high symptoms of depression before treatment, reported lower mean scores in all four quality of life domains 6-12 months following diagnosis. The following graphs show the mean patient QoL scores for each domain; physical Figure 19, psychological, Figure 20, social relationships Figure 21 and environment domain Figure 22 by scores of patients depressive symptoms before treatment.

---

<sup>34</sup> Depression: High levels of depressive symptoms are based on a score of 8 or above on the Hospital anxiety and depression scale (HADS). Patient low depression is based on a score of 0-7 on the HADS.

Figure 19 changes over time in PHYSICAL QoL in patients with high depression compared with patients with low depression scores.

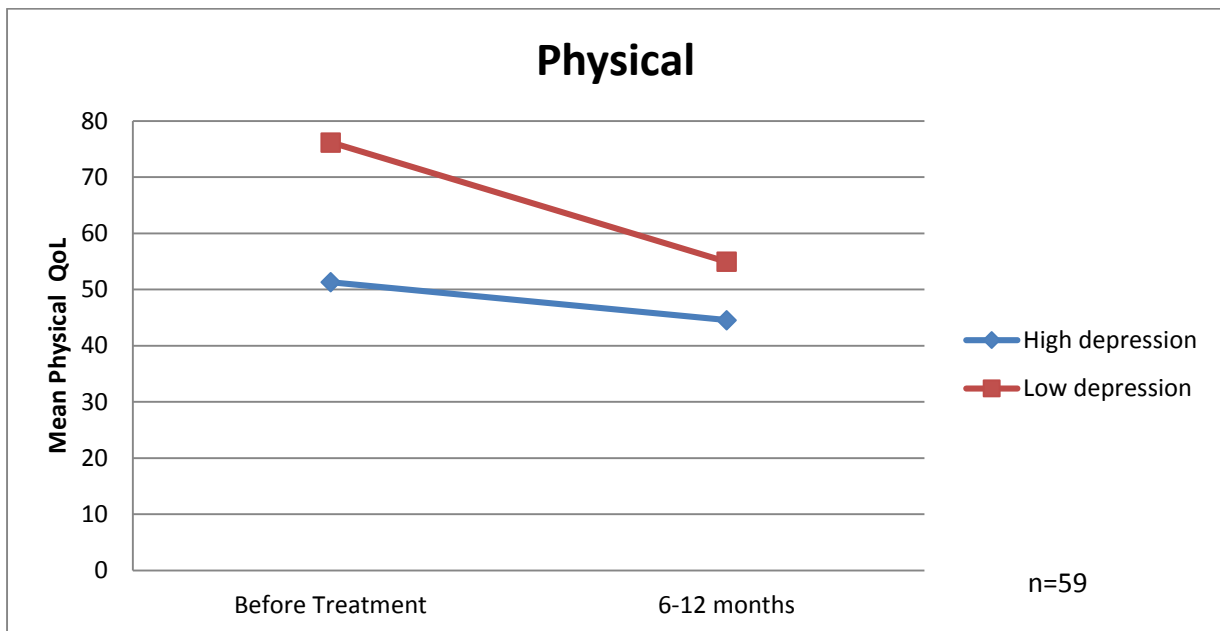


Figure 19 shows a decline in physical QoL over time in both high and low depression groups. However, patients had high symptoms of depression before treatment reported lower mean scores 6-12 months following diagnosis than patients who reported low depressive symptoms.

Figure 20 changes over time in PSYCHOLOGICAL QoL in patients with high depression scores before treatment

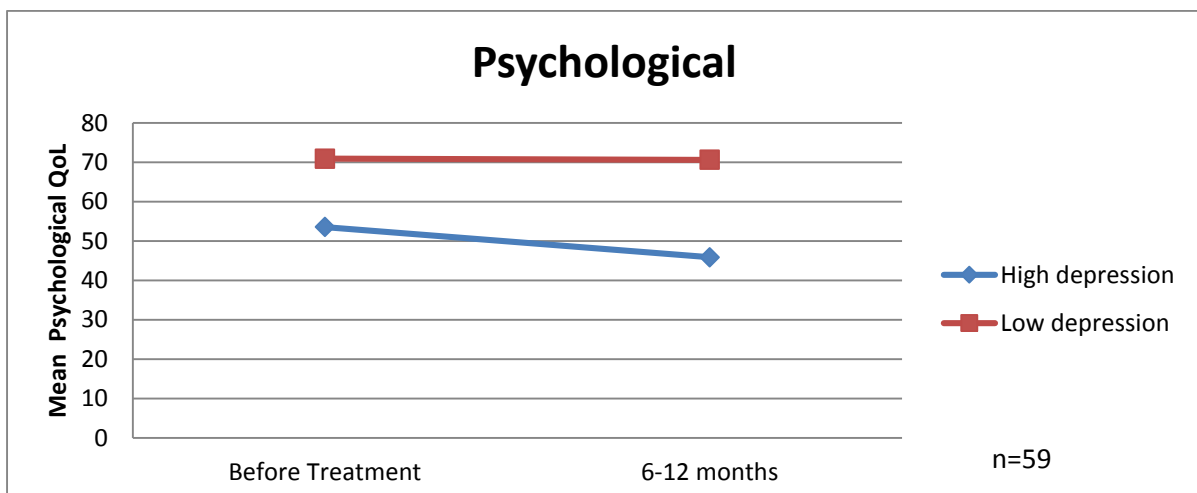


Figure 20 shows patients with low scores of depression before treatment show no change in mean score within the psychological QoL domain 6-12 months following diagnosis. In contrast, patients who reported high symptoms of depression before treatment reported lower mean scores at both time points.

Figure 21 changes over time in SOCIAL RELATIONSHIPS in patients with high depression scores before treatment

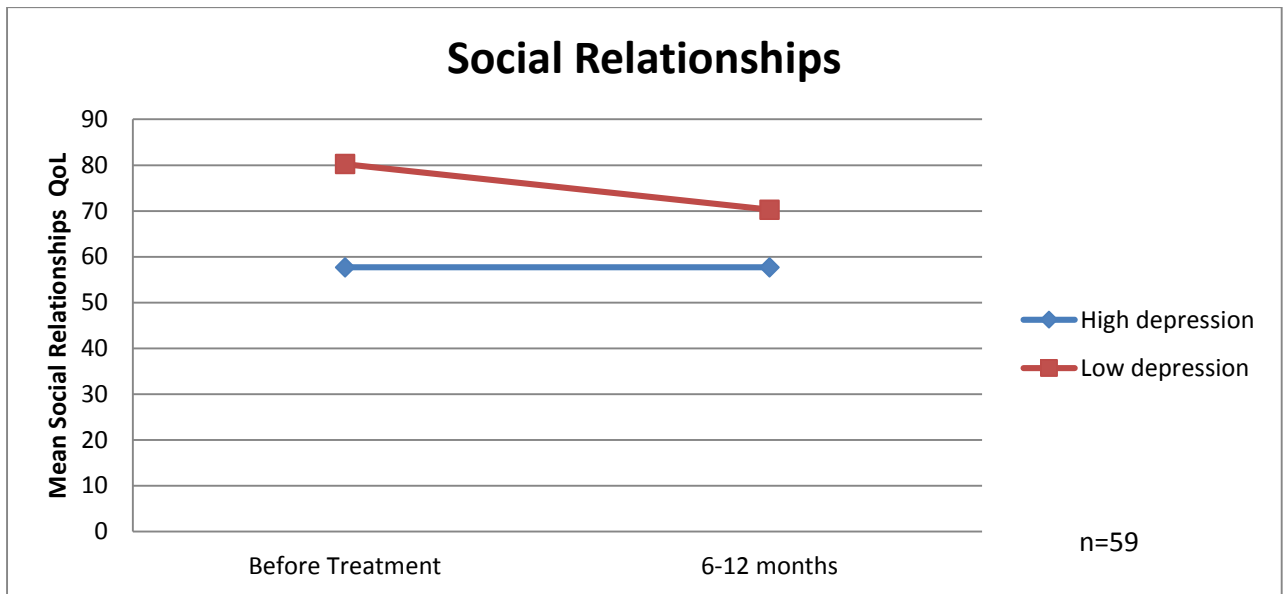


Figure 21 shows a decline in the social relationships domain for patients in the high and low depression groups. However, patients in the high depression group showed lower mean scores at both time points.

Figure 22 changes over time in ENVIRONMENT QoL in patients with high depression scores before treatment

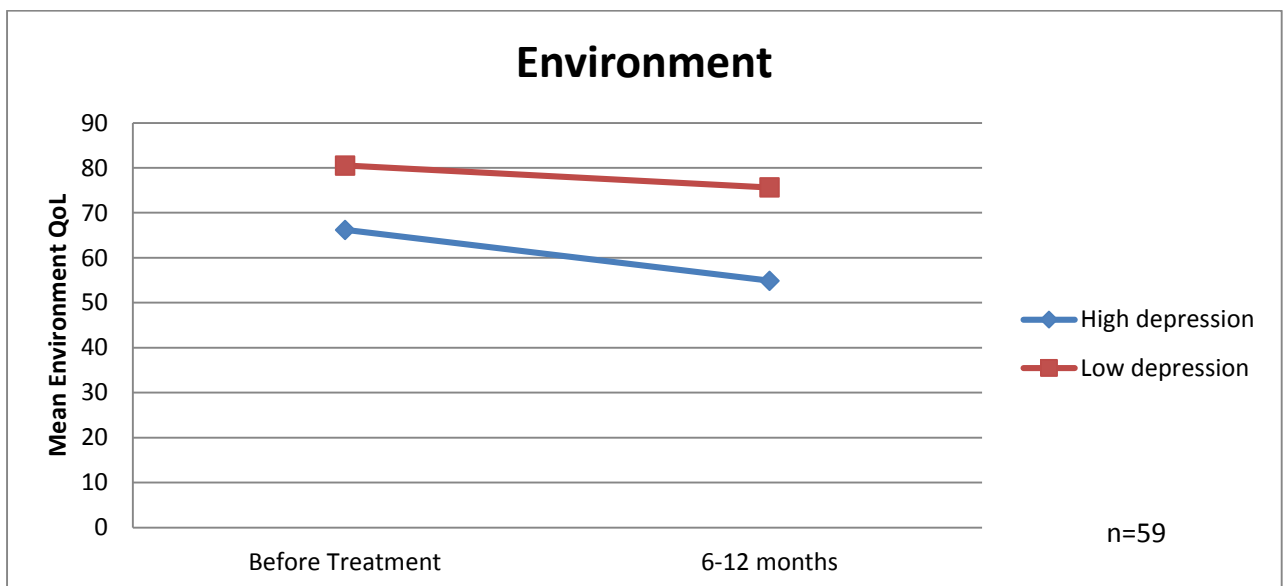


Figure 22 shows a decline over time for patients in the high and low depression group, however patients with high depression scores before treatment showed lower mean scores 6-12 months following diagnosis.

### 3.6.2 Descriptive analysis: Caregiver (partner only) psychological distress before treatment and patient QoL 6-12 months following diagnosis.

HNC patients who had partner (n=30) reporting high symptoms of depression before treatment, reported lower QoL over time. The following graphs show patient QoL scores over time by level of depressive symptoms in partners before treatment. Patients mean physical QoL is presented in Figure 23, Psychological in Figure 24, Social relationships in Figure 25 and environment domain in Figure 26.

Figure 23 changes over time in patients PHYSICAL QOL by PARTNER depression scores before treatment

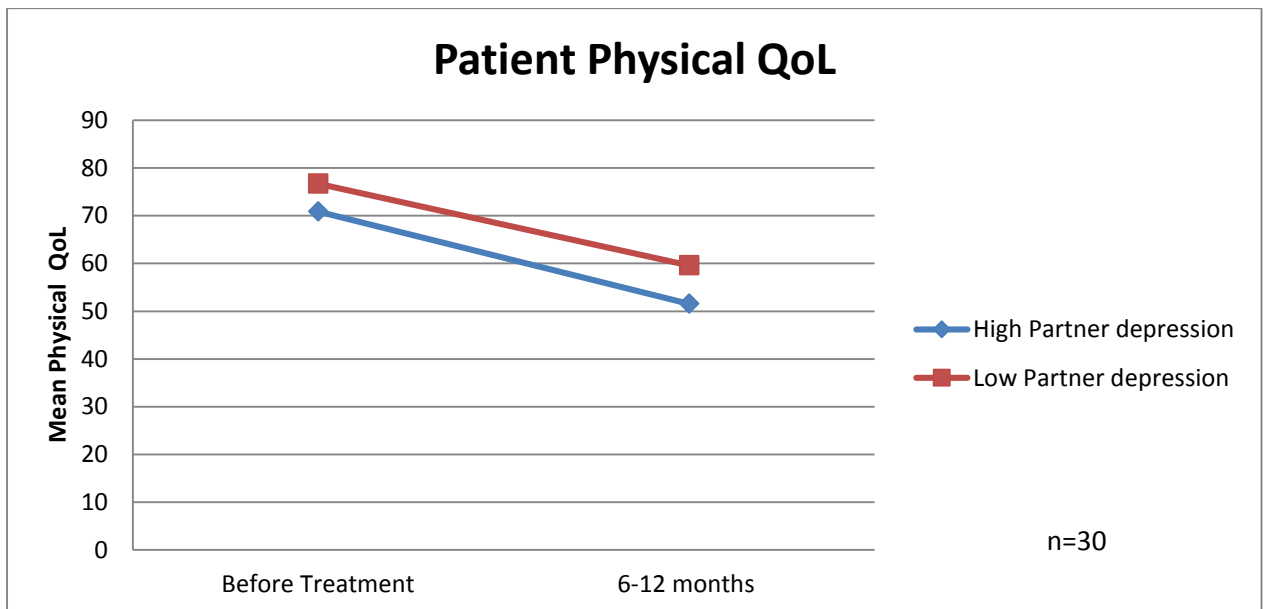


Figure 23 shows patients who had with partner with high symptoms of depression before treatment were showing lower physical QoL 6-12 months following diagnosis.

Figure 24 changes over time in patients PSYCHOLOGICAL QoL by PARTNER depression scores before treatment

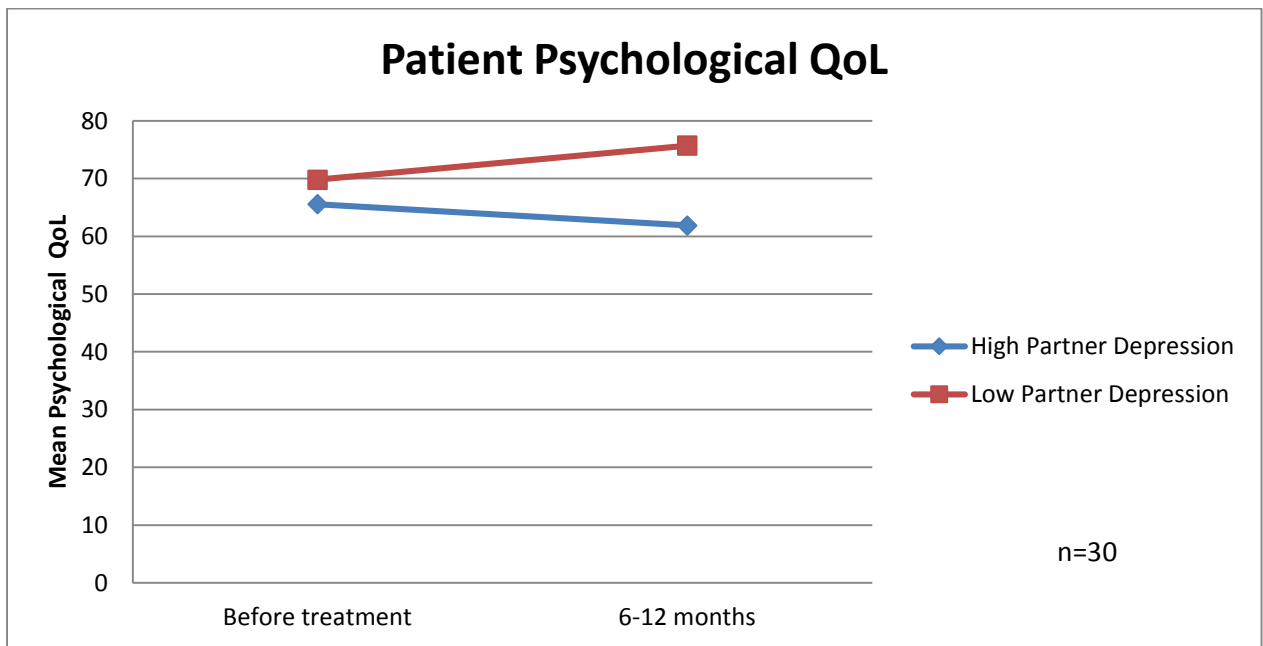


Figure 24 shows patients who had a partner with low depression before treatment, had better psychological QoL 6-12 months following diagnosis. In contrast, patients whose partner reported high symptoms of depression before treatment, showed lower psychological QoL over time. This particularly highlights the negative impact of partners' depressive symptoms on patients psychological wellbeing.

Figure 25 changes over time in patients SOCIAL RELATIONSHIPS by PARTNER depression scores before treatment

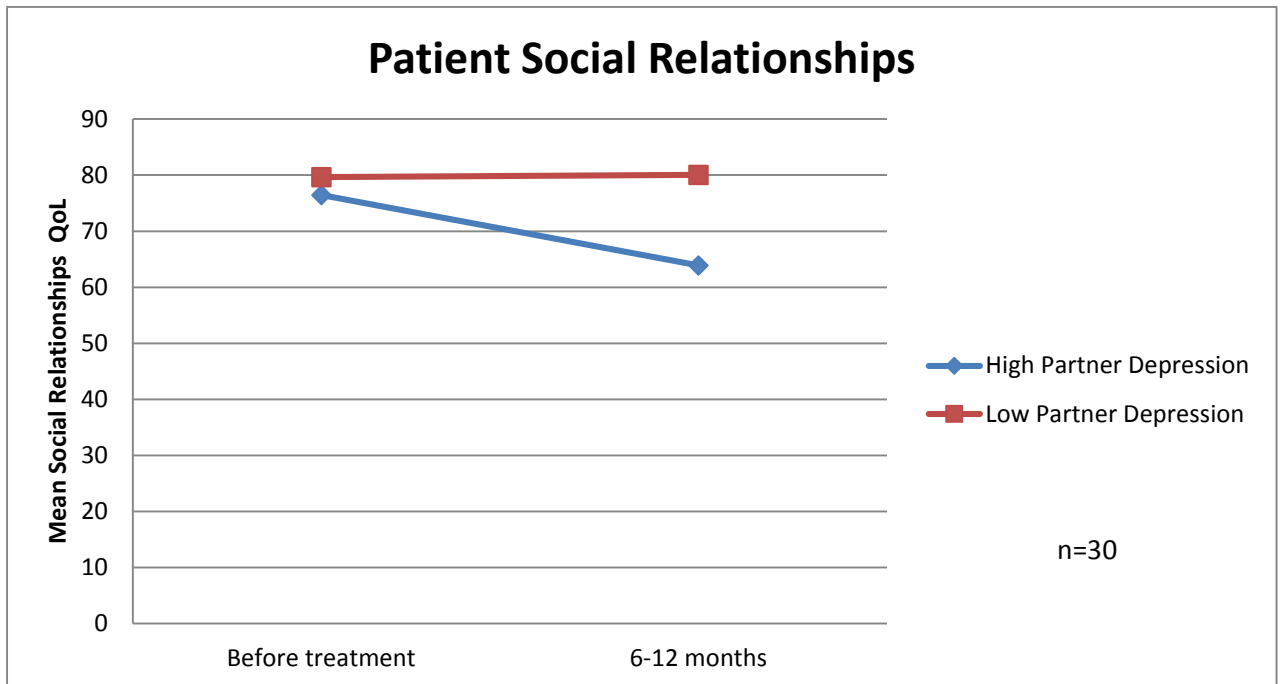


Figure 25 shows patients reported lower scores at 6-12 months in the social relationships domain, when they had a partner who reported high symptoms of depression before treatment.

Figure 26 changes over time in patients ENVIRONMENT QoL by PARTNER depression scores before treatment

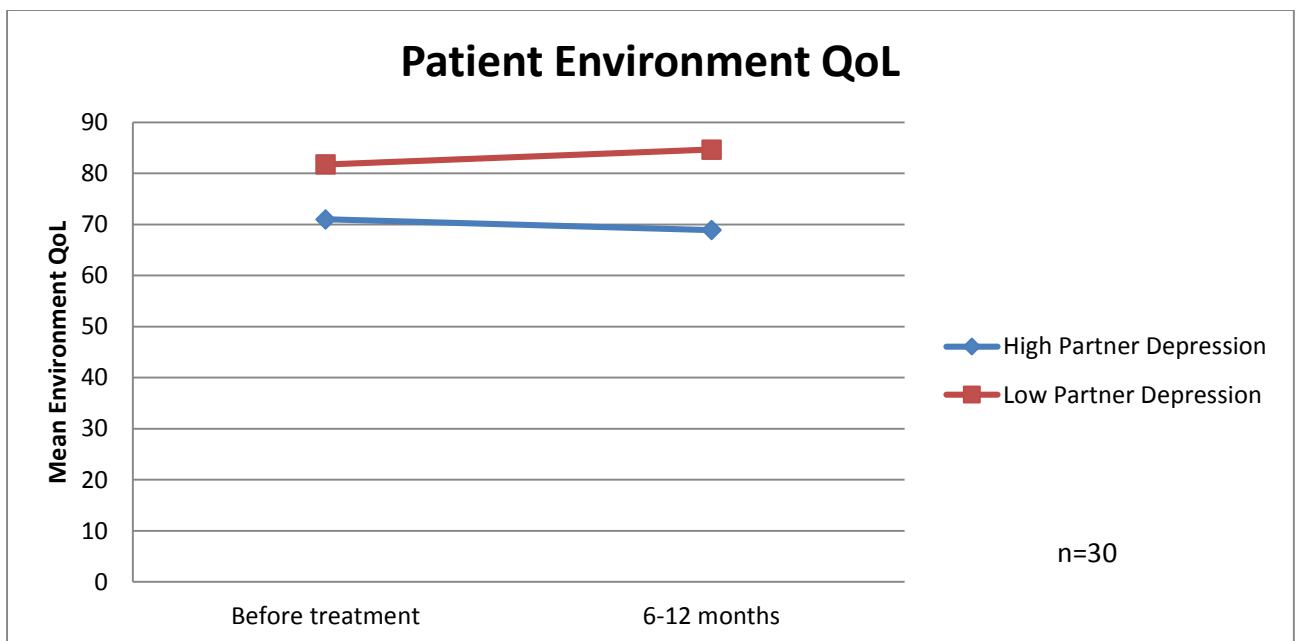


Figure 26 shows lower scores within the environment domains when patient's partner is showing high symptoms of depression at diagnosis.

### 3.7 Testing the association between patient psychological distress and caregiver psychological distress before treatment on patient QoL 6-12 months following diagnosis (Testing hypothesis iii and iv)

The results of the univariate regression analysis addressing patient psychological distress before treatment and patient QoL 6-12 months following diagnosis indicated patients with high psychological distress showed lower QoL in the physical, psychological, and environment domains 6-12 months following diagnosis (Table 23). This suggests patient’s psychological distress before treatment is associated with their QoL 6-12 months following diagnosis. There was no association between patient depression before treatment and the social relationships domain 6-12 months following diagnosis.

**Table 23 Showing the association between depression before treatment (time point 1) and quality of life domains 6-12 months following diagnosis (time point 2), n=59.**

Predictor variable				
Patient Depression Before treatment	Patient QoL 6-12 months	N	Percentage Change [95%CI]	p-value
	Physical	59	30[1-51]	0.04*
	Psychological	59	35 [13-51]	0.01*
	Social Relationships	59	19 [-7 to 39]	0.13
	Environment	59	33[7-51]	0.02*

Table 23 shows the percentage change and 95% confidence intervals for each QoL domain by patients’ depressive symptoms before treatment.

A second univariate analysis indicated that partner’s with elevated depressive symptoms before treatment was associated with patient QoL 6-12 months following diagnosis, see Table 24. Findings showed, patients were reported 29% lower scores in physical QoL, and 29% lower scores in psychological QoL 6-12 months post diagnosis (p<0.05).



**Table 24: Showing the association between depression in HNC couples and quality of life 6-12 months following diagnosis, n=30.**

		N=30	
Patient QoL Domain	Predictor Variable	Percentage Change [95%CI]	p-value
Physical	Patient depression	34 [-2-57]	0.06
	Partner depression	29 [3-49]	0.03*
Psychological	Patient depression	36 [6-57]	0.02*
	Partner depression	29 [5-47]	0.03*
Social Relationships	Patient depression	26 [-3 to 47]	0.08*
	Partner depression	19[-4 to 37]	0.10
Environment	Patient depression	36[2-59]	0.04*
	Partner depression	16[-16 to 39]	0.29

\*p<0.05

Table 24 shows the percentage change and 95% confidence intervals for each QoL domain by patients depressive symptoms before treatment.

### **3.8 Summary of patient and caregiver psychological distress on HNC patients' QoL**

A significant association between psychological distress and patient QoL was found at each of the data collection points.

#### **Testing Hypothesis i and Hypothesis ii: Psychological distress and patient QoL before treatment.**

The univariate model showed that; patients with high depression and high anxiety reported lower QoL within all four domains. Elevated depressive symptoms showed the strongest statistical association ( $p < 0.001$ ). Caregiver depression was also significantly associated with lower patient QoL in the physical, psychological, social relationships and environment quality of life domains (univariate model).

A multivariate model (adjusted for patient age and gender) showed patients with high symptoms of depression and caregivers with high symptoms of depression were both independently associated with patients physical QoL ( $p < 0.05$ ) when tested within the same regression model. The multivariate model showed no statistical association between caregiver depression and the psychological, social relationships and environment domain, however, descriptive statistics showed clinically meaningful differences in mean scores with those patients who had a caregiver showing elevated symptoms of depression before treatment, report lower mean scores within the physical, psychological, social relationships and environment domains (Table 19). To examine the direction of these associations, pathway and mediation analyses were conducted. A mediation analysis suggested that before treatment, if patients had a caregiver with depression in addition to their own depression, they were more likely to report lower physical QoL (before treatment) compared to patients who did not have a distressed caregiver ( $p < 0.05$ ). This provided evidence and supported hypotheses i and ii which proposed that before treatment, patients have poorer quality of life if HNC patients and their caregivers have high levels of psychological distress.

The results found an association between psychological distress and patients QoL but more significantly highlighted the influence of caregiver depression on patients physical QoL, which has not been previously shown within HNC.

**Testing hypotheses iii and iv: Psychological distress before treatment and patients QoL 6-12 months following diagnosis.**

Due to limitations in sample size, it was not possible to undertake multivariate analyses on model two, thus these findings are based on an unadjusted univariate model. The statistical model showed there was an association between psychological distress before treatment and patient QoL 6-12 months following diagnosis within all four QoL domains. This model supported the proposed hypothesis which predicted patients who show elevated depression before treatment will show poorer quality of life at 6-12 months post diagnosis. There was also a univariate analysis indicated patients who had a partner with elevated depression before treatment showed poorer QoL 6-12 months post diagnosis, providing further support for proposed hypotheses iii and iv.

### **3.9 Role of socio-demographic and Clinical factors on patient QoL**

The previous results sections 3.2 to 3.8 described the sample and reported on the associations between psychological distress in patients and caregivers and patients QoL. This section investigates the association between socio-demographic factors and clinical variables on patients QoL. Although, not the primary aim of this thesis, it was important to examine the role of these factors on patient QoL.

### 3.9.1 Descriptive Analysis: Patient QoL and Socio demographic variables

In total, 90 HNC patients completed the WHOQOL-BREF self-report measure before treatment. The total sample ranged between the ages 27-94, with patients predominantly White British, male with mean age of 64. Sixty-six per cent were married or living with a partner (see Table 10, for patient socio-demographics). The clinical variables of the patient sample showed the majority being newly diagnosed (85%), with 46% having a diagnosis of cancer of the oral cavity (Table 11, for patient clinical factors).

The mean scores for the four QoL domains (WHOQOL-BREF; scale 0-100) by patient demographic variables are displayed in Table 25. The table also shows the overall mean score and 95% confidence interval for each domain for the total sample (n=90).

**Table 25 Socio-demographics and HNC patients' Quality of life before treatment (n=90) Mean and SD of WHOQOL-BREF domains**

		WHOQOL-BREF Domains							
		Physical		Psychological		Social relationships		Environmental	
		Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI
<b>Overall Mean Score for HNC patients</b>	<b>N=90</b>	<b>66.01</b>	<b>61.60-70.87</b>	<b>65.38</b>	<b>60.15-68.60</b>	<b>74.68</b>	<b>65.50-78.86</b>	<b>74.68</b>	<b>70.98-78.38</b>
<b>Socio-demographics</b>									
Age	<b>N</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>
18-59	32	66	23.19	65.91	15.77	65.91	15.77	72.19	18.00
60-74	38	70.05	23.62	67.53	14.59	67.53	14.59	76.71	19.30
75-95	20	57.35	20.96	60.45	15.94	60.45	15.94	74.80	13.85
Gender									
Male	65	67.43	23.32	66.37	13.72	75.88	19.42	75.55	16.28
Female	25	62.32	22.88	62.80	19.15	71.56	21.42	72.40	21.09
Education									
None	41	60.32	22.11	64.15	14.77	73.46	19.86	73.61	15.92
G.C.S.E/ALEVEL/Equivalent	26	66.42	24.68	65.92	18.28	73.12	17.82	73.04	20.99
Higher Degree	22	74.86	20.93	66.86	13.57	77.91	22.94	77.73	16.86
Marital status									
Married/Living with partner	59	68.15	23.13	66.46	13.43	76.37	19.51	77.37	16.67
Single	18	71.89	18.48	69.50	15.93	75.39	17.61	76.61	14.57
Divorced/Widowed	13	48.15	22.27	54.77	19.29	66.00	24.11	59.77	19.79
Ethnicity									
White British/White Other	75	68.71	21.08	65.95	14.72	75.77	19.01	77.35	15.99
Ethnic Minority	15	52.53	28.90	62.53	18.69	69.20	24.21	61.33	20.15

Table 25 shows, patients aged 75 and over, those who were divorced or widowed, ethnic minority patients and patients with lower education are showing lower mean scores across the four QoL domains. The statistical significance of these differences is shown in Table 26. Divorced and widowed patients showed particular low scores within the social relationships domain. The table showed small differences in all four QoL domains between single patients and those with a partner.

**Table 26 univariate linear regression model of statistically significant socio-demographic variables and <sup>35</sup>patient QoL before treatment**

N=90				
Quality of life domain	Socio-demographic	Predictor variable	<sup>36</sup> Percentage change 95%[CI]	p value
<b>Physical</b>				
	Age	75+	22[4-37]	0.07
	Education	Higher degree	-32 [-62 to -8]	0.03
	Marital status	Widowed/Divorced	29 [10-43]	0.01
	Ethnicity	Ethnic Minority	22 [3-37]	0.02
<b>Psychological</b>				
	Marital Status	Widowed/Divorced	16 [2-30]	0.03
<b>Environmental</b>				
	Ethnicity	Ethnic Minority	27 [10-39]	0.01
	Marital status	Widowed / Divorced	28 [11-42]	0.01

Table 26 shows, patients aged 75 and over (n=20) had a 22 per cent lower score in the physical QoL domain when compared to patients 18-59 (n=32), and patients aged between 60 and 74 (n=38). Also patients with a higher degree reported 32%<sup>37</sup> reported better physical QoL when compared to patients with no qualifications and G.C.S.E/Equivalent. Also In the physical domain, widowed or divorced patients showed 29% lower physical QoL, when compared to patients who were married or living with a partner. This association was also shown within the psychological and environmental domain. Ethnic minority patients were also reporting 22% lower physical health than White British/ White other patients, and 27% lower environment QoL. There was no statistically

<sup>35</sup> No significant statistical association between socio-demographic variables and social relationships.

<sup>37</sup> For regression modelling to take place the WHOQOL- bref was log transformed, this was then back transformed to give a percentage change in coefficient values. When the scale was log transformed due to the negative skew of the original WHOQOL-BREF domains, the scale was transformed and converted the negative coefficients to represent a positive change i.e. negative coefficient shows better quality of life. Thus the direction of change in the transformed variables are represent; negative coefficient meaning a positive change i.e. better quality of life, and a positive coefficient meaning a decrease in quality of life scores The standard interpretation of coefficients in a regression analysis is that a one unit change in the independent variable results in the respective regression coefficient change in the expected value of the dependent variable while all the predictors are held constant. Interpreting a log transformed variable can be done in such a manner; however, such coefficients are routinely interpreted in terms of percent change

significant association between; gender and the four WHOQOL domains, ( $p>0.05$ ), or age and the psychological, social relationships or environmental domains ( $p>0.05$ ). Also, there was no significant statistical difference between educational level and the psychological, social relationships and environment domain of QoL ( $p>0.05$ ).

### 3.9.2 Clinical variables and Quality of life

Descriptive data for clinical variables and patient QoL before treatment is summarised in Table 27. Table presents the mean and SD for each QoL domain by clinical variables before treatment.

**Table 27 Clinical variables and HNC patients' Quality of life: Mean and SD of WHOQOL-BREF domains before treatment**

N=90		WHOQOL- BREF domains											
Clinical Variables		Physical			Psychological			Social relationships			Environment		
			Mean	SD		Mean	SD		Mean	SD		Mean	SD
Cancer	First Cancer		66.35	22.99		65.53	15.49		75.35	18.45		74.61	17.05
	Recurrent cancer		64.00	25.17		64.46	15.37		70.69	27.93		75.08	21.84
Stage of Cancer	Early stage		71.53	25.20		67.20	13.15		79.40	13.44		77.6	15.83
	Loco-regionally advanced		62.95	21.94		64.70	16.76		72.57	22.70		72.75	18.97
SCC	SCC		66.47	23.43		66.13	15.39		75.33	19.51		75.31	17.34
	Not SCC		63.00	22.18		60.50	15.15		70.42	23.21		70.58	20.09
Site of Cancer	Oral Cavity		68.88	20.94		65.32	16.48		79.29	16.27		77.61	17.21
	Oropharynx		65.35	24.44		66.17	15.5		71.48	24.96		73.52	17.97
	<sup>38</sup> Other-		61.25	26.39		64.67	14.58		69.58	20.23		70.25	18.57

Table 27 shows before treatment, there were small differences in mean scores across the four quality of life domains. The largest differences were found between site of cancer and stage of cancer which are shown in Figure 27 and Figure 28. However, the differences in site of cancer may be explained by the grouping of the variable, as the other category contained a heterogeneous HNC sites (nasopharynx, larynx, and salivary gland) which we were unable to analyse separately due to small size.

<sup>38</sup> nasopharynx, larynx, salivary gland



Figure 27 Clinical Variables and Patient QoL before treatment: Site of Cancer

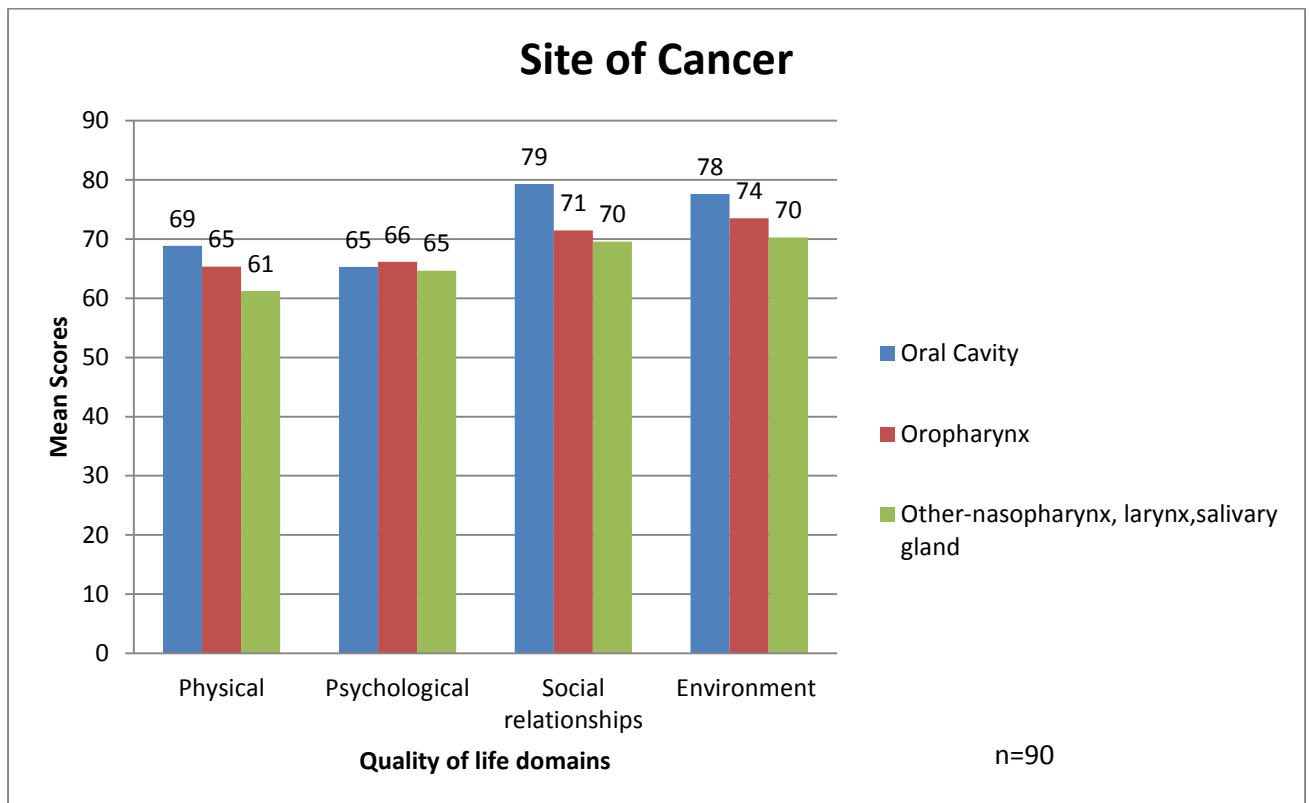
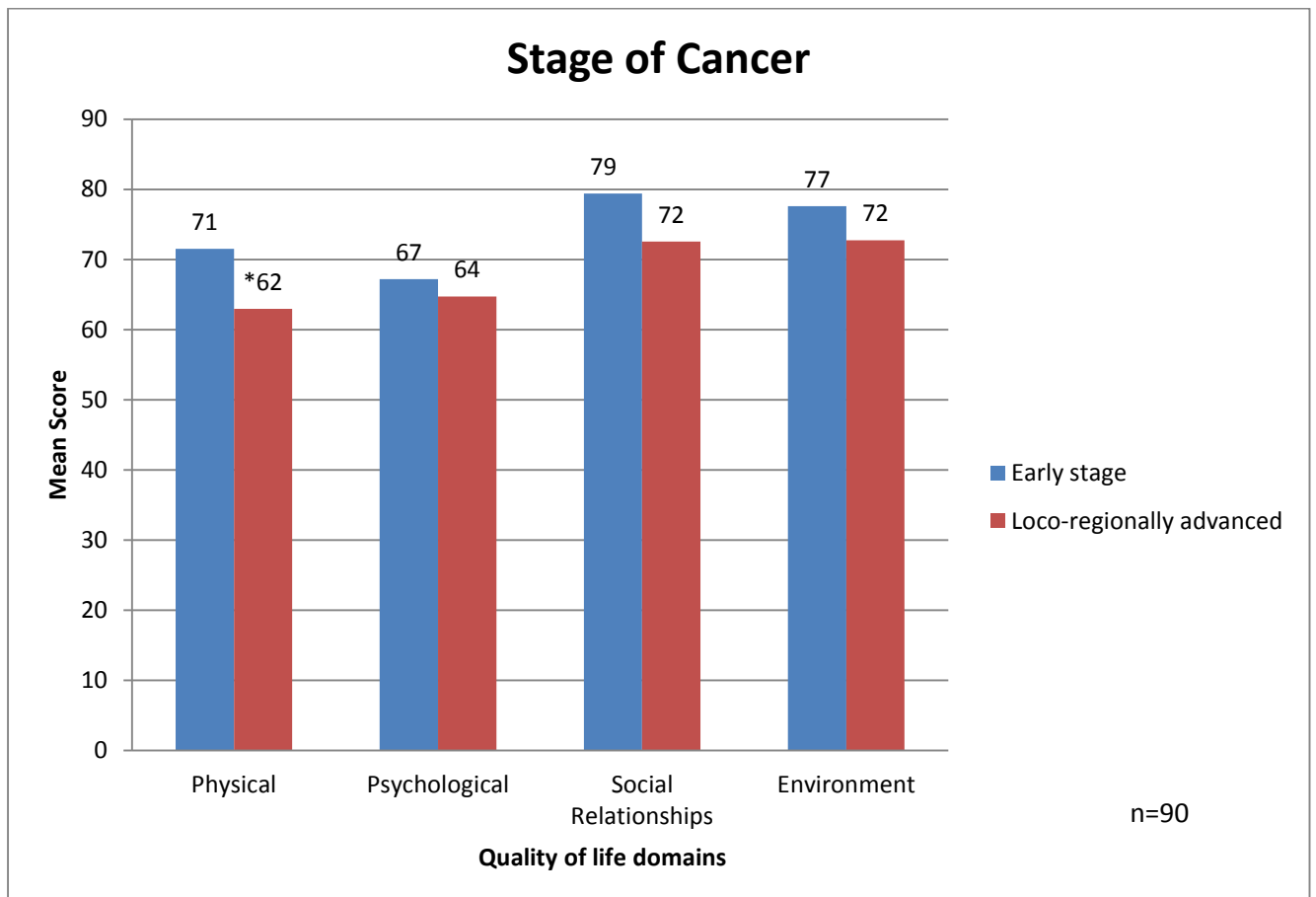


Figure 27 shows patients diagnosed with cancer in the <sup>39</sup>nasopharynx, larynx, and salivary gland are reporting slightly lower mean scores in all four domains, however these differences were not statistically significant ( $p > 0.05$ )

<sup>39</sup> These sites were grouped into one category due to small patient numbers within each site.

Figure 28 Mean scores of stage of cancer and patients QoL before treatment (n=90)



\*<sup>40</sup>p=0.06 (trend towards significance)<sup>41</sup>

Figure 28 shows before treatment, patients with loco-regionally advanced disease are reporting lower mean scores within all four quality of life domains. There was no statistical difference within the physical, psychological, social relationships and environment domain however the physical domain did show a trend towards significance [<sup>40</sup> $\beta=16$ , 95% CI -1 to 30,  $p=0.06$ ].

<sup>40</sup> Regression analysis ( $\beta$  represents percentage change of back transformed coefficient)

### 3.9.3 HNC patients QoL before treatment and 6-12 months following diagnosis

Fifty-nine HNC patients completed the QoL measure before treatment and 6-12 months following treatment Table 28 presents the mean, median and standard deviation (SD) of QoL scores over the two time points. The largest decline in QoL is shown within the physical QoL domain, followed by social relationships domain, which shows a 10 point change in its mean score ( $p < 0.001$ ).

**Table 28 shows the mean, median and SD of changes in patients scores before treatment and 6-12 months post diagnosis: (N=59)**

N=59 WHOQOL-BREF-Domain:	Before Treatment			6-12 months			<sup>43</sup> p-value
	<sup>42</sup> Median	Mean	SD	Median	Mean	SD	
Physical	81	72.26	21.57	56	53.32	13.17	0.001*
Psychological	69	68.21	13.4	69	66.75	21.92	0.80
Social relationships	75	76.67	20.05	70	68.23	24.42	0.001*
Environmental	81	78.26	15.09	75	72.68	22.31	0.001*

Table 28 shows there was a statistically significant difference before treatment compared to scores 6-12 months following diagnosis in the physical, social and environmental QoL domain. In the total sample, there was no difference over time within the psychological domain.

### 3.9.4 Changes in mean scores of patient QoL by clinical variables

Table 29 presents descriptive mean scores showing the changes in patients' QoL before treatment and 6-12 months following diagnosis based on clinical variables.

<sup>42</sup> The WHOQOL-BREF questionnaire was not normally distributed, hence the descriptive table presents the median values of each domain. Many studies have presented the Mean values of the WHOQOL-BREF (including the authors of the questionnaire) therefore to allow for comparisons across the research, both median and mean values of each domain have been presented.

<sup>43</sup> Statistical differences measured by non-parametric test the Wilcoxon matched paired test as the WHOQOL-BREF was not normally distributed.

**Table 29 Descriptive statistics (N, Mean and standard deviation) showing HNC patient QoL by clinical variables over two time points (n=60)**

WHOQOL-BREF Domains									
		Physical		Psychological		Social relationships		Environmental	
		Mean (SD)		Mean (SD)		Mean (SD)		Mean (SD)	
Clinical Variables	N	Before Treatment	6-12 months	Before Treatment	6-12 months	Before Treatment	6-12 months	Before Treatment	6-12 months
Treatment									
Surgery alone	23	70.52 (25.40)	54.26 (13.48)	65.65 (13.90)	62.87 (25.33)	72.35 (24.00)	67.96 (27.98)	78.48 (17.70)	72.13 (23.92)
Surgery & adjuvant	25	75.64 (18.37)	54.32 (11.57)	71.40 (11.59)	71.12 (18.40)	83.24 (12.11)	70.08 (20.55)	79.44 (13.21)	74.40 (23.17)
<sup>44</sup> Missing data	12								
Site:									
oral cavity	25	73.88 (19.44)	53.60 (13.91)	67.60 (14.90)	68.80 (21.90)	79.28 (16.54)	73.80 (22.47)	81.00 (12.06)	73.88 (18.13)
Oropharynx	15	70.53 (26.70)	53.47 (9.36)	69.73 (11.91)	70.20 (20.20)	77.13 (24.06)	65.57 (24.03)	75.93 (19.48)	72.27 (25.87)
<sup>45</sup> other-	20	71.94 (21.31)	52.94 (15.96)	68.06 (13.34)	59.44 (23.59)	71.88 (22.03)	61.06 (27.48)	76.00 (15.47)	69.67 (26.04)
Cancer									
First cancer	50	74.19 (19.69)	54.53 (13.36)	69.81 (12.55)	68.17 (19.81)	78.87 (16.83)	70.57 (21.67)	79.19 (13.05)	72.67 (22.10)
Recurrence	10	63.20 (28.37)	47.60 (11.04)	60.70 (15.37)	60.10 (30.42)	66.30 (30.16)	57.50 (33.79)	73.90 (22.83)	72.70 (24.50)

<sup>44</sup> The missing 12 patients under went, chemo-radiotherapy (this group was excluded from the analysis due to small sample size.

<sup>45</sup> Nasopharynx, larynx, salivary gland and unknown primary were grouped into one category due to small sample size of individuals sites.

<sup>46</sup> Staging									
Early	24	76.67	55.13	69.92	68.58	80.50	73.79	79.83	75.09
		(18.97)	(14.69)	(9.39)	(22.58)	(12.28)	(24.73)	(12.53)	(22.78)
Loco regionally advanced	30	69.67	51.80	67.80	65.93	74.60	64.45	76.90	71.00
		(23.20)	(12.55)	(15.91)	(22.17)	(24.54)	(23.93)	(17.46)	(22.33)
Missing	6								

Table 29 shows a decline in mean scores within the QoL domains over the two time points. However, the differences within the clinical variables were small. For example, 6-12 months following treatment, there was no difference in physical QoL between patients who underwent surgery compared to patients who underwent surgery and adjuvant treatment. There was a very small difference in mean scores within the physical domain and site of cancer. The largest difference in mean scores was shown between site of cancer and the psychological domain and social relationships domain; where patients within the: Nasopharynx, larynx, salivary gland and unknown primary group showed a decrease in mean scores, particularly when compared to Oral cavity patients. Also, patients with recurrent cancer, showed lower mean scores within all four QoL domains 6-12 months following diagnosis. In contrast to time point 1, there were small differences in the mean scores between early and loco-regionally advanced disease patients.

---

<sup>46</sup> Staging based on \*Descher, D.G. & Day, T, (2008) American joint committee on Cancer (AJCC), Early stage disease: Stage I,II Locoregionally advanced: Stage III or IV

**Stage of cancer and QoL.** Before treatment, univariate analysis showed association between stage of cancer and physical QoL and patient with <sup>47</sup>loco-regionally advanced disease [ $\beta=-16$  95% CI -1-30,  $p=0.06$ ] however, there were no statistical differences between these factors and the psychological, social, or environmental domains  $p>0.05$ . Interestingly, there at 6-12 months following treatment (n=59), there was no statistically significant differences ( $p>0.05$ ) between the loco regional advanced disease patients and those with early stage disease. Both patient groups reported similar levels of QoL within all four QoL domains.

**New cancer and recurrent cancer patients and QoL.** There was no statistical difference between new cancer and recurrent cancer patients before treatment in the four domains of quality of life ( $p>0.05$ ), However, patients with recurrent cancer (n=11), at time point 2 reported 30% lower scores within the physical domain [ $\beta=-30$ , 95%CI 3-49,  $P=0.03$ ] and within the social relationships domain ( $p=0.09$ ) when compared to new head and neck cancer patients. However, due to the small sample size of this patient group, this finding must be approached with caution.

**Treatment and QoL.** Patients who received radiotherapy alone (n=4) or received chemo-radiotherapy (n=9) were excluded from analysis as patient groups were too small for results to be generalised. There were no statistically significant differences between patients who underwent surgery alone compared to patients who underwent surgery and adjuvant treatment ( $P>0.05$ ) before treatment or 6-12 months following treatment ( $p>0.05$ ).

**Site of cancer and QoL.** There were no statistically significant associations between site of cancer and patient reported quality of life within all four domains before treatment or 6-12 months following treatment. However, 6-12 months following treatment within the social relationships domain, there was a difference between the mean scores of oral cavity and oropharynx, which although not statistically significant is of clinical relevance (Table 29).

---

<sup>47</sup> The Cancer staging was performed in accordance with the AJCC staging system for head and neck cancer. \*Descher, D.G. & Day, T, (2008) American joint committee on Cancer (AJCC), Early stage disease: Stage I,II Locoregionally advanced: Stage III or IV

### 3.10 Conclusions: Socio-demographic and Clinical factors on patient QoL

**Socio-demographic factors and patient QoL:** In summary, results showed patients age 75 and over, ethnic minority patients and individuals with more advanced disease as potential predictors of patients physical quality of life before treatment. Patients who were widowed or divorced also showed significantly lower physical QoL than patients who were single, married or living with their partner.

**Clinical variables and patient QoL:** There were no statistically significant associations between stage of cancer, tumour Site, on the psychological, social relationships and environment domains of patient QoL before treatment or 6-12 months following treatment. These findings suggest these clinical variables play a minimal role on patients' perceptions of their quality of life.

Also, although, patients staged with loco-regionally advanced disease were reporting lower quality of life score within the physical domain, when compared with early disease patients before treatment, there was no difference 6-12 months following diagnosis. Both groups reported similar levels of QoL within all four domains. Also, there was no significant statistical difference between new cancer and recurrent cancer patients before treatment in the four domains of quality of life ( $p>0.05$ ). Similarly, there were no statistically significant associations between site of cancer and patient reported quality of life within all four domains before or 6-12 months following treatment.

In conclusion, the present findings identified; age, marital status, ethnicity and cancer staging as significant predictors of patients physical quality of life before treatment. However, at 6-12 months there were no statistical differences between treatment, stage of cancer, or tumour site, where patients are reporting similar levels of QoL within these domains. These findings strengthen the evidence that clinical variables may play a minimal role in the impact on patients' perceptions of their quality of life.

### **3.11 Overall summary of quantitative findings**

The aims of the quantitative analysis were to firstly measure the prevalence levels of psychological distress in patients and their caregivers and secondly, examine the association of patient and caregiver psychological distress on patients QoL.

#### **3.11.1 Research aim 1: Summary of prevalence of psychological distress in patients and caregivers**

A longitudinal analysis showed a significant proportion of HNC patients had high prevalence levels of psychological distress, particularly depression 6-12 months following diagnosis. The strength of these findings are prevalence levels were collected at two time points and therefore show differences in prevalence levels before treatment and 6-12 months following diagnosis. Depressive symptoms were found to increase over time, with 17% of patients reporting scores of 8 and above on HADS-depression scale. This increased to 27%, 6-12 months following diagnosis. This is significantly higher than the 10% prevalence levels reported within the general population (Mitchell et al., 2013). Anxiety did not follow this pattern and decreased over time. The high prevalence rates of depressive symptoms are of particular clinical significance and highlight that a significant proportion of HNC patients are experiencing high levels of psychological distress. These results indicate these elevated levels of psychological distress post diagnosis may be indicative of patients who are finding the adjustment to cancer more difficult.

Similarly, a second key finding within the analysis of prevalence of psychological distress was caregivers; particularly the partner of HNC patients reported significantly higher levels of anxiety and depressive symptoms than HNC patients. Longitudinal analysis showed, these high prevalence rates were reported before treatment and 6-12 months following diagnosis. This suggests a subset of caregivers is experiencing high prevalence of psychological distress which does not subside 6-12 months following diagnosis. These high prevalence rates suggest HNC cancer is not an individual experience and appears to have as much of an impact on caregivers psychological wellbeing as HNC patients.

#### **3.11.2 Research aim 2: Patient and Caregiver psychological distress associated with patient QoL**

Findings showed higher degrees of anxiety and depression was associated with patient QoL, with a negative impact on all four QoL domains. There was also some tentative evidence that the



increased level of caregiver psychological distress had a negative impact on patients QoL, thus supporting our proposed hypothesis. However, wide confidence intervals and small sample size question the strength of these associations. Nevertheless, a multivariate regression analysis and descriptive analysis showed caregivers with elevated symptoms of depression in particular showed a decrease in QoL. The current study also presented some evidence to suggest that pre-treatment psychological distress may predict QoL 6-12 months following diagnosis. These findings were based upon univariate analysis thus it would be prudent to not over interpret these as firm findings. However, as an exploratory model, these findings show that there is scope for patient and caregivers psychological distress to influence patient QoL 6-12 months following diagnosis with the descriptive findings supporting this hypothesis.

### **3.11.3 Research aim 3: To explore the “lived experiences” of HNC patient-partner couples, where partners reported high levels of psychological distress before treatment (qualitative)**

To further explore the quantitative findings and to assist with further understandings of the role psychological distress may play on patients QoL, qualitative interviews were conducted on a sub sample of patient-partner couples.

The next chapter of the thesis introduces the qualitative findings of the study, where partners of HNC patients who showed elevated psychological distress before treatment were purposively selected and interviewed to further understand the underlying mechanisms that contributed to increased levels of psychological distress.



## 4. Qualitative study

This chapter specifically focuses on the qualitative component of this thesis and includes a review of the current qualitative literature within HNC, an introduction to the qualitative method used and details of how participants were selected. Firstly, there is an overview of each participant who was interviewed and a description of the data analyses. The results are then presented, followed by a discussion of the key findings, including an evaluation of the methodology.

## 4.1 Qualitative study Abstract

**Title:** “We got cancer” - an interpretative phenomenological analysis of the lived experience of head and neck cancer patients and their distressed partners.

**Aims:** The primary aim of the qualitative study was to gain a deeper understanding of the lived experiences of HNC couples, with specific focus on patients who have a partner showing an elevated level of psychological distress prior to treatment.

**Sample:** A purposive sample of six participants, (three HNC couples) took part. Patients were aged between 50 to 65 (mean age 58) and partners between 50 to 61 (mean age 55). All three patients had been diagnosed with HNC in the last 12 months with no previous history of cancer. Partners were ‘healthy’ with no reported physical health problems.

**Method:** HNC patients whose partner reported elevated levels of psychological distress (HADS) at diagnosis were purposively selected. A single interview was conducted with each participant. Interviews were recorded and transcribed verbatim.

**Analysis:** An interpretative phenomenological analysis (IPA) allowed an in-depth exploration of HNC couples’ thoughts, beliefs and behaviours regarding their cancer experience.

**Results:** Three core themes were identified in the HNC couples interviews, 1) “*We got cancer*”, 2) “*It doesn’t shine as bright as it once did,*” 3) “*What would have helped?*”. These emergent themes were highlighted by HNC patients and their partners, while they experienced significant changes in their identity and quality of their relationship following the HNC diagnosis. They highlighted an increase in relationship conflict, hostility and irritability towards one another. The couples reported that this resulted in significant changes in the quality of their relationship that contributed to their levels of psychological distress. Partners of HNC patients also revealed detrimental effects on their own physical health since their partners’ diagnosis.

**Conclusion:** There is now consistent evidence that couples react as an ‘emotional system’ to cancer diagnosis, thus, healthcare professionals should begin including the partner in the basic support offered to patients. This is especially important as we now know that the distress in spouses can often be higher than in patients. The consequences of this effect on partners’ physical and psychological health raises questions on the level of social support that they can be expected to provide to the patient in the long term, particularly as they run the risk of developing medical and psychological problems themselves.

# **“We got cancer”- an interpretative phenomenological analysis of lived experience of head and neck cancer patients and their distressed partners**

## **4.2 Introduction:**

As presented in the literature review in chapter one, studies that have measured the prevalence of psychological distress in partners of HNC patients found that partners reported higher levels of psychological distress than patients (Hodges et al., 2005; Humphris & Ozakinci, 2008). These findings were further supported from quantitative results from this thesis (see chapter five). The clinical implications of such findings are significant as consequences of an increase in psychological distress in partners appear also to have a negative impact on HNC patients' quality of life (QoL). Qualitative methodology was applied to explore this association further. This allowed an insight into 'real life' explanatory models of the HNC experience for patients and their partners, rather than ones based on the preconceived notions of researchers.

## **4.3 Qualitative literature review**

There has been a steady increase in the number of studies within head and neck cancer utilising qualitative methodology. This reflects the increasing interest in patients' experiences of HNC, but also in the importance of examining quality of life from different methodological perspectives. The following studies summarise the qualitative literature that has examined the experiences of HNC patients and their partners.

A recent systematic review by Lang et al (2013) examined 29 qualitative studies exploring the psychological experiences of patients living with HNC. Findings highlighted how the physical symptoms affected QoL, particularly eating, working life and social relationships. Patients also consistently reported an 'emotional roller coaster' of experiences across the different stages of the illness trajectory. This included the emotional impact of the diagnosis which was accompanied by 'feeling a loss of control' and a new sense of awareness of their mortality Lang et al (2013) also highlighted that the increased psychological distress in patients was due to increased feelings of guilt when perceiving their dependency on others. (Lang et al, 2013). Lang's review identified some of the multiple factors that have an impact on patients' psychological distress that go beyond physical symptoms and side effects of treatment. This was also supported by a recent study conducted by Parker and colleagues (2014), which explored the experiences of cancer patients who underwent surgery for HNC. Participants identified difficulties arising from receiving insufficient, confusing, and often untimely information. Patients also reported the 'shocks and aftershocks'

following treatment and reported feeling emotionally unsupported after surgery. Although patients emphasised their physical constraints, they reported greater impact from the emotional consequences of the treatment, for which they felt less prepared (Parker, Bellamy, Rossiter, Graham, Britton, Bennett, 2014;). The emotional distress experienced by HNC patients was a common theme in the qualitative studies, as well as the guilt and burden experienced when patients felt they had become reliant on partners and family for support (Moore, Ford, & Farah, 2013; Moore, Chamberlain, & Khuri, 2004). O'Brien (2012) explored the perceived changes in intimacy of patients' relationships following HNC. Data were collected from 16 HNC patients who were at least one year post-treatment. Patients reported changes in their relationships with friends and family, but in particular with their partners. This included difficulty resuming former intimate relationships with their partners, but this went beyond physical intimacy. Patients described significant changes within their relationship which in turn had caused further emotional distress. (O'Brien, Roe, Low, Deyn, & Rogers, 2012).

The review of the qualitative literature in HNC patients opens up insights beyond the information available from the quantitative literature. Findings reveal a need to address the multifaceted impact of HNC that goes beyond the medical model of illness with qualitative and focusing on the significant emotional impact of the disease. The literature clearly demonstrates that patients are not simply affected physically by their experience of HNC.

Interestingly, at the time of the initial review of the qualitative literature in 2011, to our knowledge there had been no studies conducted specifically in partners of HNC patients. However, since 2011 the following three qualitative studies have been reported, showing a steady increase in the importance of this area.

Nund et al (2014) explored the experiences of twelve partners of HNC patients specifically focusing on caring for someone with dysphagia (problems with swallowing). Their qualitative analysis showed that partners found it difficult to function within the caregiver role. Partners highlighted their increased emotional distress and reported a decline in their physical health (Nund, Ward, Scarinci, Cartmill, & Kuipers, 2014). In a similar study, Patterson and Rapley (2013) interviewed seven HNC couples that were living with someone with dysphagia. Partners reported a transformation from partner to carer, which brought new responsibilities with changes to their normal way of life (Patterson & Rapley, 2013). There is increasing evidence that cancer can not only lead to increased psychological stress, but can also lead to positive changes. Ruf et al (2009) asked 31 patients with

HNC and 25 female partners one open-ended question: whether they had experienced any positive changes since the cancer experience, often referred to as 'post traumatic growth'. Both the majority of patients as well as their partners (81% and 84%) reported positive personal changes primarily related to areas of attitudes towards life, personal strength and relationships. There was a small proportion of their sample who reported no positive changes (19% patients and 16% partners). The main findings from the partners' perspective were that they felt their relationship was more intense since diagnosis, with improved communication, mutual understanding, and more tolerance of certain habits. Also, positive changes in relationships were reported significantly more by the female partners than by the patients (Ruf, Büchi, Moergeli, Zwahlen, & Jenewein, 2009). A similar study in prostate cancer patients found both patients and their partners reported a positive attitude toward life, personal strength, and relationships. Partners reported significantly more positive changes in relationships, especially within the partnership (Lavery & Clarke, 1999). However, both studies assumed that reporting more positive changes was associated with higher posttraumatic growth. An alternative interpretation could be that reporting more positive changes could be related to different communication skills, i.e., women have been found to be more verbal about their emotions than men (Hagedoorn, Sanderman, Buunk, & Wobbles, 2002) and therefore their findings may be biased by sex effect concerning communication, as both samples were biased to female partners and male patients.

#### **4.3.1 Summary of qualitative literature**

A consistent theme that emerges from qualitative studies of HNC patients is how patients seek emotional and psychological support from their family, specifically their partner. Partners of HNC patients reported significant changes in their QoL but more strikingly, partners also showed a decline in their physical health. Partners reported that the HNC diagnosis had changed their lives; with one study (Ruf et al 2009) showing partners experiencing positive changes within their relationship.

However, there have been very few qualitative studies in HNC couples, particularly where the patient's partner is reporting elevated psychological distress. By examining the experiences of these couples, I was able to explore further the underlying mechanisms contributing to their elevated psychological distress and examine what impact this distress was having on patients QoL. To my knowledge, this is the first study to examine this issue.

## **4.4 Aims**

The primary aim of the qualitative study was to gain deeper understanding of the lived experiences of HNC couples, with specific focus on patients who have a partner with a high level of psychological distress before treatment. The main objective of the qualitative study was to understand the underlying factors contributing to patients' and partners' psychological distress, and how this had an impact on patients' overall quality of life.

## **4.5 Qualitative Methodology**

This section introduces interpretative phenomenological analysis (IPA), which was the selected qualitative methodology used to answer the qualitative research question. I will begin by introducing IPA including its theoretical constructs followed by the rationale of choosing IPA over other qualitative methods.

### **4.5.1 What is Interpretative phenomenological analysis (IPA)**

Interpretative phenomenological analysis (IPA) is a qualitative approach that explores how participants make sense of their own experiences. IPA engages with the meaning that experiences, events and actions hold for participants. At the same time, it recognises that the researcher's own conceptions are required to make sense of the personal world of participants that is being studied through a process of interpretative activity (Smith, Flowers, & Larkin, 2009). IPA utilises small, purposively selected samples to allow in-depth, detailed examination of phenomena within an individual's experience.

### **4.5.2 Theoretical constructs of IPA**

IPA is underpinned by three theoretical constructs; 1) Phenomenology: the philosophical approach to the study of experience, 2) Hermeneutics: the theory of interpretation, and 3) Idiography: the unique experience of an individual (Smith et al., 2009).

Phenomenological analysts seek to capture the meaning and common features, or essence, of the experience or event. However, IPA recognises that, in order to be able to understand another's relationship with the world, there is a need for interpretation. Hermeneutics is the theory of interpretation. Heidegger 1962 (as cited in Smith, Flowers & Larkin, 2009) believed that seeking meanings from individuals' experiences (phenomenology) cannot be done without interpretation. Thus, the meanings of words and experiences need to be examined and interpreted within the context of the experience. The third major influence upon IPA is idiography, which examines the

'particular'. In IPA, this is applied by grouping individuals into 'unique' experience groups, for example partners with depression. Examining individuals with this 'particular' enables a sense of detail about that experience, and therefore a depth of analysis. IPA also uses a social cognitive paradigm (Fiske & Taylor, 1991) that is founded on the premise that human speech and behaviour reflect individuals' cognitions and perceptions.

#### **4.5.3 Why choose IPA?**

Whilst IPA and discourse analysis (Potter & Wetherell, 1987) share a commitment to the importance of language, they differ in regard to the status of cognition. Discourse analysis is sceptical of the possibility of mapping verbal reports onto underlying cognitions, whereas IPA is concerned with understanding what the respondent thinks or believes. The interpretive nature of IPA means that analysis can be underpinned by psychological theory. Using IPA allows the researcher to make a link between the physical conditions, the individual's cognitions about the condition and how they verbalise these cognitions. Recognising this requires interpretive work by the researcher. IPA also assumes that the participants' accounts will provide a representation of their underlying perceptions; therefore it is best suited to the present research objective.



## 4.6 Method

Recruitment for qualitative study took place 12 months following the commencement of the original study.

### 4.6.1 Participants

A triangulation method for patient sampling was undertaken where participants were selected on the basis of their pre-treatment HADS scores in the quantitative phase of the study. The HNC couples that were eligible to take part had to fulfil the following criteria:

1. Both patient and partners had completed the hospital and anxiety questionnaire before treatment and 6-12 months post treatment
2. Partner of patient had a <sup>48</sup>total score of 15 or above on the HADS questionnaire.

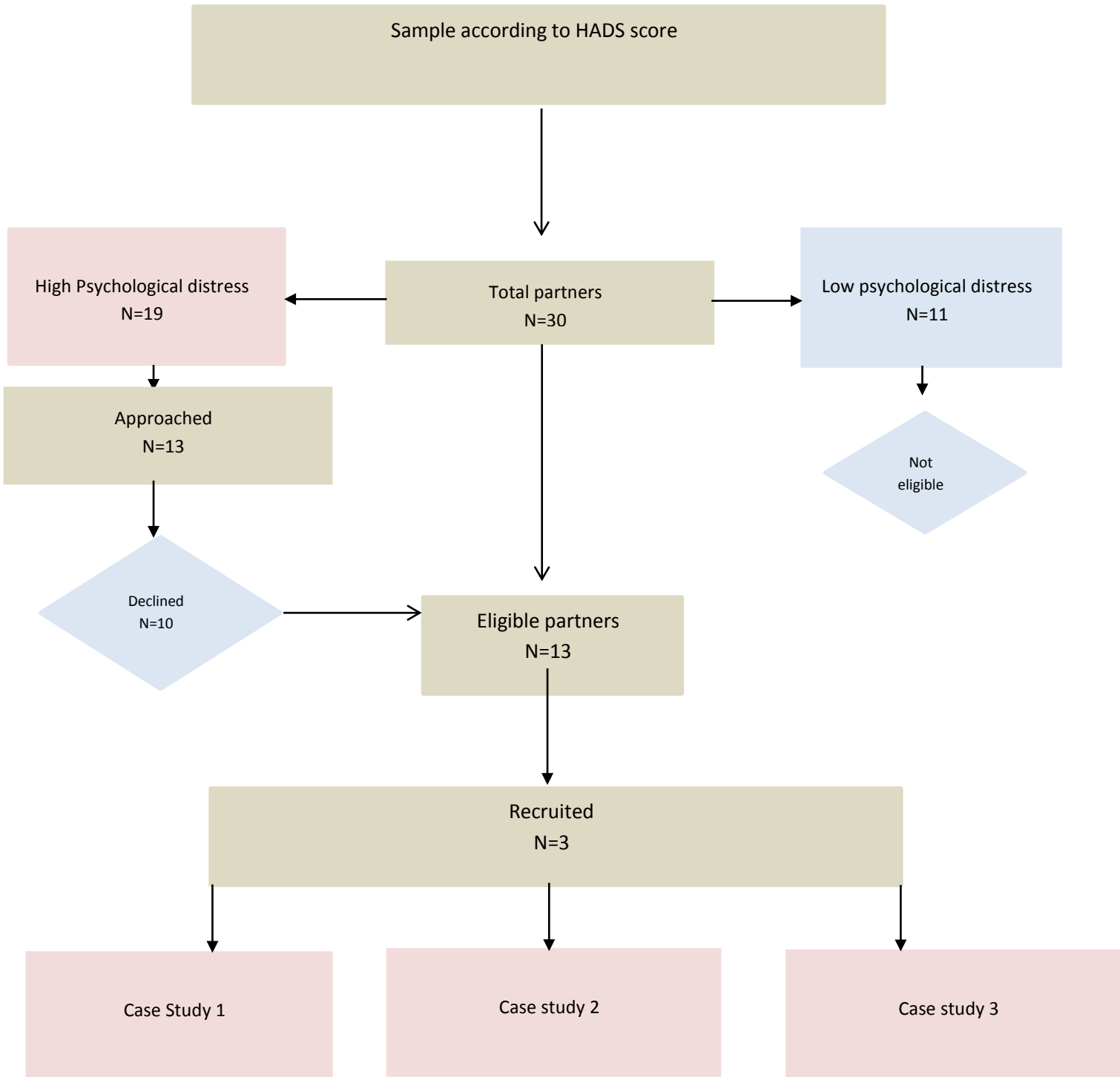
See qualitative recruitment flow chart in Figure 29 for eligible participants.

---

<sup>48</sup> Total HADS score (HADS-Anxiety score + HADS-Depression score). A score of 15 is the recommended cut off indicative of high psychological distress (Mitchell et al., 2010).

Figure 29: Eligible participants for Qualitative recruitment

49



<sup>49</sup> Recruitment for qualitative study commenced 12 months following the quantitative study

#### **4.6.2 Sample**

A purposive sample of six participants, (three HNC couples) took part. This comprised of 2 male patients and their female partners, and 1 female patient and male partner.

Although this is a relatively small sample size, which limits the generalisability of the results, this is not the primary aim of a qualitative study. The emphasis is not on hypothesis testing but rather on generating new hypotheses and gaining insight into the lived experiences of this sample.

Patients were aged between 50 to 65 (mean age 58) and partners 50 to 61 (mean age 55). All three patients had no previous history of cancer. Partners were 'healthy' with no reported physical health problems (see Table 30 for clinical details of patients). Pseudonyms have been used to ensure anonymity.

#### **4.6.3 Summary of sample**

##### **Case study 1: Mr and Mrs Smith**

Mr Smith was a white British man aged 59 who had been married for 26 years. The couple had no children and lived with their two cats. Preceding his diagnosis, Mr Smith was in full-time employment in a senior position in the public sector. However, following diagnosis, he made the decision to take early retirement.

His wife, aged 54 was in full time employment at the time of interview and also worked in a senior position within the public sector. She reported no physical health problems and described herself as being fit and well with no past history of depression.

HNC history: Mr Smith was diagnosed with a loco-regionally advanced, laryngeal squamous cell carcinoma. His treatment entailed primary surgery, where he underwent a laser resection. This took place 2 weeks following his diagnosis. Mr Smith was otherwise fit and well and reported no additional comorbidities. At the time of interview Mr Smith was 12 months post treatment.

##### **Case study 2: Julie and Jake**

Julie is a white British woman aged 50 and at the time of the interview had been living with her partner for 18 months. They had no children together, however, Julie had 3 children from a previous relationship. Her children were aged between 13 and 22 years. She also had one grandchild. Julie was not in employment at the time of the interview, but preceding diagnosis had worked full-time in a private business as a full-time administrator. She reported no additional

health problems and no previous history of cancer. However, she did report a past history of post-natal depression. Her partner Jake was white British man, aged 50 and worked as self-employed labourer. He had no children and no history of physical health problems. Jake did report a past history of depression.

HNC history: Julie was diagnosed with early stage, salivary gland adenoid cystic carcinoma, (T2N0M0), for which she had primary surgery (neck dissection) followed by a 6 week course of radiotherapy. Julie was 10 months post treatment at the time of the interview.

### **Case study 3: Mr and Mrs Jackson**

Mr Jackson is a 65 year old, white British man, married for 30 years. He had three grown up children and several grandchildren, all of whom lived in close proximity. Mr Jackson took early retirement following diagnosis, but had previously worked in the public sector as an engineer. Mr Jackson reported no past history of depression.

HNC history: Mr Jackson was diagnosed with early stage, oropharyngeal squamous cell carcinoma, (T1N0M0). Two weeks following his diagnosis, he experienced a myocardial infarction and underwent a heart bypass preceding the HNC treatment. His treatment for his SCC was a laser resection and photo dynamic therapy. However, due to a recurrence 9 months later he was undergoing radiotherapy treatment at the time of the interview.

Mrs Jackson, is white British, aged 61 who worked part-time as an administrator in the public sector. She describes herself as 'fit and well' and reports no history of physical health problems and no past history of depression.

See Table 30 for participant demographics and clinical details, including HADS scores of psychological distress.

**Table 30 Participant demographics and clinical details including scores of psychological distress**

Case Study	Participant Interview no.	Participant	Gender	Age	Marital status (years)	Primary site and treatment	Months since diagnosis	No months since treatment	Total HADS Score $\geq 15$	Past history of depression
1	1	Patient	Male	59	Married (26)	Loco regionally advanced, laryngeal Squamous cell carcinoma, T1N1M0 SCC Right vallecular, Primary surgery, (laser resection)	14	12	No	No
	2	Partner	Female	54	Married (26)		14		Yes	No
2	3	Patient	Female	50	Co-habiting (1)	Early stage, salivary gland adenoid cystic carcinoma, (T2N0M0), primary surgery (neck dissection) plus radiotherapy	14	10	Yes	Yes
	4	Partner	Male	50	Co-habiting (1)		14		Yes	Yes
3	5	Patient	Male	65	Married (30)	Early stage, oropharyngeal squamous cell carcinoma, T1N0M0, primary surgery laser resection, plus radiotherapy	12	In treatment (due to recurrence)	No	No
	6	Partner	Female	61	Married (30)		12		Yes	no

Table 30 shows the demographics and clinical details of three HNC couples that took part in qualitative interviews. HNC couples eligible for interviews were purposively selected based on total HADS score (HADS-Anxiety score + HADS-Depression score). A score of 15 is the recommended cut off indicative of high psychological distress (Mitchell et al., 2010). The table also includes details of participants past history of depression.

## **4.7 Procedure**

As this was a mixed methods design project, written informed consent for questionnaires and agreement to take part in an interview were obtained by the researcher at first contact (diagnosis). Consent was obtained from all participants to allow for purposive sampling to take place, a method commonly used within a mixed methods design. All participants who took part in the qualitative interview had previously taken part in the prospective study.

HNC patients whose partner reported high levels of psychological distress at 6 months post diagnosis (high scores of depression and anxiety on hospital and anxiety scale: HADS) were selected to take part. All participants were interviewed at their homes. A single interview was conducted with each participant. All interviews were conducted separately and each partner was assured of confidentiality from the other partner. A break was provided after 30 minutes to prevent fatigue. Interviews lasted between 30- 90 minutes. Interviews were recorded and transcribed verbatim.

## **4.8 Ethical considerations**

The study was performed in accordance with good clinical practice within the principles of research ethics and was approved by the NRES Committee London, Camberwell St Giles -. REC reference:12/LO/0351. Ethical concerns regarding any potential emotional effects caused by the qualitative interview design meant that the interviewer was on alert and took into account the negative consequences recounting potential emotive experiences may yield. The present study was carried out in close association with the participants' clinical team, which meant that if any need for support was required the researcher could refer to the clinical care team. In addition, due to the nature of the study, permission and consent from persons with HNC were required before their partners could be approached to participate.

## **4.9 Interview schedule**

The interview schedule was based on the following topic areas: diagnosis and treatment, social support and relationships, psychological impact, changes in QoL and service improvements. A semi-structured interview schedule was constructed (see Table 31 for topic guide). This allowed for flexibility during interview where answers and stories could be further probed. The same topic guide was used for patients and their partners.

**Table 31 interview schedule topic guide**

<b>Topic guide for interview:</b>	
Topics	Patient or Partner
<b>Background to diagnosis</b>	<p>“Can you tell me how your diagnosis/partner’s diagnosis of head and neck cancer came about?</p> <p>Prompts: What happened? How did you feel? How did you cope?</p>
<b>Social support and relationships</b>	<p>“Can you tell me about your relationship with your partner since your diagnosis?”</p> <p>Prompts: partner, family, friends</p> <p>Can you give me an example?</p>
<b>Psychological distress following diagnosis</b>	<p>“Can you tell me a little more about how you have felt since your/partner’s diagnosis?”</p> <p>Prompts: Most difficult, How did you cope?</p>
<b>Quality of life</b>	<p>How do you think your life has changed since your diagnosis?</p> <p>Prompts: What does QoL mean to you?</p>
<b>Service received</b>	<p>How do you think the head and neck cancer services could be improved?</p> <p>Prompts: patients, partner and family.</p>

#### **4.9.1 The interview**

The interview was semi-structured and was carried out as a conversational encounter, thus it was relatively unstructured, but guided by topic areas. The questions were open-ended, with cues and prompts if the participant was not engaging. Participants were encouraged to speak freely as this allowed insight into the areas affecting their lives to become more prominent.

### **4.9.2 Transcription**

Interview data was recorded on digital voice recorder and transcribed verbatim. All the transcripts were transcribed by the primary researcher. Particular behaviours were transcribed including crying, elevated voice and long pauses. Each transcript was verified and validated by listening to original recordings in conjunction with the transcript. This was further validated by a research assistant. Each interview was numbered and line numbers were added to the typed transcripts.

### **4.10 Analysis**

The transcripts were subjected to detailed systematic qualitative analysis case by case (IPA). A detailed step by step process of the analysis is available in the appendices (see sections 8.3)

#### **Summary of IPA stages**

(See sections 8.3 for detailed step-by-step guide of stages of IPA analysis).

Stage one involved reading transcripts several times to gain a holistic picture of individuals' accounts. Each read-through highlighted new insights with unfocused notes relating to anything within the text that appeared interesting or significant.

In stage two, the transcripts were examined further and conceptual themes were created that were felt to capture the essence of the participants' accounts.

In stage three, the emergent themes were listed and connecting themes were sought, with those related being clustered under appropriate super-ordinate conceptual headings. During this data organisation process continuous referral to interview transcripts were made to ensure themes selected were representative of individuals' personal accounts. The themes reflected the most salient meanings within the participants' narrative.

Stage four reflects the resultant framework where four super-ordinate themes emerged with sub themes within each cluster. The themes were corroborated by an experienced psychiatrist<sup>50</sup>(AK) who checked and corroborated the themes against the data.

---

<sup>50</sup> Professor Ania Korszun.



## 4.11 Qualitative Results

This section reports on the three superordinate themes derived from the analysis. The first theme presents how the HNC couples coped with the diagnosis of cancer providing insight into their emotional coping responses and behaviours. This is followed by the second theme where the effect of the cancer on the HNC couples relationship was highlighted, particularly the negative impact. The final emergent theme revealed how certain stages of the cancer were particularly difficult for the HNC couples and highlighted the types of support that would have been beneficial during these stressful periods.

## 4.12 Summary of themes:

Table 32 Master themes and subthemes from IPA analysis

<b>Table of Master themes</b>
<b>Superordinate themes and Subthemes</b>
<b>1. “We got cancer”</b>
<ul style="list-style-type: none"> <li>▪ Coping with the bad news</li> <li>▪ Being the perfect cancer partner</li> <li>▪ Being the perfect cancer patient</li> </ul>
<b>2. “It doesn’t shine as bright as it once did”</b>
<ul style="list-style-type: none"> <li>▪ <i>“You don’t give a shit, so why should I?”</i></li> <li>▪ <i>“I’m at the end of my tether”</i></li> <li>▪ <i>Communication and secrecy</i></li> <li>▪ <i>Changes in intimacy</i></li> </ul>
<b>3. What would have helped?</b>
<ul style="list-style-type: none"> <li>▪ <i>Willingness to accept emotional support</i></li> <li>▪ <i>‘Fear of the unknown’</i></li> <li>▪ <i>What can we do?</i></li> </ul>

Table 32 presents the superordinate and subthemes from the qualitative analysis of HNC couples interviews.

## 4.13 Superordinate theme one: “We got Cancer”

The superordinate theme of “We got cancer” reflected the reciprocal effects of the cancer experience identified by the HNC couples. Nested within this theme were the following subthemes:

- ***Coping with the bad news:*** This subtheme described the HNC couples’ emotional and behavioural reactions to the diagnosis.
- ***Being the perfect cancer partner and being the perfect cancer patient:*** These subthemes were the self-defined identities patients and partners felt represented their changed roles.

### 4.13.1 Coping with the ‘bad news’

Each HNC couple shared a different experience and coping response to the HNC diagnosis, highlighting the difficulty in predicting an individual’s coping response to cancer.

Finding emotional support from your partner has been shown to be an effective way of maintaining emotional health during a stressful period such as cancer diagnosis. However, what the following quotes highlight are the difficulties the HNC patients were faced with when having to ‘break the bad news’ to their partners and family. The analysis highlighted how the reactions and behaviours of one partner particularly affected the emotional and behavioural response of the other.

Mr Smith described how difficult he found telling his wife about his diagnosis. He reported that he had found this experience as distressing as the diagnosis itself. This was a common theme amongst the HNC patients. Mr Smith felt significant guilt and anxiety for placing the burden of his cancer on his wife. As a consequence, he emotionally withdrew from Mrs Smith to help him cope with these negative emotions. His quote also illustrates how he was unable to say to his wife that he had cancer: not having to directly name the cancer suggests how difficult this experience was.

*“I showed her the neck and throat cancer book and said look. She didn’t take it particularly well”*

*(Case study 1: Mr Smith, Patient, p2: 53-55)*

When Mrs Smith was told of the diagnosis by her husband, she reported feeling helpless, believing she had no control over the situation in which she had been placed.

*“It was the way he told me, he went off to get the results, then came back and told me (whilst still in work) so he wasn’t very thoughtful on that. You’ve just told me this. How do you want my reaction? All he did was touch my arm.”*

*(Case 1: Mrs Smith, Partner, p2. 35-44)*

Her quote shows how she wanted to be comforted by her husband (patient) and felt angry that she was left to deal with the diagnosis alone.

In case study 2, Julie (patient) also struggled with the diagnosis.

*“I heard the word carcinoma and I said go back did you say carcinoma? And he said yes and I said its cancer isn’t it? And he said yes I’m afraid it is. Then my daughter burst into tears.”*

*(Case 2: Julie, Patient, p5: 107-109)*

During her diagnosis, Julie described how her anxiety was increased due to the surgeon’s reluctance to name the disease as cancer. She felt because the surgeon had called it a carcinoma he was trying to minimise the seriousness of her disease. This meant she was left to name the cancer, and effectively ‘break the bad news’ to herself which increased her level of distress.

Julie’s partner Jake was not present at the consultation and was told of the diagnosis by Julie over the phone.

*“I had the strong belief and conviction that she would be ok”*

*(Case 2: Jake, Partner, p11 246-247)*

The language he uses to describe his coping response, (‘strong’ and ‘conviction’) reflect the ideologies that are often associated with cancer i.e. ‘staying strong’ and ‘being positive’. By redefining his cognitive appraisal into a positive belief (i.e. the cancer was treatable), he felt he was able to support his partner better.

In case study 3, Mr and Mrs Jackson shared similar perceptions and coping responses to the cancer. They appraised the cancer as being treatable as they felt this helped them cope with the negative impact of the diagnosis.

*"I thought oh well, what's next, I guess if you prepare that it's going to be cancer, then when they tell you it's not a shock. There you go, let's get it treated, let's move on, it was something I've got to have it done and I've got to be treated and sooner the better."*

*Case 3: Mr Jackson, Patient, p3:47-51*

*"You've got to get on with it, do it, we still don't know what is going to be the outcome but we just try our best."*

*Case 3: Mrs Jackson, Partner, p5:116-118*

In Mrs Jackson's quote, the persistent use of 'we' highlighted how the diagnosis affected the couple as a unit and not as independent individuals.

HNC patients also discussed the difficulties in managing their own emotions, as well as having to cope with the emotional reactions of others.

*"I came into the house and I said it's cancer. My daughter said 'it can't be, it must be a mistake, they got it wrong', I said 'no'. I didn't tell my son. I told him it was a lump and I was going to get it sorted. I think everyone was shocked. It's difficult because you're trying to deal with your own emotions, but they're your kids so you're worrying about your kids' emotions."*

*(Case 2: Julie, Patient p8:163-183)*

The quote highlights how difficult Julie found it to juggle her role as a mother and as a patient. She felt her identity as a mother was being taken over by the cancer which made her feel guilty and increased her levels of distress. This was a consistent theme within the HNC patients' narratives regarding the cancer diagnosis, where they revealed that having to contain the anxieties of others was as challenging as coping with the diagnosis itself.

Partners of HNC patients also expressed the same emotional demands. They not only felt responsible for the emotional wellbeing of their ill partner, but also for the additional responsibility of providing emotional support to other family members.

*"I rang my daughter immediately. And she was in floods of tears, and I said stop it, just stop it – we don't need that. He doesn't need that and you've got to be strong. Got to be strong to get through all this."*

*(Case 3: Mrs Jackson, Partner, p5: 102-107)*

Similar to Julie, Mrs Jackson highlighted how, as a mother, she also felt protective for her children in addition to her role as a wife needing to care for her husband. Her new identity as ‘cancer partner’ meant she felt she had to stay optimistic and ‘strong’, which is clear from her quote. This leads us to the next subtheme which further exemplifies how patients and partners felt the need to fulfil their new identities as ‘cancer patients’ and ‘cancer partners’.

#### **4.13.2 Being the ‘perfect’ cancer partner**

When an individual is diagnosed with cancer, the partner is usually counted upon to become the primary caregiver. As well as contending with this new role, the partners are expected to offer emotional support, adapt to the lifestyle changes, whilst having to contend with their own emotions and distress. Over time, partners revealed this became more difficult to sustain.

Partners of HNC patients reported they had acquired a new identity as the ‘cancer partner’. This meant they were to behave in a manner that was expected of them rather than in the way they would normally behave within the relationship. This new identity was as much a social expectation as a moral one and partners reported that they were regularly suppressing their own anxieties and fears, in order to be supportive of the patients’ needs. All partners revealed that they believed that their new role identity meant that they had to remain positive and optimistic and hide their emotions about the cancer. The following quotes highlight examples of this new identity as the ‘perfect cancer partner’.

*“I remember when she first got diagnosed, I went ‘you’re not going to die, you’re going to be here to talk about it, don’t worry’. I didn’t actually believe it at the time.”*

*(Case 2: Jake, Partner, p34:799-802)*

Jake revealed his fears of losing his partner to cancer, but felt it was part of his new identity as a ‘cancer partner’ to remain positive and optimistic, even when this challenged his own thoughts about the cancer. Partners reported frequently suppressing similar negative thoughts, with the belief if they discussed worries with the patient it could jeopardise their well-being. They became over-protective towards the patients but also began to feel underlying resentment and hostility.

*“It’s responding, but not showing my emotions because he’s dealing with his own, and he can’t deal with his own, so he certainly can’t deal with mine.”*

*(Case 1: Mrs Smith, Partner, p7:1163 -1166)*

Mrs Smith highlighted how she experienced significant emotional distress, and felt alone in the relationship. She felt she had been forced to put her shock and trauma regarding the cancer aside in order to provide comfort to her husband. This was acknowledged as another key role in the identity of the being the 'perfect cancer partner'.

The justification for this new identity was the 'guilt of health', where partners accepted having to deal with the negative emotional consequences within the 'cancer journey' because they were healthy. Mrs Smith's quote highlights this;

*"You don't want to unload your concerns, because they're already dealing with theirs. You don't want to off load that just comes across really selfish."*

*(Case 1: Mrs Smith, Partner, p41:932-936)*

Mrs Smith's language in the above quote, in her use of the phrase 'off load', reflects the burden she experienced. Partners in the interviews often used this kind of terminology to express their problems and anxieties, again avoiding clinical words such as 'burden' or 'anxiety' as these would be a reflection of them failing in their identity as a the perfect cancer partner.

Partners reported another key role in the identity of 'being the perfect cancer partner' was to avoid any cancer related conversations as partners believed feared upsetting the patient.

*"All I can imagine with me getting upset and getting tearful is she might think 'oh he thinks I'm going to die. Is it worth me carrying on if he thinks I'm going to die? Is it worth me trying? If he gives the impression that he doesn't think that I'm going to live'. I didn't want to give her that impression. The only impression I wanted to give her were positive ones. Even though at times I thought this is getting a bit heavy."*

*(Case 2: Jake, partner, p39-:911-916)*

Jake's quote particularly highlights the internalised fear he had about losing his partner. This shows the significant emotional burden he had bottled up. The quote from Jake shows how partners were suppressing these difficult emotions and choosing not to share them with their partner or family members for fear of being perceived as being unable to cope in 'being the perfect cancer partner'.

All three partners discussed deterioration in their physical health and wellbeing within the first twelve months of their partner's diagnosis, which demonstrates the potential adverse health implications for caregivers of cancer patients.

*"I know I'm under stress, I'm really suffering from shoulder pain, and it's the tension. "*

*(Case 1: Mrs Smith: Partner, p38:863-864)*

*"My own health hasn't been good. Been smoking, my smoking doubled with stress. There is also that feeling of 'what's the point?' You start getting 'what's the point' attitude."*

*(Case 2: Jake partner. P31- 724-728)*

*"I have come out a bit rashy at the moment – I think this is how the stress has come out – I've got steroids and God knows what, but it's very strange it's all come out now. I think stress comes out in different ways doesn't it?"*

*(Case 3: Mrs Jackson, Partner, p16:372-379)*

These quotes emphasise how the impact of cancer not only affected the partners emotional wellbeing but also had a negative impact on their physical health. This has significant implications for the kind of support that partners are able to provide to patients if their own physical health becomes compromised.

#### **4.13.3 'Being the perfect cancer patient'**

Further evidence of the interdependence of the patient-partner relationship was shown within this subtheme of 'being the perfect cancer patient'.

HNC patients believed they also had the moral and social pressure to become the 'perfect cancer patient'. The persistent emphasis on 'staying positive' and 'fighting cancer' was causing an increase in psychological distress. This is highlighted in Julie's quote.

*"I felt guilty that I wasn't doing enough, but I didn't have the energy to do anymore – I really isolated myself. I felt guilty because I didn't want to bring everyone down."*

*(Case 2: Julie, Patient, p17: 381-388)*



In Julie's quote she disclosed her difficulty in staying optimistic throughout the course of her cancer experience. She highlighted how she felt responsible for not just her own emotions and wellbeing but also her partner's and family's. When she was unable to continue being 'the perfect cancer patient' she highlighted how she became emotionally detached from her family, which compromised her abilities to cope with the cancer.

The extract by Mr Smith presents an example of the significant anxiety he was experiencing but would not disclose to his partner.

*"My cancer became all-consuming and I found myself thinking about it more and more and it got to the stage where I was thinking about it all the time. Everything reminded me of it – my swallowing, I had problems swallowing which is a natural after effect following surgery so I was having trouble swallowing and having trouble speaking. If I was speaking for a long time I was aware. When I shaved I was aware of my scar, and still am, and so it was everything – all my thoughts were CANCER CANCER CANCER."*

*(Case 1: Mr Smith, Patient, p8: 191-200)*

'Being the perfect cancer patient' meant patients were unwilling to express any negative emotions to their partner or family, as this would reflect their weakness and make their families think they were 'giving up'. Instead, they engaged in avoidant coping behaviours such as disengaging from them and held negative cognitive appraisals of themselves, such as feeling like a failure.

#### **4.13.4 Summary of “We got cancer”**

The theme of ‘we got cancer’ highlighted the reciprocity of emotions, where patients and their partners reported emotional responsibility for one another. Couples reported similar feelings of guilt, fears, and anxieties related to the diagnosis and throughout the cancer journey. They also adopted similar coping strategies (emotional withdrawal and avoidance) to deal with these negative emotions, particularly following the diagnosis. The analysis also revealed the need for HNC couples to present themselves as being the ‘perfect’ cancer patient or partner. This new identity became an antecedent to increased distress, particularly when they felt they were unable to fulfil the roles of staying positive and optimistic.

Patients and partners both revealed changes to their relationship following the diagnosis. This is commonly reported in cancer, however, in this study an increase in relationship conflict and irritability towards one another was revealed. This resulted in significant changes to the quality of their relationship with frequent desires to leave the relationship. This is the focus of the next theme “*It doesn’t shine as bright as it once did*”

## 4.14 Superordinate theme two:

### “It doesn’t shine as bright as it once did”

The second superordinate theme “it doesn’t shine as bright as it once did” reflects the negative changes within HNC couples’ relationships since the cancer diagnosis. Partners, in particular, reported how they found the transition from treatment to ‘resuming normal life’ particularly challenging.

The subthemes included:

- **‘You don’t give a shit, so why should I?’** Partners’ indicated the lack of appreciation from patients for the support they were providing which led to increased hostility towards the patient.
- **‘I’m at the end of my tether’:** Highlighted the increased relationship conflict reported by HNC couples since the cancer diagnosis.
- **Communication and secrecy:** Revealed the difficulties HNC couples showed in communicating about the cancer to one another.
- **Changes in intimacy:** HNC couples gave examples of the changes in the quality of their relationship following treatment.

#### 4.14.1 ‘You don’t give a shit, so why should I?’

In most relationships there are times when one partner feels they are giving more or may feel unappreciated for what they contribute in the relationship. This was a particularly strong theme as the HNC couples struggled with feeling their care was not good enough and/or were feeling unappreciated.

This imbalance of emotions caused increased distress but also contributed over time to increased hostility towards the patient.

*“He should show his appreciation more, just so I know it’s there.”*

*(Case 1: Mrs Smith, Partner, p35: 804-806)*

Mrs Smith’s quote showed how she felt her increased responsibilities, paired with the lack of emotional support from her husband (patient) contributed to her feeling her care and support was

being undervalued. A consequence of these negative perceptions was that Mrs Smith reported feeling critical and less tolerant of her husband.

*“No, you are not ill, you have cancer. Of course it’s an illness but you’re being treated. You are being helped.”*

*(Case 1: Mrs Smith, Partner, p28:638-643)*

Mrs Smith’s quote revealed the underlying resentment she had developed towards her husband, which, she explained, was due to feeling she was putting more into the relationship than she was getting in return. She justified these negative feelings by believing he was no longer ill thus allowing her to feel anger towards him: he was being treated and helped, unlike her having to deal with everything alone. The extent of Mrs Smith’s hostility was revealed in the following extract from the interview.

*Mrs Smith: “There’s a little part of me, which still in the back of my head thinks he won’t live much longer, so you don’t need to walk away, because eventually, that will be dealt with. It’s a terrible thing to say, but it would solve an awful lot of problems if the cancer does come back and finish him off.”*

*Interviewer: “How often do you feel that way?”*

*Partner: “More regularly than I should. I can’t say it’s every day, it’s when he has an appointment or something like that, that’s the way it is.”*

*(Case 1: Mrs Smith, Partner, p17:378-404)*

Mrs Smith’s extract shows her deep resentment towards the patient, which she revealed was due to a culmination of internalising her own emotions, lack of emotional support and inability to share and discuss the cancer with her husband.

Similarly Jake also revealed increasing resentment towards his partner.

*“I started to think, if you don’t give a shit, why do you want me to? I used to get annoyed.”*

*(Case 2: Jake, Partner, p19:453-455)*

Jake also expressed a negative attitude towards his partner Julie during treatment, where he criticised the way she was dealing with her illness.

*“There was times when she was having radiotherapy and she didn’t want to go, I came down and I was fuming, and I thought ‘how am I going to word this in a way that she will go?’ So I basically turned it around and said ‘there’s people who aren’t going to get this chance because they are dead, because cancer killed them, so you are disrespecting all these dead people so you better get off your ass and get dressed, you’re making a mockery of all those people up there looking down on you, looking down on you, thinking I would love to be in your shoes.’ I tried to put a positive spin on it to make her believe ‘yeah he’s right’.”*

*(Case 2: Jake, Partner, p8:186-202)*

The quote had an underlying aggressive tone illustrated by the language used in Jake’s quote; (‘fuming’ ‘dead’ ‘mockery’).

The contrasting quote from his partner Julie highlights her passivity and vulnerability during treatment period, with a desire for partner to give her ‘permission’ to be able to convey emotions which she still felt the need to internalise. This is an example of how negative support i.e. hostility from partner may contribute to increased feelings of helplessness in patient.

*“When I was having radiotherapy, I used to sit there and say I don’t want to go; I don’t want to go today. He would say ‘you will go, you will be fine, chop chop’, I didn’t want him to let me cry but sometimes I would’ve liked him to have said ‘cry today, let it all out’.”*

*(Case 2: Julie patient, p9:194-196)*

#### **4.14.2 ‘I’m at the end of my tether’**

All three HNC couples revealed an increase in conflict within their relationship since the cancer diagnosis. Unexpectedly, partners were more open to reveal the causes of the conflict than the HNC patients.

One explanation given by partners was feeling emotionally hurt, as they felt their care was being undervalued.

*“Sometimes I think she felt that I weren’t good enough, I weren’t doing enough, and I weren’t saying the right thing.”*

*(Case 2: Jake, partner, p12:266-268)*

*“I used to say ‘there ain’t no fucking manual on how to get someone through cancer’.”*

*(Case 2: Jake, partner, p34:790-792)*

Jake’s quotes highlighted how his feelings of failing in his caregiving role shifted into feelings of frustration with his partner. He revealed how he had started to question why he was trying so hard to satisfy Julie’s emotional needs. He reported feeling resentment and anger towards her and disclosed that he became less tolerant of her cancer.

*“I come almost to the end of my tether, because she was doing all of the wrong things, and I would get annoyed.”*

*(Case 2: Jake, Partner, p22:512-521)*

Similarly, Mrs Smith revealed an increase in irritability with her husband, but similar to Jake, she also felt she was becoming more emotionally withdrawn from her husband.

*“He would snipe, snipe and I got worn down, so I thought I don’t need this.”*

*(Case 1: Mrs Smith, Partner. p9:214-216)*

Partners revealed how their emotional withdrawal from patients was a sign of their dissatisfaction within the relationship. Partners discussed how their increased hostility, coupled with their feelings of resentment, resulted in thoughts of leaving the relationship.

*“I felt claustrophobic, is a good way of describing it. I felt like I didn’t want to be here at times. I thought I don’t want to be.”*

*(Case 2: Jake, Partner, p29:650-653)*

Feeling trapped in the relationship was a common theme from the partners who felt the cancer had taken over their lives and their relationships.

*“I still love the woman, but it doesn’t seem too bright as it once did.”*

*(Case 2: Jake, Partner, p21:487-489)*

Jake’s use of metaphor reflects how he perceived a change in his relationship, exposing the cancer as a period of darkness.

Patients and their partners revealed how the increase in conflict contributed to their low mood but more significantly revealed their frequent desires to want to leave the relationship.

*“Before treatment, I said I would do anything for our relationship to work. After the treatment, I couldn’t be bothered, couldn’t care less.”*

*(Case 2: Julie, Patient, p11:250-253)*

*“We both thought a few times we would split up, you know, I think she probably thought the same thing.”*

*(Case 2: Jake, Partner, p22:506-510)*

The quotes from Jake and Julie demonstrate their desire to leave the relationship. For Jake, the combination of increased responsibilities (emotional and practical) paired with the perception of feeling his support was not good enough resulted in him feeling unappreciated and alone. Over time, this had developed into feeling hostile and resentful towards Julie, particularly once her treatment had ended. He also reported anger, and resentment when he felt his emotional and practical support was being taken for granted. Similarly, Julie felt her inability to openly discuss her emotions with Jake combined with her increased fatigue and side effects contributed to her increased levels of psychological distress but also impacted on her all aspects of her quality of life and wellbeing.

Another significant indicator underlying the HNC couples increased reports of distress, that contributed to their relationship dissatisfaction was the communication breakdown between them.

#### **4.14.3 Communication and secrecy**

All three couples revealed a negative communication pattern throughout the cancer experience. Both patients and partners avoided discussion about the cancer. This pattern was especially shown in partners. Partners frequently worried about saying the wrong thing and felt by disclosing emotions

about the cancer they could hinder the patient's wellbeing. The following quote by Jake highlights his own desire not to talk about the cancer for his own wellbeing as well as his partners.

*"If you have too many nights where you are discussing it, it will weaken your resolve. I won't get up to go to work the next day because I can't sleep. I'm not saying you have to shove it aside, but sometimes you have to, it doesn't go away, it doesn't go away, but you can't keep talking about it too much or worrying yourself"*

*(Case 2: Jake, Partner, p7:142-147)*

Jake's quote highlighted the increased emotional burden he felt from the cancer and the impact on his own well-being. The contradictions within his quote particularly show the difficulty he found coping with his partner's cancer, and he avoided cancer-related conversations for his own wellbeing as much as for his partner's. Again the language he uses within the quote, 'weaken', highlights the challenges in staying strong throughout the cancer experience.

Subsequently, patients often reported feeling the burden and guilt of making their partner anxious. They revealed how they would have felt less burdened if their partner and family members disclosed their fears and worries about the cancer, which then would have helped to normalise their own feelings.

*"We had a row and he said 'don't you think I have thoughts of your funeral and the future without you'. I said I'm glad you actually said that because thank God you did have those fears which are normal. I needed to hear them."*

*(Case 2: Julie, Patient, p10:208-216)*

Julie's quote indicates how she craved validation that her thoughts were not dysfunctional. She talked of her need for emotional validation and was relieved that her partner was able to communicate his emotions, as for Julie this meant that he did care about her which validated her insecurities about their relationship.

As demonstrated in the previous theme, the dysfunctional communication related to the cancer was often the underlying cause to increased conflict in relationships. This included patients choosing not to share information about the cancer with their partners, which resulted in partners feelings isolated and unappreciated.



An example of lack of communication included patients choosing to attend appointments without the support of their partners. Mrs Smith revealed how she felt that she wasn't trusted and was pushed away by her husband, which contributed to feelings of helplessness. In contrast, Mr Smith (patient with cancer?) felt he was being protective of her feelings and not wanting to burden his partner. This highlights how due to the lack of communication, the emotional appraisal was influenced by their own perceptions of the event, which, when in a highly stressed environment, was more likely to be appraised negatively. Mr Smith's quote (below) also highlights how he avoids any cancer related conversation with his partner, which Mrs Smith revealed contributed to her increased anxiety as she was left to 'think the worst'. Mrs Smith was extremely tearful through her interview and cited the lack of communication within her relationship regarding the cancer as the underlying cause of her elevated distress, but also the increased hostility and resentment she felt towards her husband.

*"I'm a very private person and I would say since that day (diagnosis) we have hardly ever spoken about it, we never spoke about how I feel really, we never really speak."*

*(Case 1: Mr Smith, Patient, p9:227-232)*

*"He's never ever wanted me at any appointment, and I have to respect that, that's what he wants me to do (cries)."*

*(Case 1: Mrs Smith, Partner p2:47-49)*

There were also several conflicting accounts within couples in how they perceived changes in their relationship.

*Patient*

*"We have a strong relationship, we have been with each other 26-27 years so we have a strong understanding relationship."*

*(Case 1: Mr Smith, Patient, p16:393-396)*

*Partner*

*"I would have happily left him because of the lack of emotion and just (being) fed up. He can be a difficult person. Not to others, but to those close to him he's an absolute bastard."*

*(Case 1: Mrs Smith, Partner, p9:200-203)*

*"Wife is more important to me than anything else."*

*(Case 1: Mr Smith, Patient, p16:406-408)*

*"If the prognosis was short term, that's what I am saying, it would sort things out. Then I could get on."*

*(Case 1: Mrs Smith, Partner, p22:500-502)*

*"If me and my partner can get through it, which I'm sure we can."*

*(Case 2: Julie, Patient, p11:245-246)*

*"I still love the woman it doesn't seem too bright as it once did."*

*(Case 2: Jake, Partner, p21:487-489)*

The extracts here show how patients retained hope in maintaining their relationship, in contrast to partners, who expressed increased hostility and resentment towards the patient.

This emphasised the unique challenges to communication encountered by HNC couples and the consequences of negative impact of poor communication regarding the cancer.

The interviews revealed that the communication between HNC couples is not straightforward. Some patients wanted to communicate, whereas other did not. A similar pattern was found in partners. The problems occurred when one person within the couple wanted to communicate and the other was resistant to talking about the cancer. A quote from Jake illustrates this:

*"There were a few times I would come home from work and say I do not want to come home and talk about fucking cancer. I can't keep talking about it. A couple of times we had dinner and she brought it up and I went 'do we have to talk about it now?' I didn't want to. We knew it was going on, none of us were stupid we all knew what was going on."*

*(Case 2: Jake, Partner, p37:869-87)*

Jake's quote is an example of how a partner's negative response may discourage open communication between the couple. Jake's partner Julie revealed how she found Jake's inability to communicate contributed significantly to her levels of anxiety and distress related to the cancer.

The interviews reveal that lack of communication not only had an impact on distress in couples but also affected quality of patient-partner relationship.

#### **4.14.4 Changes in intimacy**

The absence of activities and spending 'quality' time together was reported by all three couples. HNC couples' definition of intimacy was multifaceted as they reflected on the relationship that existed prior to diagnosis and treatment. The narratives of HNC couples highlighted not only the loss of physical affection but also the loss of the sense of belonging within the relationship.

This was illustrated in the below quotes from Julie.

*"I think he started to get fed up with me because I was in a bad mood all the time, sex life was gone, not interested."*

*(Case 2: Julie, Patient, p13:289-293)*

*"I did think, 'I wonder if he will go off with someone else.' I started thinking who is going to want to be with me. Because when I met him I was quite positive and energetic. I started thinking I'm not the person he met so he's not going to want to be with me."*

*(Case 2: Julie, Patient, p25:574-579)*

Julie's quotes highlight the issues of self-esteem and insecurities, but also paranoia she experienced within the relationship, particularly as her partner Jake, had become more distant.

*"I suppose we have become a little (more) distant from each other than before, without even realising it."*

*(Case 2: Jake, Partner, p18: 409-411).*

Jake (partner) described how the changes in the relationship occurred after the treatment. He felt it was this period that was most difficult, where the challenge was to try and rebuild the relationship following the roller coaster of emotions throughout the cancer experience.

*“We both thought a few times we would split up, you know, I think she thought the same thing too, this is after we went through it all (treatment).”*

*(Case 2: Jake, Partner, p22:506-510)*

In Jake’s extract, he revealed how the thoughts and desires of leaving the relationship occurred after the treatment had ended. This was a frequent theme amongst all the HNC couples that reflected the difficulties patients and partners experienced when trying to return their lives to normal. The resentment in partners was more prevalent at this period when they reported finding it difficult to return to the relationship they had before the cancer.

There was an undercurrent in the HNC couples of mourning and loss for the relationship that existed prior to the diagnosis. Partners particularly expressed a sense of loss of a close relationship. This was particularly highlighted in quote from Mrs Jackson (partner).

*“I think you feel it’s a bit unfair as well you know. You’re just getting to your 60s which is comparatively young. We’ve always been healthy. You think ‘oh you can start relaxing now’ more and then you know.”*

*(Case 3: Mrs Jackson, Partner, p11:239-243)*

Mrs Jackson’s narrative reflected mournful and resentful undertones, where she felt cheated by the cancer for taking over her life as well her husband’s. She questions why this would be happening to them as a couple, which further reflected her grief.

*“We miss our breaks, because we cancelled our holiday which was supposed to be big. Because we’re older now we must start doing these things so we, we, we cancelled that. We had a weekend away, but we had to cancel that, a friends 60<sup>th</sup>. Because obviously treatment comes first. It would be nice to just clear off somewhere. NEVERMIND.”*

*(Case 3: Mrs Jackson, Partner, p8:186-196)*

Although Mrs Jackson did not directly state that she blamed her husband for the changes to her relationship, the language and examples she chose to present to the researcher indicated the loss she perceived. Indirectly, she was blaming her husband and his cancer for the loss of her 'quality of life'.

#### **4.14.5 Summary of "it doesn't shine as bright as it once did"**

The theme 'it doesn't shine as bright as it once did' demonstrates the significant impact and emotional strain that is placed on the relationship of couples living with HNC cancer. HNC couples showed high levels of relationship dissatisfaction, including hostility towards one another, resentment and in some cases a desire to leave the relationship. The lack of communication was the most common identifiable cause of negative thoughts and feelings between couples. Interestingly, couples reported the changes in relationship were even more marked once the treatment had finished, where the adjustment back to 'normal' life was more difficult than expected.

## 4.15 Superordinate theme three:

### What would have helped?

The final superordinate theme, *What would have helped?*, highlighted patients' and partners' perceptions of the care they received and introduced their views and recommendations on what they would have found helpful during their experience of living with cancer. Each couple revealed various stages of the cancer that they found most difficult and the type of support that would have been beneficial during these difficult periods.

Subthemes included:

- **Willingness to accept emotional support** explores the partner's reluctance to accept emotional support.
- **'Fear of the unknown'** examines a need for better emotional support for patients, but also for the partner and family, particularly during times of increased emotional distress i.e. diagnosis, and treatment.
- **What can we do?** Reports suggestions and recommendations for the type of support patients and partners would be willing to accept.

#### 4.15.1 Willingness to accept emotional support

Patients highlighted feeling excessive guilt and anxiety for placing the burden of cancer on their partners and believed that if there had been emotional support available for their partner it would have made them less anxious. Julie's quote below is an example of this.

*"I would've felt better, definitely. Because I wouldn't have felt guilty. I would've been quite happy if he had the chance to off load to somebody. Go talk to someone else about that. I knew he was scared, it irritated me why he kept doing the stiff upper lip."*

*(Case 2: Julie. Patient, pg35 802-808)*

The quote reveals the guilt and anxiety Julie felt for placing the burden of cancer on her partner. As demonstrated in the previous themes, these feelings of guilt eventually resulted in negative emotional responses including increased resentment and anger. Therefore the benefits of emotional support for

partners could have a direct effect in decreasing patient's psychological distress and improving their quality of life, by lifting their burden of guilt.

However, there was a clear conflict within partners' dialogue in relation to receiving emotional support. Partners identified a need but felt conflicted as to whether they 'deserved' any emotional support. An example of why partners were reluctant to accept support is demonstrated in the below extract from Mrs Smith:

*"I don't think the non-victim takes it up (support) the same way the victim does because I think you feel, how do I word this. You (patient) need it because it's happening to you. I don't need it because it's not happening to me. Are my needs therefore different? Is it a sign of weakness? Does it look like a sign of weakness?"*

*"You're the one who needs everything because you are in the middle of it. I don't need anything, because I should be stronger and see things through. (Cries)... Equally, it's like now, look at me I'm a mess but it's where do you separate the feeling of what's happening from the whole package? I don't think you can. I therefore, I think it is unjustified to have somebody to speak to."*

*(Case 1: Mrs Smith, Partner, p28-29: 647-664)*

Mrs Smith's quote indicates her conflicted emotions. Emotional support had become a reward which she felt she did not deserve. Her husband was the 'victim' and therefore not responsible for the cancer so he was entitled to sympathy and support unlike her as the 'non-victim'. Mrs Smith acknowledged she needed support, but held a belief that if she were to accept, she would be failing in her role as the perfect 'cancer partner'. She also highlighted the stigma attached to receiving support for emotional wellbeing, particularly the belief that seeking and accepting emotional support would be a sign of 'weakness'. This would have challenged the 'staying strong' obligation she felt she had to retain in keeping with her identity as the 'perfect' cancer partner. These themes were consistent in the narratives amongst the HNC partners, who felt conflicted between needing support and their willingness to accept support.

Mrs Smith suggested there is a need for an 'automatic appointment' for partners from diagnosis. She highlighted that if there were a compulsory appointment, she would have not felt as if she was 'asking' for help thus would not be confronted by her perception of emotional support being a sign of

weakness. Having a compulsory appointment would have allowed her an outlet to discuss worries and fears related to cancer without the concern of being judged.

*Mrs Smith: "It should be an automatic appointment almost that you can't get out of. Because I think for most people it would be that initial appointment that would be the hardest to go to, probably at diagnosis because it would make you feel part of it. So you make a connection."*

*Interviewer: "Would you want Mr Smith to attend the appointment with you?"*

*Mrs Smith: "Oh God, not with, never with, no no noooo."*

*(Case 1: Mrs Smith, Partner, p30:688-702)*

#### **4.15.2 'Fear of the unknown'**

This subtheme examines the increased psychological distress partners experienced following treatment. All three HNC partners reported that the first contact they had with the patient following the surgery was particularly distressing. They revealed it was at this point that they realised the reality of HNC and how it was going to change the rest of their lives.

*"I found it hard to walk into the ward because I didn't know what I would find (cries). I think that's when you need someone (professional) to go in with you. If it's somebody that has made a connection with you already then that would be supportive because then you can talk to them after. They would be there to say that was perfectly normal. You don't know what you're going to see. That is probably when I was at my worst."*

*(Case 1: Mrs Smith, Partner, p32:732-747)*

Mrs Smith's quote shows her increased distress following her husband's surgery. This occurred from not knowing what to expect and therefore not being mentally prepared for the reality of seeing her husband looking vulnerable. This was consistently reported amongst partners who felt psychologically unprepared for the first contact following treatment. Partners revealed seeing their partner looking 'ill' triggered the negative thoughts and feelings experienced at diagnosis. These included the worries about their future together but also the fears of losing their partner. It was suggested by partners that emotional support during this time, would have been beneficial to help cope with these thoughts and feelings.



The couples, who had experienced adjuvant radiotherapy treatment, reported how they would have also benefited from having better written and verbal information about the psycho-social impact of the treatment. This is specifically highlighted in Jake's quote.

*"The radiotherapy, what it does to your relationship it's bad. It's not good. It's not just the six weeks. It's the six weeks after. 12 weeks. Three months, a lot of turbulence. A lot of mood swings, you know."*

*(Case 2: Jake, Partner, p49:1158-1166)*

Jake's quote suggests the significant impact of the treatment on his relationship with his partner. He believed if he was given more information about psychological side effects, such as increased irritability and fatigue, he would have been better prepared to deal with these factors.

*"I suppose if there is something you could do, most people who have had the operation and the cancer removed (surgery) most people don't know what they still have to come, we didn't. We were too busy patting ourselves on the back. 'Oh it's out-brilliant.' We've only got the radiotherapy to go. When really the radiotherapy was bigger than the actual operation and what it can do to your relationship and then you see that person ill. So if there is something you could do. You could probably ante up on trying to get people to understand after the operation that there is a lot more to come. Because we were totally unaware of what radiotherapy entails. The radiotherapy is actually worse than the operation to live with as a partner."*

*(Case 2: Jake, Partner p48:1134-1139)*

#### **4.15.3 What can we do?**

This subtheme identified possible systems of support that HNC couples felt would have helped improve their emotional needs and reduce psychological distress.

- **Cancer buddies**

HNC couples found comfort in speaking with friends who had been through similar experiences but felt they did not want to continuously burden them with talking about their cancer. They revealed they would have liked to have had an external source of support, for example a former patient, to be able to talk with from diagnosis.

*Julie: "It would've been nice to have talked to another patient that had been through the same thing."*

*Interviewer: "At what point would you have felt that would have been useful?"*

*Julie: "As soon as I was diagnosed I think and through the whole thing."*

*(Case 2: Julie, Patient, p29:668-675)*

Patients believed another patient who shared their diagnosis and been through a similar journey, would have allowed them to communicate their treatment concerns or simply share thoughts about their cancer which they felt unable to do with their partners and clinical team members in the busy clinical environment.

*"I often felt the clinical team was too busy and they have got so much to do. I would always go 'yes I'm fine' because I didn't want to burden them with more because I knew what a big job they were doing."*

*(Case 2: Julie, Patient, p36-7:839-857)*

Julie's quote highlighted her continual worries about being a burden, and felt that an anonymous service where patients could openly discuss their fears and worries within a controlled environment would have also been beneficial. This would have reduced her fears of being judged and also reduced the emotional responsibilities on others.

*"Somebody to waffle on to about how I felt. Similar to I suppose like you have Samaritans or Child Line. Sounds silly but do you know what I mean. Where you, I suppose, have semi-professional people because they would know what you are talking about, like a counsellor like that at the end of the phone. When everyone else is asleep and I'm awake at 3am and sometimes choked up and someone then to talk to rather than thinking is this normal and Googling and frightening myself more."*

*(Case 2: Julie, Patient, p36:839-846)*

- **Couples counselling**

Partners reported the same emotional needs and concerns as the patients and felt they would have also benefited from talking to other cancer partner's about their experiences.

*"It needs to be someone who experienced it, not someone who is experiencing it."*

*(Case 1: Mrs Smith, partner P44.1004-1005)*

In addition, partners emphasised a need for improvement in communication within their relationship, as they believed the lack of communication was the underlying factor to the increased levels of conflict and relationship dissatisfaction following the diagnosis.

*"I think there is definite room for couples' counselling."*

*(Case 1: Mrs Smith, partner p34. 784-791)*

Mrs Smith believed couples' counselling would have helped facilitate better communication between her and her husband, which had completely broken down following the diagnosis. The difficulty in communication was reported amongst all HNC couples, where poor communication and emotional avoidance became the common coping strategies when faced with cancer related problems.

Therefore, improving communication channels between couples during the cancer may have assisted with couples' overall relationship quality and therefore improved their quality of life.

#### **4.15.4 "What would have helped summary"**

Currently, in the treatment of HNC, emphasis is quite rightly placed mainly on physical functioning and increasingly health-related quality of life factors are also highlighted during consultations. However, minimal focus, if any, is applied to the emotional impact of the cancer and there is no specified multidisciplinary team member assigned to this role. There appears not only to be a significant need for this service, but also for an additional shift to provide emotional support to the partner and family members. Overall, patients were satisfied with the health services they had received for their cancer. Several suggestions by patients and their partners were made which highlighted the lack of emotional support currently available within HNC service. However, there is a potential barrier between offering support and willingness to accept support, particularly within partners of HNC patients.

## 4.16 Summary of Qualitative findings

The findings of this and other studies show that partners play an integral part within a patient's rehabilitation process and that the impact of the cancer on the partner of HNC patient is as significant as the impact on the patient. Partners of HNC sufferers essentially became 'secondary patients' with levels of emotional distress similar, if not higher than the patients' with additional consequences on physical health.

The present findings indicate that partners who show increased levels of distress pre-treatment may find it more difficult to adjust to the emotional challenges across the cancer experience. The most frequently reported concerns of partners were finding the best ways of being supportive whilst contending with own distress. This was challenging as they were experiencing such high levels of psychological distress themselves. Therefore, they found it more difficult to internalise their own fears and anxieties as well as contending with the patient's fears and anxieties. Over time internalising their distress became more difficult and due to their increasing levels of distress, partners were more likely to be sensitive to the negative aspects of the disease, struggling to remain positive and optimistic.

HNC couples reported a decline in satisfaction in their relationship which was reported to contribute to an increase in their levels of psychological distress. An exploratory model of the findings is reported in Figure 30.

Figure 30: An Exploratory model showing the impact of HNC on patients and their partners.

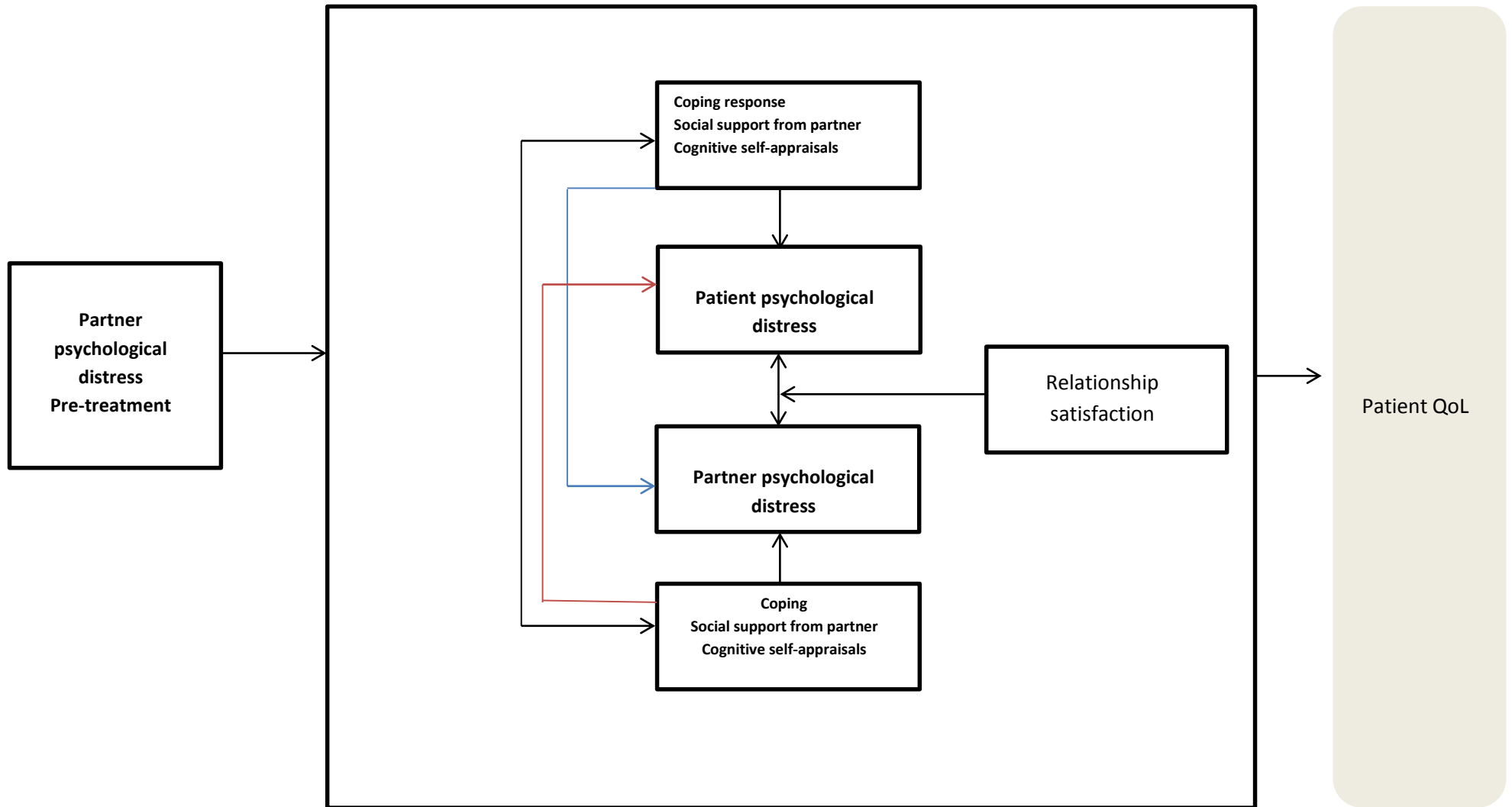


Figure 30 shows an exploratory model of the findings from the qualitative study. The model shows the relationship between patients and their partners' psychological distress and how this impacts patients' QoL. The analysis found partners' psychological distress before treatment contributed to each of the following constructs: cognitive response, social support from partner, cognitive self-appraisals and patient psychological distress. The results of this study show that patients' and partners' coping behaviours, perceptions of support and cognitive self-appraisal (for example negative cognitions of guilt, blame, burden) were affected by each other's responses. Also, patients' psychological distress was directly affected by their coping style, perceived support from partner as well as their partner's psychological distress, coping style, and perceived social support. The same factors were found for partners' psychological distress. The model also explains how our findings showed patient-coping style, perceived partner-support, and appraisals of cancer were related to each partner's coping style, social support and appraisals of cancer. Furthermore, relationship satisfaction during treatment and following treatment was reported as the most significant contributing factor in patient and partner psychological distress. All these factors affected HNC patients overall QoL.

This model proposes that partners who show high levels of distress before treatment are less able to engage in this coping process effectively and therefore this will have a negative impact on patients' psychological distress, poorer quality of support and maladaptive coping responses e.g. avoidant coping response, therefore effecting patient QoL.

## 4.17 Qualitative Discussion

To the knowledge of the author, this is the first qualitative study that specifically examines the experiences of HNC couples, where the patient's partner reported high levels of psychological distress before commencement of treatment.

In summary, three key themes were raised within the present analysis. "We got cancer", which reflected the reciprocal effect of the cancer, "it doesn't shine as bright as it once did" highlighted the negative impact of HNC with couples relationship and "what would have helped?" introduced views and recommendations from the HNC couple presenting recommendations for what would have helped during their cancer experience.

The analysis of interviews highlighted how when one partner is diagnosed with the cancer, both partners experienced stress associated with the illness. A dominant theme was the notion of adhering to an ideal of being the 'perfect cancer partner' which was entrenched in patients' and partners' perceptions of how they believed they should behave when faced with the cancer. Both held preconceived ideas of what was expected from them in their new identities. They revealed feeling obliged to present a constant persona of 'fighting the cancer' and 'staying strong'. However, what was clear within participant's narrative was the inability to sustain this positivity, which led to feelings of inadequacy, self-blame and guilt. Reave, (1997) highlighted how staying positive during cancer opens the possibility for blame and guilt when patients with cancer are unable to sustain this way of thinking (Reave, 1997). This raises the question of positive and negative thinking in cancer care. The psycho-oncology literature concerned with coping strategies suggests that the coping style of thinking positively and maintaining a fighting spirit is correlated with the cancer patient's overall level of mental health and mortality rates (Allison, Guichard, Fung, & Gilain, 2003). Our findings showed this coping style could also represent an additional stressor for cancer patients. In this case, thinking positively does not represent an accurate report of how one thinks, but rather a conversational idiom, summarising a socially normative moral requirement. This is supported by Petticrew and colleagues, (2002) who found no clear association between a thinking positively coping style and recurrence or survival in cancer (Petticrew, Bell, & Hunter, 2002). Petticrew et al (2002) concluded that people with cancer should not feel pressured into adopting particular coping styles to improve survival or reduce the risk of recurrence. As our sample was purposively selected to include partners with psychological distress at diagnosis, this may explain why this sample in particular were finding it more difficult to maintain a 'positive thinking' and

'fighting spirit' during their cancer experience.. When an individual is experiencing elevated symptoms of psychological distress, they may be more likely to adopt a negative thinking pattern, which was highlighted within the interviews. This may explain why patients and partners found it more difficult to adhere to the 'perfect cancer partner' role. Future studies examining HNC couples that are not experiencing elevated symptoms of psychological distress could help determine whether these findings are limited to individuals who are more vulnerable to the effects of stress. As our quantitative findings showed, prevalence of partners with psychological distress in high (40% depressive symptoms at diagnosis: see Figure 14), therefore the partners interviewed may not be exceptions.

The second emergent theme within the data was "it doesn't shine as bright as it once did", which reflected the negative changes that occurred within the patient-partner relationship. A dominant theme found within the interviews was the negative exchanges within the patient-partner relationship. HNC couples revealed increased hostility, relationship conflict and resentment towards one another. This increased hostility and resentment towards patients raises several clinically relevant implications.

Firstly, it highlights the significant demands that are placed on partners of cancer patients. These demands result in caregiver strain and possibly caregiver burnout. Caregiver burnout has been described as a measure of emotional and cognitive response to caregiving, and has two key concepts. Emotional exhaustion, which refers to a loss of emotional resources and to a feeling that one lacks the energy to invest relationships and depersonalisation, which refers to a negative and indifferent attitude toward patients (Ybema et al., 2002).

For caregiving partners, caregiver burnout may be a consequence of increased emotional exhaustion over time, with the increased hostility and resentment towards patients indicating depersonalisation. This would explain why some partners of HNC patients showed increased hostility and started to show dysfunctional thoughts and resentment towards the patient. A second clinical implication of increased hostility towards the patient is the quality of support provided by the 'well' partner who holds these dysfunctional thoughts. Negative social support, particularly negative behaviours has been found to increase psychological distress in patients and therefore decrease QoL (Manne, Taylor, Dougherty, & Kemeny, 1997; Manne, Ostroff, Winkel, & Grana, 2005).



Finally, increased hostility towards the patient was reported as the antecedent to increased relationship conflict consequently increasing stress to the patient, which may contribute to elevated psychological distress and affect patient QoL. Our findings would suggest that partners who experienced elevated psychological distress pre-treatment were more susceptible to show increased hostility within the relationship.

Another key finding from the qualitative interviews was the negative impact of poor communication between couples. Manne et al (1997) highlighted two types of communication strategies that were commonly employed amongst patients with cancer. First was 'positive communication' which suggests the benefits of open communication, including disclosure of feelings and concerns to one's partner, and second was 'negative communication', which involves criticising one's partner, avoiding cancer related concerns and or pressuring ones partner to discuss ones concerns (Manne et al., 1997). All three couples within the study indicated 'negative communication' where patients were less willing to communicate with their partners about the cancer. The consequences of such behaviours meant that there were frequent misunderstandings between couples with increased withdrawal from one another. Negative communication contributed to increased hostility and resentment within the relationship.

Similar findings have been supported by larger quantitative studies which have shown how negative communication such as avoiding cancer related conversations have been associated with greater distress for both partners (Manne, Ostroff, Winkel, Grana, 2005). Our findings identify the potential clinical need to improve communication amongst HNC couples, particularly where one or both partners are experiencing heightened psychological distress. Better communication between couples would facilitate reciprocal influence, which in turn would have a positive effect on intimacy between the couple and improve the patient and partner outcomes.

Currently within HNC, details regarding physical functioning and health related quality of life factors are often highlighted during consultations. Minimal focus, if any, is applied to the emotional impact with no specified multidisciplinary team member assigned to this role. There appears to be a significant need for this service, but also an additional shift to provide emotional support to the partner and or family member. Overall, patients were satisfied with the services they had received for their cancer, but suggested emotional support for their family and partners would be beneficial for their wellbeing in addition to their partners.

However, unexpectedly, partners were resistant to accept direct emotional support. One explanation for this resistance may be that the partner might perceive acceptance of help as a failure in their role as the caregiver. This is supported by Thoits (1991; as cited in Hagedoorn et al 2002) who suggested that if taking care of your partner is an important part of one's identity, problems in this area or failing in caregiving task (for example asking for help) will cause considerable distress. This may explain a partner's resistance to accept emotional support. Hagedoorn et al (2002) argued this may be especially relevant in women, as maintaining social relationships and taking care of the spouse and children have been mainly the responsibility of women Hagedoorn et al., 2002). Our findings would suggest, although partners of patients are reporting elevated symptoms, if offered emotional support for this distress, partners may be unwilling to accept it.

The majority of studies that have examined relationship satisfaction following cancer treatment show how relationships were strengthened and couples emerged more tightly bonded (Lavery & Clarke, 1999). The disparity between the present findings may be explained as the present study was purposively selected to interview partners who were showing increased psychological distress. These individuals may be more likely to report lower relationship satisfaction as Hagedoorn et al (2008) found a negative association between elevated levels of psychological distress and marital satisfaction (Hagedoorn, Sanderman, Bolks, Tuinstra, 2008; Manne, Taylor, Dougherty, & Kemeny, 1997). The unique aspect of the present study is the insight into lived experiences of HNC couples who are showing elevated levels of psychological distress which appear to show a difference in adjusting to the cancer when compared to findings that have examined couples adjustment to cancer, not accounting for levels of psychological distress (Lavery & Clarke, 1999).

#### **4.17.1 Strengths of qualitative study**

One of the strengths of the qualitative findings is the use of the IPA method for analysis allowing an exploration of the explanations underlying HNC couples' thoughts, beliefs and behaviours regarding their cancer experience. It allowed for a deeper more personal analysis into the lived experiences of HNC patients living with a partner experiencing psychological distress before treatment. These findings provide a deeper insight and complement the quantitative findings.

Another strength is that participants were purposively recruited to present a homogeneous sample in terms of the levels of partner psychological distress, therefore giving a unique perspective into the underlying factors contributing to this distress. Although the sample was small, it was still sufficient enough to provide in-depth analysis of HNC related issues, revealing new insights and

identifying several clinical implications for further research and application. As open-ended interview was utilised; the data collected from HNC couples represented topics and themes that were important for the participants and not researcher-led.

Furthermore, a good rapport was gained with all participants who answered all questions, including the most sensitive. In future work it might be even more useful to have, shorter interviews over a longer period to provide richer data and allow for greater engagement with participants which may give even deeper insight into HNC.

#### **4.17.2 Limitations**

The explorative nature of the present study has its methodological limitations. Firstly, the sample comprised predominantly white British couples, with more male than female patients. Although there are more male than female HNC patients in the general population, a more diverse sample in terms of ethnicity and gender might have revealed different findings. For example, previous studies have suggested that there are ethnic/cultural differences with regard to the level of comfort that individuals have with depending on their partners for emotional support (Kagawa-Singer, & Wellisch, 2003). Because so little is known about differences with regard to couples communication and intimacy across different ethnic groups, future studies would benefit from evaluating cultural differences.

There was a low rate of study acceptance for the qualitative interviews, which suggests the difficulty HNC couples may have in expressing their narratives of the cancer experience. Study refusers may also have been more distressed at 12 months when approached which may have biased the present results towards less distressed individuals. There is the risk that the couples that were willing to participate were those who had a great need to narrate their experiences. The nature of the study may also mean people may struggle to express what they are thinking and feeling as there are things they do not wish to self-disclose, wanting to present themselves in the best possible manner. However, I would argue that we achieved a great deal of openness from our participants with open verbal dialogue regarding sensitive issues.

Analysis of findings was interpretative and thus dependent on the researcher's ability and experience. An experienced psychiatrist (AK) was involved in the process of analysis, providing constant comparisons and discussion of findings that strengthened the validity of the interpretation.

### 4.17.3 Assessing validity

The centrality of researcher subjectivity within IPA means that traditional research evaluation criteria such as representative samples are irrelevant (Smith et al., 2009). Each theme is supported by verbatim extracts providing a 'grounding in examples' (Brocki & Wearden, 2006, p. 97) which show validation of themes.

<sup>51</sup>Lucy Yardley's four broad principles for assessing the quality of qualitative research were followed to assess the validity of the present findings (Yardley, 2000). This involves attention to four broad principles; sensitivity to context, commitment and rigour, transparency and coherence and impact and importance.

**Sensitivity to context:** Within the present study sensitivity to context is presented by each emergent theme being validated by quotes from the participants. In addition, a key aspect of IPA is validating each theme with the existing literature, which is presented in the discussion.

**Commitment and rigour:** Commitment was demonstrated in several ways within the present study. Firstly, there was a degree of attentiveness to each participant within the study. Secondly, the interviews were listened and re-read multiple occasions. Thirdly, transcripts were transcribed verbatim and checked by two independent auditors to check audio matched each script. Rigour refers to the thoroughness of the study. The sample was carefully selected to address our principle research question. The analysis was conducted systematically following several stages of interpretation to reach the final themes. To reduce researcher bias, an independent auditor was involved in the process of analysis, providing constant comparisons and discussion of findings which strengthened the validity of the interpretation.

**Transparency and coherence:** Each stage of analysis is detailed within the qualitative methods section 4.6 and appendix 8.3. In terms of coherence, the emergent themes were consistent with existing literature and supportive of quantitative findings.

**Impact and importance:** The analysis has identified key areas for future research and presented a unique insight into the underlying factors that contribute the HNC couples' psychological adjustment and factors that impact on QoL. Therefore findings are of clinical relevance and importance.

---

<sup>51</sup> Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215–228.

Within IPA, and the qualitative paradigm in general, there is more of a focus on the possible transferability of findings from group to group rather than generalisation. Smith et al. (2009) also argue for 'theoretical generalisability', where the reader may be able to 'assess the evidence in relation to their existing professional and experiential knowledge' Thus it can be argued that idiographic qualitative research such as IPA has much to contribute to our understanding of phenomena, as it can complement actuarial claims derived from quantitative studies.

#### **4.17.4 Implications for clinical practice?**

These findings clearly show that patient and partner distress are related. Recommendations from the present findings would be; including partners in clinic conversations, paying attention to their questions and concerns and including them in treatment plans (if patient agrees). Another recommendation would be facilitating positive communication i.e. encouraging patients to be open about their cancer to their partners, as communication difficulties dominated poor adjustment to cancer in both patients and their partners.

## 4.18 Overall Qualitative Conclusions

In my repeated listening, transcribing and re-reading through the transcripts, some very clear themes within the couples were soon apparent. Interestingly, without any prompting, the structures of the narratives often followed the trajectory of the disease. From the diagnosis, multiple hospital procedures, treatment phase to their point of interview (12 months post diagnosis). These are all times when an intervention could be made to improve the patients cancer treatment outcome.

Other features within the interviews included descriptions of diagnostic procedures, stories of the endless waiting in hospitals, initial denial of symptoms but most dominant was the impact of the cancer on the patient-partner relationship. Unexpectedly, there was very little talk of pain and discomfort from the patients, and although the topic of the impact of HNC on patient's physical health was raised by the interviewer, participants did not particularly engage with this question.

After close examination for similarities and variability between the three case studies, I feel the themes that have been presented share the 'lived' experiences of head and neck cancer within this sample the next step would be to look at couples with low distress or different cultural backgrounds to get even more insight into our patients lives.



## 5 General discussion

This final chapter discusses the overall conclusions that can be drawn from the quantitative and the qualitative results of this study. Firstly, a summary of the data is presented and how these relate to the original aims of the thesis. The methods are also critically discussed with suggestions for possible improvements. Finally, a discussion of the clinical significance of these findings with reference to future proposed clinical interventions for patients and their caregivers are reported.



## **5.1 Aims and Findings**

This study, to the best of my knowledge, is the first to assess the impact of caregivers' psychological states on HNC patients' QoL. To address this issue, a mixed methods longitudinal design was undertaken. This was a key strength of the study as the quantitative phase was able to give an insight into the prevalence of psychological distress, and assess and explore factors involved in the association between psychological distress and QoL. The qualitative findings further complemented the quantitative results by providing a deeper understanding of the 'lived experiences' of HNC couples.

## **5.2 Prevalence of psychological distress in patients and caregivers**

One of the aims of this study was to measure the prevalence of psychological distress (anxiety and depression) in patients and their caregivers (partners and family members) before treatment and 6-12 months following treatment. The present findings showed 17% of HNC patients reported clinical levels of depressive symptoms before treatment, increasing to 27% 6-12 months following diagnosis. This increased prevalence suggested a proportion of patients experienced a significant period of stress associated with the cancer which continued at least up to 6-12 months following diagnosis. This indicates that measuring psychological distress pre-treatment may identify patients who are at greater risk for distress at 6-12 months following diagnosis. This is supported by Funk et al, (2006) who found pre-treatment scores of depression were predictive of patients' scores 12 months following diagnosis (Funk et al., 2012). The longitudinal assessment of psychological distress is a significant strength of this study, as previous studies have only presented prevalence levels at one time point (Akira Kugaya, Akechi, Okuyama, & Nakano, 2000; Pandey et al., 2007; Rogers et al., 2006). Caregivers, particularly the partners of patients, reported significantly higher symptoms of depression and anxiety than the patient at both time points. These findings support the study by Braun et al 2005 who found 40% of spouse caregivers of advanced cancer patients (lung and gastrointestinal) showed elevated symptoms of depression compared to 20% in patients (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007).

Measuring the prevalence of psychological distress in partners and family enhances the current caregiving literature by providing a prospective measurement of psychological distress within head and neck cancer, but more importantly it also lends weight to the assertion that caregivers of HNC patients have higher levels psychological distress than patients.

### **5.2.1 Why is the prevalence of psychological distress higher in caregivers than in HNC patients?**

One explanation for the disparity in psychological distress levels may be due to the changes in emotional demands made over time. Before and during treatment great physical and emotional demands are placed upon caregivers, not only to provide emotional support to patients, but also practical support, such as attending appointments and caring for them following treatment (Stenberg et al., 2010). In contrast, patients themselves receive active support from the health care team and therefore may also feel more supported emotionally. This would explain the differences in prevalence levels particularly before treatment, where partners show significantly higher symptoms of psychological distress than patients (43% v 17%). Differences between patients and their caregivers did become smaller over time. Patients showed increased levels of psychological distress 6-12 months following diagnosis, whereas caregivers' levels slightly decreased. This may be explained by changes in the emotional demands of HNC once treatment has finished or nearing completion. Patients are often expected to begin making the transition of 'getting back to normal' with less support from the clinical team than they may have received within the first few months of diagnosis. This is when patients may be left to adjust to the many changes that HNC has imposed upon their lives. Those patients who report psychological distress, particularly depressive symptoms, maybe those who are finding the adjustment back to 'normality' more difficult. At the same time, 6-12 months following diagnosis, caregivers may strive for a return to their normal lives after providing both practical and emotional support to patients.

However, further and more detailed explanations for the increase in psychological distress specifically in partners were revealed through the qualitative interviews. Partners reflected on the difficulties and challenges of dealing with their own emotions during diagnosis and discussed the increased burden by this new identity as the 'cancer partner' whose role was to remain positive and support patient. Feelings of guilt ensued if they were to indulge in these negative emotions and therefore they chose to internalise anxieties and worries. These feelings were particular dominant at diagnosis and thus may be one of the explanations for increased anxiety shown by elevated HADS scores during this time. This explanation is supported by Stenberg et al (2010) who reported effects on caregivers when caring for a patient with cancer, with the most commonly reported being emotional problems and the increased responsibilities during and after treatment and rehabilitation.

Gender differences may provide an alternative explanation to the disparity in prevalence of psychological distress between patients and their caregivers, as women partners and family members dominated the caregiver sample. Women within the general population are more likely to acknowledge and report elevated symptoms of depression and anxiety (Piccinelli & Wilkinson, 2000) and therefore the present findings may have reflected these differences. However, the findings from breast cancer studies where the caregivers are predominantly male (Braun et al., 2007; Hannum, Giese-Davis, Harding, & Hatfield, 1991; Manne et al., 1997), support the present results and have shown that male partners also report higher symptoms of psychological distress than patients, which would therefore question this possible explanation.

### **5.3 Association between patient and caregiver psychological distress and patient QoL**

A second key aim of the present study was to examine the association between patient and caregiver psychological distress and patient QoL. The findings showed HNC patients with psychological distress showed significantly lower scores in the physical, psychological, social relationships and environment QoL domains. Multivariate analysis showed depressive symptoms were the strongest independent predictor of patient QoL at both time points, supporting the findings by Howren and colleagues (2010) who found that depressive symptoms before diagnosis, were associated with poorer HRQOL one year later. The present findings expanded on Howren's study (2010), and suggested depressive symptoms in patients not only affected their physical QoL, but also factors associated with social relationships and environmental factors (i.e. work and financial). This gave a greater insight to the impact of psychological distress on a wider construct of QoL. These findings suggested that HNC patients' emotional state during cancer, not only affected their physical wellbeing, but also every aspect of their day-to-day lives. In addition to these findings, a more pertinent result was patients who had a caregiver (partner and family members) showing psychological distress also showed poorer QoL. To the knowledge of the author, this result is the first within HNC to show this association. Further to this finding, the current study also presented evidence which showed patients had lower QoL 6-12 months following diagnosis if their caregivers reported high levels of psychological distress before treatment. However, these findings were based upon univariate analysis and as previously stated, it would be prudent not to over-interpret them as firm findings. However, as an exploratory model, these findings showed that there is scope

for patient and caregivers psychological distress to influence patient QoL 6-12 months following diagnosis.

### **Why would caregivers' psychological distress affect patients' QoL?**

There could be several explanations why caregivers' psychological distress had a negative impact on patients' QoL.

Caregivers who were suffering from increased psychological distress, particularly at diagnosis, may have become less emotionally resourceful and utilised more negative coping behaviours, such as avoidance or emotional withdrawal, to alleviate the negative thoughts about a patient's cancer. These avoidant coping behaviours may have resulted in caregivers becoming less emotionally available for the patient which would have a negative impact on the quality of social support caregivers were able to offer and thus in turn resulting in poor social support for the patient. This explanation is based upon the Lazarus and Folkman's transactional model of stress and coping which proposes that increased stress can impact individuals coping response which can result in negative coping behaviours such as avoidance (Folkman & Lazarus, 1986; Hulbert-Williams, Morrison, Wilkinson, & Neal, 2013; Lazarus .and Folkman, 1984). This may therefore have a negative impact on a patient's QoL due to poorer social support from the caregiver. Northouse et al (2001) showed when spouse caregivers were highly distressed, cancer patients reported more problems adjusting to the illness over time (Northouse, Templin, & Mood, 2001)

Furthermore, the qualitative study highlighted how distressed partners (i.e. partners who reported psychological distress at diagnosis) reported increased resentment, hostility and anger towards the patient over time, which resulted in increased relationship conflict and relationship dissatisfaction (see chapter 6 add section number qualitative discussion). Findings by Manne et al (1997) found that patients reported higher symptoms of psychological distress and lower QoL, when they perceived their partners to be showing negative behaviours towards them. Therefore, negative social support from caregivers may have also been a contributing factor to patients' lower QoL.

The recognition that social relationships can be a source of strain is not new, but there appears to be a great need to further examine the consequences of negative social support particularly within cancer, as the present findings suggest that caregivers' own psychological distress may reverse the

positive 'buffering effects' of social support as originally proposed by Cohen and colleagues (Cohen & Wills, 1985).

Although it is tempting to discuss the association of findings in causal terms, assumptions of causality cannot be made based from the present. For example, high psychological distress in partners and caregivers may be a reaction to the patient's psychological distress and vice versa. However, what the present findings showed was the importance of the caregiver's role in HNC, and how their psychological functioning had an effect on the patient's functioning.

With consistent evidence showing that couples react as an 'emotional unit' to cancer diagnosis, healthcare professionals should begin including the partner in the basic support they offer to patients. This is especially important as our findings have shown distress in caregivers; particularly in partners, where it can be higher than in patients. If partners or family members are to become active agents of help for the patient, it is proposed they should first be prepared psychologically for the task.

#### **Do clinical factors have affect patients' QoL?**

The present findings also showed 6-12 months following diagnosis there were no statistical differences between treatment, stage of cancer, or tumour site. Patients reported similar levels of QoL within these domains. These findings strengthen the evidence that clinical variables may play a minimal role in the impact on patients' perceptions of their QoL.

One explanation for these findings may be that the WHOQOL-BREF may lack sensitivity when identifying differences between HNC symptoms and side effects as the physical domain captures an overall picture of physical health and is not focused on specific symptoms. However, the strength of using this measure was that it gave a more holistic representation of how HNC affected each aspect of patients' life, which was more beneficial due to the heterogeneity of our HNC sample. If used in clinical practice the WHOQOL-BREF would assist clinicians in making judgement about the areas in which a patient is most affected by disease, and making treatment decisions.

Another explanation for this finding is how the HNC patients perceived their QoL. Carr et al (2001) proposed that an individual's perception of QoL may be based more on their expectations and experiences of health, rather than the disease itself. If the expectations do not match the experience of health, the level of QoL will be low. Conversely, someone who has adapted his expectations to the change in his or her health due to a severe illness might experience a significant improvement of QoL (Carr et al., 2001). This suggests that QoL may become more influenced by

perceptions of the illness and expectations of treatment rather than the actual illness itself. This implies the psychological experience of the cancer may have a greater impact on patients' QoL than the physical experience.

These findings suggest that health care professionals should not assume that everyone will respond the same way to a given disease or given stage of disease. There will be patients who are diagnosed with advanced disease who are resilient due to personality or due to a history of life experiences that has enabled them to cope with the current trauma in a healthy way. In other words, all people with advanced disease may not report poor QoL. Similarly, one cannot assume that someone who has been diagnosed with a very early and easily treatable disease will respond with a mild level of distress that dissipates with time.

There may be other factors in a patient's life, like whether they have support available and whether they are facing other life trauma that may determine of how they respond to their disease. An example of this was shown in a study by Vartanian et al (2009) who showed the majority of patients considered a radical surgical procedure an acceptable treatment and reported a good quality of life. They found that over 90% of patients reported that they would undergo the same treatment if they had it to do again, and 95% reported that they would not like to exchange their present outcome for another treatment option with a lower chance of cure but with a possibly improved quality of life (Vartanian & Kowalski, 2009).

## 5.4 Methodological evaluation

A particular strength of the present study was that recruitment took place at two cancer sites, covering two large London areas. This increased the availability of new HNC patients and also reduced selection bias which can result from single site studies. However, unfortunately due to language constraints and lack of validated measures in other languages, 85% of our sample was white British or white other with the exclusion of 17% of eligible patients being unable to participate due not having English as their first language. Therefore the current findings can only be generalised to this sample. This is a limitation of the results as currently very little data exists examining the impact of HNC on an ethnically diverse sample.

A second strength of the study was its longitudinal design. This allowed for more conclusive findings in the patterns shown in the data, particularly in terms of prevalence of psychological distress. However, longitudinal design studies require a large sample size which was a limitation of the present study, albeit, a good proportion of patients and their caregivers agreed to take part with only 20% declining initial participation. Considering these were newly diagnosed patients and caregivers, this response rate was better than anticipated and above what has previously been reported in similar studies (Puts et al., 2009) However, the difficulty in maintaining patient and caregiver contact, particularly at a time of intense stress was reflected in follow up numbers. Firstly, there was a 20% mortality rate of patients which contributed to attrition, but also it was difficult to retain both patient and their caregivers. Several reasons were cited for non-participation, including the experience of undertaking research too stressful at the present time. This further highlights the challenges of conducting research in this sample. Several strategies were employed to improve participant attrition. One technique was to ask participants to complete questionnaires at their follow-up appointments. This significantly improved response rates in patients, however the caregiver did not always attend each appointment with the patient so direct contact was not always possible. I also retained contact with all patients and caregivers following consent through telephone calls and at follow-up appointments. Reminder letters were also sent, however I was mindful of how difficult the first 6 months of HNC can be. Postal returns may have further increased the burden already experienced by the caregiver and patient. Variability in timings of returned questionnaires could have also confounded the results, with patients returning questionnaires when feeling less psychologically distressed or better physically. The variability of time was accounted for by examining the mean differences between participants who completed

questionnaires at six months compared to those who completed questionnaires 7-12 months. There were no statistically significant differences between these two groups. This supports previous findings which have shown small changes in QoL and psychological difference between 6 and 12 months (Funk et al, 1997; Hammerlid et al, 1999). Another issue with the timing of questionnaires was at 6 months some patients may still have been in treatment which may have confounded the results. It was difficult to control for this variable due to the heterogeneity of HNC sites included in the current sample. This meant treatment periods and modalities differed. Also treatment complications and cancer recurrence were common amongst the HNC patient sample, therefore strict time guidelines were difficult to adhere to.

Although the follow-up sample size was small, this did not significantly affect the representativeness of the data. Analysis of non-respondents characteristics revealed no differences concerning disease site variables, such as tumour stage, site and treatment. The only difference that was found was patients with loco-regionally advanced disease were less likely to complete questionnaires 6-12 months following diagnosis. However, 51% of the final sample was loco regionally advanced disease patients therefore the results were not biased to early disease patients.

The small sample size also limited the sub group analysis that could be undertaken. This may have been a particular limitation when analysing the clinical factors, particularly site of cancer as heterogeneity of each site can result in very different treatment and QoL outcomes. Previous studies have found large differences in QoL and symptoms by type of HNC (Hammerlid & Taft, 2001). This highlights the need for more homogenous groups in HNC research, particularly when examining caregivers as different HNC cancers may place more burden on the partner or family of these patients. A homogenous sample of HNC patients would control for this variability, however due to the short recruitment time frame and rarity of some HNC cancers, sample size would still be an issue.



## 5.5 Data Analysis

The relatively small data set meant that there was a limitation in conservative statistical analysis that could be undertaken. However, a strength of the data was I was able to transform the data from the WHOQOL-BREF which was not normally distributed which meant a parametric regression model could be fitted which is a robust statistical method for assessing association compared to a non-parametric analysis. Although transforming data means the original scale is changed, it is a common statistical method and I was able to<sup>52</sup>back transform the transformed coefficient to allow the data to become more clinically relevant and interpretable. Although, the small sample meant that limited data modelling could be conducted on the longitudinal data and the wide confidence intervals observed highlights the potential variability in data. However, statistically significant associations and differences do not necessarily translate to clinically significant relationships (see de Vet et al., 2006). I would argue that the present findings still showed several important clinically significant findings which are applicable and relevant to clinical practice.

## 5.6 Measures

### 5.6.1 HADS

The questionnaires in the study were well tolerated and accepted by the patient with minimal missing data. The strength of using the HADS questionnaires was it was short, easy for participants to complete and the ease of scoring suggests it could be readily applied within a busy clinical environment. Also, the HADS has been frequently used in general population sample and cancer population which meant that I was able to use this measure in both patients and their caregivers, which allowed for direct comparison in psychological distress based on the same measure. The HADS has also been consistently validated within HNC population and is one of the most commonly used questionnaires for identifying psychological distress (depression and anxiety) in oncology patients. (Archer, Hutchison & Korszun, 2008; Drabe, Zwahlen, & Büchi, 2008; Hodges & Humphris, 2009; Jenewein et al., 2008; Katz, Kopek, Waldron, Devins, & Tomlinson, 2004; Shiraz, Rahtz, Bhui, Hutchison, & Korszun, 2014)

---

<sup>52</sup> The standard interpretation of coefficients in a regression analysis is that a one unit change in the independent variable results in the respective regression coefficient change in the expected value of the dependent variable while all the predictors are held constant. Interpreting a log transformed variable can be done in such a manner; however, such coefficients are routinely interpreted in terms of percent change. To make the data clinically meaningful the coefficients were back transformed to represent a percentage change. This percentage change allowed interpreting the effect of the variable on the outcome variable

The cut off scores for psychological distress were carefully selected where a 85% specificity in clinical levels of depression in cancer patients when a score of  $\geq 8$  was selected (Mitchell et al., 2013). A lower cut off score would have given increased sensitivity, however this may have diluted the results with a false positive sample.

Interestingly, a study by Katz (Katz et al., 2004) suggested in HNC patients a cut off score of 5 was optimal score yielding a sensitivity of 100%, specificity of 89.6% and a positive predictive value of 68.8%. There have been few studies that have opted for this lower cut off score, however future studies utilising this score may be of value as the present study may have missed patients based upon a pre-determined cut off score, which is always a disadvantage of using categorical data.

### **5.6.2 WHOQOL-BREF**

This project introduced a holistic method to examining QoL in HNC patients. QoL was defined as a state of physical, mental and social wellbeing and what has been presented represents the complexity of measuring such a subjective construct. The WHOQOL-BREF questionnaire was selected as the main outcome measure as it fulfilled the task of presented multi-dimensional perspective of QoL. The advantages of this measure were that it presented an alternative perspective of HNC patients' QoL, which has not previously been shown within this field. If used in clinical practice, the WHOQOL-BREF would assist clinicians in making judgement about the areas in which a patient is most affected by disease, and making treatment decisions. However, the WHOQOL-BREF is purely a subjective measure of QoL, it may be less useful in providing an objective measure of physical functioning e.g. symptom or treatment related pain which may be a limitation if used in a clinical environment.

To my knowledge, this is the first study in the UK to have used this questionnaire within a HNC sample, therefore, adding further originality to this thesis.

## 5.7 Reflection

The recruitment of HNC patients was one of the most challenging yet crucial processes in the PhD study. Table 33 reflected on the several challenges faced and presents solutions used to overcome each obstacle.

**Table 33: General methods recruitment challenges**

Challenge	Description	Solution
Increasing patient numbers	This study was initially a single site study, recruiting only at Bart's NHS trust.	However, applied for an ethics amendment to include another site (University college of London Hospitals, UCLH).
Lack of new HNC patients	The initial inclusion criteria involved only patients who were to be treated by surgery. This stringent inclusion criterion meant that there were limited new patients to recruit (less than one a month).	Applied for an amendment for the study to allow for surgery and adjuvant treatment patients.  Also included new recurrent cancer patients as this made up a proportion of new cancers and limited research on the patient sample
Lack of partners	After a couple a months in clinic, it was quickly recognised that many patients did not have partners. This was due to several reasons:  A proportion of patients were widowed  Due to lifestyle factors such as excessive alcohol consumption a large proportion of patients were single, separated or divorced  Patients frequently attended with family members particularly those from ethnic minority backgrounds	Applied for amendment to include family members' as they were primary caregivers, providing care for the patient. Therefore the impact on their wellbeing may be just as important as that of partner.  This helped increase recruitment numbers
Identifying patients	Identifying new patients was very difficult in busy clinical environment	Attended weekly MDT meeting  Patients were highlighted at MDT by chair person

	<p>Follow up clinics and new clinics run within the same clinic. There was no system of identifying new patient via the lists. e.g. ENT, OMFS, oncology clinics all same day</p>	<p>Registrars also notified researcher when new patient is diagnosed.</p> <p>Access to NHS computerised records, Checking patient notes and MDT lists.</p>
Consenting patients	<p>Difficult time for patients, as often receiving diagnosis of cancer.</p>	<p>I was introduced by the consultant to each potential patient and became part of the clinical team, therefore present during new diagnosis consultations</p> <p>Introduced by clinicians as member of clinical team.</p> <p>A clinical judgement was made at the appropriateness of consenting at first contact. This was discussed with the clinical team. If it was felt inappropriate, I arranged to meet with patients at their next appointment.</p>
Completion of questionnaires	<p>Initially, participants were given questionnaire to take away and complete at home. This resulted in minimal patients completing and returning questionnaires.</p>	<p>I decided to consent patients at clinic; and if they were willing they were asked to complete questionnaires at point of consent.</p> <p>This helped not only to collect data but establish rapport with participants which was critical for follow up.</p> <p>This resulted in excellent return rate in questionnaires and patients' were more willing to take part, once rapport was established.</p>
Follow up	<p>Pre-treatment, 6 months</p> <p>Follow up was extremely difficult in this patient group as treatment happened very quickly (diagnosis to treatment sometimes less than 2 weeks)</p> <p>Another challenge was patient death, which was emotionally challenging.</p>	<p>After patients had been consented, A photocopy of consent form was sent in the post with thank you letter. In addition, when questionnaires had been received, a letter of acknowledgement was also sent.</p> <p>Next appointment was documented to ensure follow-up in clinic</p>

		<p>Aim to do follow up questionnaires in clinic before their appointment time.</p> <p>If this was not possible, participants were called to notify that they will receive a follow up questionnaire in the post.</p>
<p>Practicalities of conducting research in clinics, e.g. rooms to see patient</p>	<p>Minimal space in clinics to undertake consent</p>	<p>This was a continual problem. Established liaison with nursing and administration staff to ensure clinic room was available to discuss project with patients.</p>

## 5.8 Future developments in treatment of HNC patients

The results from this thesis raise several clinical issues, with the following suggestions recommending how these findings can be applied within clinical practice to improve QoL and wellbeing of HNC patients.

### **Screening for psychological distress:**

Increased identification of psychological distress is particularly important because depression in cancer is readily treatable. Given the time constraints in most clinics, easy screening techniques would be of greatest interest to surgeons and oncologists. Screening patients for psychological distress at significant time points during the cancer trajectory may allow identification of those at greater risk. Also, due to the heterogeneity of HNC, it is recommended that measuring psychological distress may give a better indication to a patient's adjustment to cancer than measuring QoL.

A further extension of this screening would be a recommendation to screen a patient's caregiver for psychological distress. By screening partners and caregivers pre-treatment, HNC clinicians can identify individuals that may be at higher risk of poor adjustment to cancer, particularly as our findings show the reciprocal effects of psychological distress. This means that, in a relationship, when one person is emotionally distressed, it's more than likely the other person will also become distressed regardless if they are the patient or the partner.

### **Emotional support**

Another recommendation would be for a support intervention to be in place specifically for partners and caregivers. As highlighted within the qualitative interviews, partners are reluctant to discuss their fears and worries about the cancer with the patient as they fear this would have negative impact on their wellbeing. Having an intervention or support system in place for caregivers would not only reduce burden for caregivers, but also relieve patients of worrying about their partner, which was also documented within the qualitative interviews. A targeted intervention for caregivers and patients with elevated distress would be beneficial, particularly those who identify increased distress at point of diagnosis. These individuals are at greater risk of showing elevated distress at later stages and may be finding cancer adjustment more difficult.

Despite the increased levels of psychological distress amongst HNC patients, depression in particular remains under diagnosed and under treated amongst cancer patients. In an interesting

study by Fabio and colleagues, 2008 patients were asked what they would most like the surgeon to attend to on a clinic visit and also asked the surgeon to rate what they think is important to the patients from a lot of possible answers(Fabio, Koller, & Nascimbeni, 2008). They found that whilst 26% of cancer patients wanted surgeons to attend to their emotional state, none of the surgeons thought that this was important to the patients. This shows just how important it is to continue alerting clinicians to the psychological impact of cancer.

## 6 Final conclusions

There were three key findings within the present study.

- Firstly, psychological distress in caregivers, particularly partners was higher than in HNC patients.
- Secondly, HNC patients who had a caregiver with psychological distress showed lower QoL and
- Finally, the qualitative study showed the negative impact of HNC on the patient-partner relationship. Utilising a mixed methods design was a significant strength to the final results. The quantitative and qualitative methods used together added a greater insight and understanding to the aims of this thesis that might have been missed if only a single method was used.

This thesis has presented a unique perspective into the measurement of QoL, and presented findings that have not previously been shown within this clinical population.

This thesis was titled “We got cancer” which came from a quote from a partner of a HNC patient who stated that when her husband was diagnosed with the cancer, she also was ‘diagnosed’. This reflected the interdependence of cancer which was demonstrated throughout this thesis. HNC affects both the individual and his or her collective social network. Like other serious illnesses, it changes lives by changing people's psychology, their life span, and their quality of life.

What this study has shown is the importance of the caregiver’s role in HNC, and how their psychological functioning has an effect on the patient’s functioning. If partners or family members are to become active agents of help for the patient, they should also be prepared psychologically for the task.

*“There ain’t no fucking manual on how to get someone through cancer”*

*(Partner extract, case 2: p34 790-792)*



## 7 References

- Allison, P. J., Guichard, C., Fung, K., & Gilain, L. (2003). Dispositional Optimism Predicts Survival Status 1 Year After Diagnosis in Head and Neck Cancer Patients. *Journal of Clinical Oncology*, 21(3), 543–548. doi:10.1200/JCO.2003.10.092
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington DC.
- Archer, J., Hutchison, I., & Korszun, A. (2008). Mood and malignancy: head and neck cancer and depression. *Journal of oral pathology & medicine : official publication of the International Association of Oral Pathologists and the American Academy of Oral Pathology*, 37(5), 255–70. doi:http://dx.doi.org/10.1111/j.1600-0714.2008.00635
- Argiris, A., Karamouzis, M. V, Raben, D., & Ferris, R. L. (2008). Head and neck cancer. *Lancet*, 371(9625), 1695–709. doi:10.1016/S0140-6736(08)60728
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, 51(6), 843–857. doi:http://dx.doi.org/10.1016/S0277-9536(00)00065-4
- Bigatti, S. M., Wagner, C. D., Lydon-Lam, J. R., Steiner, J. L., & Miller, K. D. (2011). Depression in husbands of breast cancer patients: relationships to coping and social support. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 19(4), 455–66. doi:10.1007/s00520-010-0835-8
- Bilal, S., Doss, J. G., Cella, D., & Rogers, S. N. (2014). Quality of Life associated factors in head and neck cancer patients in a developing country using the FACT-H&N. *Journal of Cranio-Maxillofacial Surgery*. doi:10.1016/j.jcms.2014.11.024
- Bonner, J. a, Harari, P. M., Giralt, J., Cohen, R. B., Jones, C. U., Sur, R. K., ... Ang, K. K. (2010). Radiotherapy plus cetuximab for locoregionally advanced head and neck cancer: 5-year survival data from a phase 3 randomised trial, and relation between cetuximab-induced rash and survival. *The Lancet. Oncology*, 11(1), 21–8. doi:10.1016/S1470-2045(09)70311-0
- Bowman, K. F., Rose, J. H., & Deimling, G. T. (2006). Appraisal of the cancer experience by family members and survivors in long-term survivorship. *Psycho-oncology*, 15(9), 834–45. doi:10.1002/pon.1039
- Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: spouse caregivers. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 25(30), 4829–34. doi:10.1200/JCO.2006.10.0909
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21(1), 87–108. doi:10.1080/14768320500230185
- Carr, A., Gibson, B., & Robinson, P. (2001). Is quality of life determined by expectations or experience? *BMJ*, 322(May), 1240–1243. doi:http://dx.doi.org/10.1136/bmj.322.7296.1240

- Chandu, A., Smith, A., & Rogers, S. (2006). Health-related quality of life in oral cancer: a review. *Journal of oral and maxillofacial ...*, 64(3), 495–502. doi:10.1016/j.joms.2005.11.028
- Chang, H.-K., & Chen, M.-L. (2004). Physical symptom profiles of depressed and nondepressed patients with cancer. *Palliative Medicine*, 18(8), 712–718. doi:10.1191/0269216304pm950oa
- Chen, A. M., Farwell, D. G., Luu, Q., Vazquez, E. G., Lau, D. H., & Purdy, J. A. (2012). Intensity-Modulated Radiotherapy is Associated with Improved Global Quality of Life Among Long-Term Survivors of Head-and-Neck Cancer. *International Journal of Radiation Oncology, Biology, Physics*, 84(1), 1–6. doi:10.1016/j.ijrobp.2011.11.026
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological bulletin*, 98, 310–357.
- Cohen., J. Cohen., P. West., G.S., Aiken., L. S. (2003). *Applied Multiple Regression/Correlation Analysis for the Behavioral Sciences*.
- Conway, D. I., Hashibe, M., Boffetta, P., Wunsch-Filho, V., Muscat, J., Vecchia, C. La, & Winn, D. M. (2009). Enhancing epidemiologic research on head and neck cancer: INHANCE – The international head and neck cancer epidemiology consortium. *Oral Oncology*, 45(9), 743–746. doi:10.1016/j.oraloncology.2009.02.007
- De Graeff, A., De Leeuw, J. R., Ros, W. J., Hordijk, G. J., Blijham, G. H., & Winnubst, J. A. (2000). Long-term quality of life of patients with head and neck cancer. *The Laryngoscope*, 110(1), 98–106. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10646723>
- De Raeve, L. (1997). Positive thinking and moral oppression in cancer care. *European journal of cancer care*, 6(4), 249–56. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2354.1997.00043.x/full>
- De Vet, H. C., Terwee, C. B., Ostelo, R. W., Beckerman, H., Knol, D. L., & Bouter, L. M. (2006). Minimal changes in health status questionnaires: distinction between minimally detectable change and minimally important change. *Health and quality of life outcomes*, 4(Mic), 54. doi:10.1186/1477-7525-4-54
- Drabe, N., Zwahlen, D., & Büchi, S. (2008). Psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer. *Psycho-oncology*, 204, 199–204. doi:10.1002/pon
- Dropkin, M. jo. (1999). Body Image and Quality of Life After Head and Neck Cancer Surgery. *Cancer Practice*, 7(6), 309–313. doi:10.1046/j.1523-5394.1999.76006.x
- Duffy, S. a, Terrell, J. E., Valenstein, M., Ronis, D. L., Copeland, L. a, & Connors, M. (2002). Effect of smoking, alcohol, and depression on the quality of life of head and neck cancer patients. *General hospital psychiatry*, 24(3), 140–7. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12062138>
- Duvvuri, U., & Myers, J. N. (2009). Cancer of the head and neck is the sixth most common cancer worldwide. *Current problems in surgery*, 46(2), 114–7. doi:10.1067/j.cpsurg.2008.10.002

- Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-oncology*, 13(8), 562–76. doi:10.1002/pon.773
- El-Deiry, M., Funk, G. F., Nalwa, S., Karnell, L. H., Smith, R. B., Buatti, J. M., Yao, M. (2005). Long-term quality of life for surgical and nonsurgical treatment of head and neck cancer. *Archives of otolaryngologyhead neck surgery*, 131(10), 879–885. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16230590>
- Epstein, J., Robertson, M., & Emerton, S. (2001). Quality of life and oral function in patients treated with radiation therapy for head and neck cancer. *Head & neck*, 23(May), 389–398. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1002/hed.1049/abstract>
- Fabio, F. Di, Koller, M., & Nascimbeni, R. (2008). Long-term outcome after colorectal cancer resection. Patients' self-reported quality of life, sexual dysfunction and surgeons' awareness of patients' needs. *Tumori*, 94, 30–35. Retrieved from [http://www.tumorionline.it/r.php?v=328&a=3871&l=2454&f=allegati/00328\\_2008\\_01/fulltext/07-Di Fabio \(30-35\).pdf](http://www.tumorionline.it/r.php?v=328&a=3871&l=2454&f=allegati/00328_2008_01/fulltext/07-Di%20Fabio%20(30-35).pdf)
- Ferlay, J., Soerjomataram, I., Ervik, M., Dikshit, R., Eser, S., Mathers, C., Bray, F. (2014). GLOBOCAN: Cancer Incidence and Mortality Worldwide. *International Journal of Cancer*. doi:10.1002/ijc.29210 PMID:25220842 Published online 9 October 2014
- Fiske, T. S., Taylor, E. S. (1991). *Social Cognition* (2nd ed.). New York: McGraw-Hill.
- Foley, K. L., Farmer, D. F., Petronis, V. M., Smith, R. G., McGraw, S., Smith, K., ... Avis, N. (2006). A qualitative exploration of the cancer experience among long-term survivors: comparisons by cancer type, ethnicity, gender, and age. *Psycho-oncology*, 15(3), 248–58. doi:10.1002/pon.942
- Folkman, S., & Lazarus, R. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of personality ...*, 50, 571–579. Retrieved from <http://psycnet.apa.org/journals/psp/50/3/571/>
- Funk, G. F., Karnell, L. H., & Christensen, A. J. (2012). Long-term health-related quality of life in survivors of head and neck cancer. *Archives of otolaryngologyhead neck surgery*, 138(2), 123–133. doi:10.1001/archoto.2011.234
- García-Peris, P., Parón, L., Velasco, C., De La Cuerda, C., Camblor, M., Bretón, I., ... Clave, P. (2007). Long-term prevalence of oropharyngeal dysphagia in head and neck cancer patients: Impact on quality of life. *Clinical nutrition Edinburgh Scotland*, 26(6), 710–717.
- Glanz, K., Rimer, B., & Viswanath, K. (2008). *Health Behavior and Health Education: Theory, Research, and Practice* (4th ed.). San Francisco: Jossey-Bass.
- Hagedoorn, M., & Molleman, E. (2006). Facial disfigurement in patients with head and neck cancer: The role of social self-efficacy. *Health Psychology*, 25(5), 643–647.
- Hagedoorn, M., Sanderman, R., Buunk, P. B., & Wobbles, T. (2002). Failing in spousal caregiving: The “identity-relevant stress” hypothesis to explain sex differences in caregiver distress. *British Journal of Health Psychology*, 7, 481–494. doi:10.1348/135910702320645435

- Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, C. J. (2008). Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychol Bull*, 134(1), 1–30.
- Hagedoorn, M., Kreicbergs, U., & Appel, C. (2011). Coping with cancer: The perspective of patients' relatives. *Acta oncologica (Stockholm, Sweden)*, 50(2), 205–11. doi:10.3109/0284186X.2010.536165
- Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychological bulletin*, 134(1), 1–30. doi:10.1037/0033-2909.134.1.1
- Hagedoorn, M., & Kuijer, R. (2000). Marital satisfaction in patients with cancer: Does support from intimate partners benefit those who need it most? *Health Psychology*, 19(3), 274–282. doi:10.1037/10278-6133.19.3.274
- Hammerlid, E., Bjordal, K., Ahlner-Elmqvist, M., Jannert, M., & Kaasa, S Sullivan M., et al. (1997). Prospective longitudinal quality-of-life study of patients with head and neck cancer: A feasibility study including the EORTC QLQ-30. *Otolaryngology--Head and Neck Surgery*, 116(6, Pt1.), 666–673.
- Hammerlid, E., Mercke, C., Sullivan, M., & Westin, T. (1998). A prospective quality-of-life study of patients with laryngeal carcinoma by tumor stage and different radiation therapy schedules. *Laryngoscope*, 108(5), 747–759.
- Hammerlid, E., & Taft, C. (2001). Health-related quality of life in long-term head and neck cancer survivors: a comparison with general population norms. *British Journal of Cancer*, 84(2), 149–156. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2363699&tool=pmcentrez&rendertype=abstract>
- Hannum, J. W., Giese-Davis, J., Harding, K., & Hatfield, A. K. (1991). Effects of Individual and Marital Variables on Coping with Cancer. *Journal of Psychosocial Oncology*, 9(2), 1–20. doi:10.1300/J077v09n02\_01
- Hiten, J. (2012). Aiming to reduce late detection of head and neck cancer. *The British journal of general practice : The journal of the Royal College of General Practitioners*, 62(597), 181–2. doi:10.3399/bjgp12X636029
- Hodges, J.L, Humphris, M.G., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social science medicine*, 60(1), 1–12. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15482862>
- Hodges, J.L., & Humphris, M.G. (2009). Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-oncology*, 18(8), 841–8. doi:10.1002/pon.1346
- Hulbert-Williams, N. J., Morrison, V., Wilkinson, C., & Neal, R. D. (2013). Investigating the cognitive precursors of emotional response to cancer stress: re-testing Lazarus's transactional model. *British Journal of Health Psychology*, 18(1), 97–121. doi:10.1111/j.2044-8287.2012.02082.x

- Humphris, G., & Ozakinci, G. (2008). The AFTER intervention: a structured psychological approach to reduce fears of recurrence in patients with head and neck cancer. *British journal of health psychology*, 13(Pt 2), 223–30. doi:10.1348/135910708X283751
- Hutton, J. M., & Williams, M. (2001). An investigation of psychological distress in patients who have been treated for head and neck cancer. *The British journal of oral & maxillofacial surgery*, 39(5), 333–9. doi:10.1054/bjom.2001.0645
- Jacobi, I., van der Molen, L., Huiskens, H., van Rossum, M. A., & Hilgers, J. M. F. (2010). Voice and speech outcomes of chemoradiation for advanced head and neck cancer: a systematic review. *European archives of oto-rhino-laryngology : official journal of the European Federation of Oto-Rhino-Laryngological Societies (EUFOS) : affiliated with the German Society for Oto-Rhino-Laryngology - Head and Neck Surgery*, 267(10), 1495–505. doi:10.1007/s00405-010-1316-x
- Jenewein, J., Zwahlen, R. a, Zwahlen, D., Drabe, N., Moergeli, H., & Büchi, S. (2008). Quality of life and dyadic adjustment in oral cancer patients and their female partners. *European journal of cancer care*, 17(2), 127–35. doi:10.1111/j.1365-2354.2007.00817.x
- Johansson, M., Rydén, A., & Finizia, C. (2011). Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - a longitudinal study. *BMC cancer*, 11(1), 283. doi:10.1186/1471-2407-11-283
- Kagawa-Singer, M., & Wellisch, D. K. (2003). Breast cancer patients' perceptions of their husbands' support in a cross-cultural context. *Psychooncology*, 12, 24–37.
- Katz, M. R., Irish, J. C., Devins, G. M., Rodin, G. M., & Gullane, P. J. (2000). Reliability and validity of an observer-rated disfigurement scale for head and neck cancer patients. *Head & Neck*, 22(2), 132–141. doi:10.1002/(SICI)1097-0347(200003)22:2<132::AID-HED4>3.0.CO;2-K
- Katz, R. M., Kopek, N., Waldron, J., Devins, M. G., & Tomlinson, G. (2004). Screening for depression in head and neck cancer. *Psychooncology*, 13(4), 269–80. doi:Doi 10.1002/Pon.734
- Kelly, C., Paleri, V., Downs, C., & Shah, R. (2007). Deterioration in quality of life and depressive symptoms during radiation therapy for head and neck cancer. *Otolaryngology--head and neck surgery : official journal of American Academy of Otolaryngology-Head and Neck Surgery*, 136(1), 108–11. doi:10.1016/j.otohns.2006.06.1278
- Kissane, D. W., Bloch, S., Burns, W. I., Patrick, J. D., Wallace, C. S., & McKenzie, D. P. (1994). Perceptions of family functioning and cancer. *Psycho-Oncology*, 3(4), 259–269. doi:10.1002/pon.2960030403
- Kugaya, A., Akechi, T., Okuyama, T., Nakano, T., Mikami, I., & Okmura, H. et al. (2000). Prevalence, predictive factors, and screening for psychologic distress in patients with newly diagnosed head and neck cancer. *Cancer*, 88(12), 2817–2823. doi:10.1002/1097-0142(20000615)88:12<2817::AID-CNCR22>3.0.CO;2-N
- Lang, H., France, E., Williams, B., Humphris, G., & Wells, M. (2013). The psychological experience of living with head and neck cancer: a systematic review and meta-synthesis. *Psycho-oncology*, 22(12), 2648–63. doi:10.1002/pon.3343

- Lavery, J. F., & Clarke, V. A. (1999). Prostate cancer: Patients' and spouses' coping and marital adjustment. *Psychology, Health & Medicine*, 4(3), 289–302. doi:10.1080/135485099106225
- Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1(3), 141–169. doi:10.1002/per.2410010304
- Lazarus R. S. and Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Leoncini, E., Vukovic, V., Cadoni, G., Pastorino, R., Arzani, D., Bosetti, C., ... Boccia, S. (2015). Clinical features and prognostic factors in patients with head and neck cancer: Results from a multicentric study. *Cancer epidemiology*, 39(3), 367–74. doi:10.1016/j.canep.2015.02.004
- Leventhal, H., Brissette, I., & Leventhal, E. . (2003). The Common-sense model of self-regulation of health and illness. *The self-regulation of health and illness behaviour*. (In L. D. Cameron & H. Leventhal (Eds., Ed.). London and New York: Routledge.
- Lutgendorf, S. K., Sood, A. K., Anderson, B., McGinn, S., Maiseri, H., Dao, M., ... Lubaroff, D. M. (2005). Social support, psychological distress, and natural killer cell activity in ovarian cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 23(28), 7105–13. doi:10.1200/JCO.2005.10.015
- Magné, N., Marcy, P. Y., Chamorey, E., Guardiola, E., Pivot, X., Schneider, M., ... Bensadoun, R. J. (2001). Concomitant twice-a-day radiotherapy and chemotherapy in unresectable head and neck cancer patients: A long-term quality of life analysis. *Head & neck*, 23(8), 678–82. doi:http://dx.doi.org/10.1002/hed.1095
- Manne, S., Taylor, K., Dougherty, J., & Kemeny, N. (1997). Supportive and negative responses in the partner relationship: Their association with psychological adjustment among individuals with cancer. *Journal of Behavioral ...*, 20(2), 101–125. doi:10.1023/A:1025574626454
- Manne SL, Ostroff J, Winkel G, Grana G, F. K. (2005). Partner unsupportive responses, avoidant coping, and distress among women with early stage breast cancer: patient and partner perspectives. *Health Psychology*, 24(6), 635–41. doi:10.1037/0278-6133.24.6.635
- Mehanna, H M, De Boer, M. F., & Morton, R. P. (2008a). The association of psycho-social factors and survival in head and neck cancer. *Clinical otolaryngology : official journal of ENT-UK ; official journal of Netherlands Society for Oto-Rhino-Laryngology & Cervico-Facial Surgery*, 33(2), 83–9. doi:10.1111/j.1749-4486.2008.01666.x
- Mehanna, Hisham M, & Morton, R. P. (2006). Does quality of life predict long-term survival in patients with head and neck cancer? *Archives of otolaryngology--head & neck surgery*, 132(1), 27–31. doi:10.1001/archotol.132.1.27
- Minako, D., Tashiro, M., Miyashita, M., Asakage, T., Takahashi, K., Saito, K., Ichikawa, Y. (2010). The mediating effects of social support and self-efficacy on the relationship between social distress and emotional distress in head and neck cancer outpatients with facial disfigurement. *Psycho-Oncology*, 8–11. doi:10.1002/pon
- Mitchell, A. J., Ferguson, D. W., Gill, J., Paul, J., & Symonds, P. (2013). Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *The Lancet Oncology*, 2045(13), 1–12. doi:10.1016/S1470-2045(13)70244-4

- Moore, K. A., Ford, P. J., & Farah, C. S. (2013). "I have quality of life...but...": Exploring support needs important to quality of life in head and neck cancer. *European Journal of Oncology Nursing*, 18(2), 1–9. doi:10.1016/j.ejon.2013.10.010
- Moore, R. J., Chamberlain, R. M., & Khuri, F. R. (2004). A qualitative study of head and neck cancer. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer, 12(5), 338–46. doi:10.1007/s00520-003-0532-y
- Morton P R. (1995). Review Article Evolution of quality of life assessment in head and neck cancer. *The Journal of Laryngology and Otology*, 109(November), 1029–1035. doi:10.1017/S0022215100131962.
- National Comprehensive Cancer Network. (1999). NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network. *Oncology*, 13(5A), 113–47.
- Northouse, L., Templin, T., & Mood, D. (2001). Couples' adjustment to breast disease during the first year following diagnosis. *Journal of behavioral medicine*, 24(2), 115–136. doi:10.1023/A:1010772913717
- Nund, R., Ward, E. C., Scarinci, N. A., Cartmill, B., & Kuipers, P. (2014). Carers' experiences of dysphagia in people treated for head and neck cancer: a qualitative study. *Dysphagia*, 29(4), 450–458. doi:10.1007/s00455-014-9527-8
- O'Brien, K., Roe, B., Low, C., Deyn, L., & Rogers, S. N. (2012). An exploration of the perceived changes in intimacy of patients' relationships following head and neck cancer. *Journal of clinical nursing*, 21(17-18), 2499–2508. doi:10.1111/j.1365-2702.2012.04162.x
- Osthus, A. A., Aarstad, A. K. H., Olofsson, J., & Aarstad, H. J. (2011). Head and neck specific Health Related Quality of Life scores predict subsequent survival in successfully treated head and neck cancer patients: a prospective cohort study. *Oral oncology*, 47(10), 974–9. doi:10.1016/j.oraloncology.2011.07.010
- Ostroff, J., Ross, S., Steinglass, P., Ronis-Tobin, V., & Singh, B. (2004). Interest in and barriers to participation in multiple family groups among head and neck cancer survivors and their primary family caregivers. *Family process*, 43(2), 195–208. doi:10.1111/j.1545-5300.2004.04302005...
- Oxford Cancer Intelligence Unit. (2010). Profile of head and neck cancers in England. Retrieved from [http://library.ncin.org.uk/docs/10054-OCIU-Head\\_and\\_Neck\\_Profiles.pdf](http://library.ncin.org.uk/docs/10054-OCIU-Head_and_Neck_Profiles.pdf)
- Pandey, M., Devi, N., Thomas, B. C., Kumar, S. V., Krishnan, R., & Ramdas, K. (2007). Distress overlaps with anxiety and depression in patients with head and neck cancer. *Psycho-oncology*, 16(6), 582–6. doi:10.1002/pon.1123
- Parker, V., Bellamy, D., Rossiter, R., Graham, V., Britton, B., Bennett, L., & Giles, M. (2014). The experiences of head and neck cancer patients requiring major surgery. *Cancer nursing*, 37(4), 263–70. doi:10.1097/NCC.0b013e31829ded0e
- Patterson, J., & Rapley, T. (2013). Head and neck cancer and dysphagia; caring for carers. *Psycho-Oncology*, 22(8), 1815–1820. doi:10.1002/pon

- Pavot, W., & Diener, E. (1993). Review of the Satisfaction With Life Scale. *Psychological Assessment*, 5(2), 164–172. doi:10.1037/1040-3590.5.2.164
- Petticrew, M., Bell, R., & Hunter, D. (2002). Influence of psychological coping on survival and recurrence in people with cancer: systematic review. *BMJ*, 325, 1–10. Retrieved from <http://www.bmj.com/content/325/7372/1066.1.short>
- Peveler, R., Carson, A., & Rodin, G. (2002). Depression in medical populations. *BMJ*, (325), 149–152.
- Piccinelli, M., & Wilkinson, G. (2000). Gender differences in depression Critical review. *The British Journal of Psychiatry*, 177, 486–493. Retrieved from <http://bjp.rcpsych.org/content/177/6/486.short>
- Pitceathly, C, & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: a review. *European journal of cancer (Oxford, England : 1990)*, 39(11), 1517–24. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12855257>
- Pitceathly, Carolyn, Maguire, P., Haddad, P., & Fletcher, I. (2005). Prevalence of and Markers for Affective Disorders Among Cancer Patients' Caregivers. *Journal of Psychosocial Oncology*, 22(3), 45–68. doi:10.1300/J077v22n03\_03
- Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. London: SAGE Publications Ltd.
- Pulte, D., & Brenner, H. (2010). Changes in survival in head and neck cancers in the late 20th and early 21st century: a period analysis. *The oncologist*, 15(9), 994–1001. doi:10.1634/theoncologist.2009-0289
- Purdue, M. P., Hashibe, M., Berthiller, J., La Vecchia, C., Dal Maso, L., Herrero, R., ... Hayes, R. B. (2009). Type of alcoholic beverage and risk of head and neck cancer--a pooled analysis within the INHANCE Consortium. *American journal of epidemiology*, 169(2), 132–42. doi:10.1093/aje/kwn306
- Puts, M. T. E., Monette, J., Girre, V., Wolfson, C., Monette, M., Batist, G., & Bergman, H. (2009). Participation of older newly-diagnosed cancer patients in an observational prospective pilot study: an example of recruitment and retention. *BMC cancer*, 9, 277. doi:10.1186/1471-2407-9-277
- Rabin, C., & Pinto, B. (2006). Cancer-related beliefs and health behavior change among breast cancer survivors and their first-degree relatives. *Psycho-Oncology*, 15(8), 701–712. doi:10.1002/pon.1000
- Rogers, N. S., Rajlawat, B., Goru, J., Lowe, D., & Humphris, G. M. (2006). Comparison of the domains of anxiety and mood of the University of Washington Head and Neck Cancer Questionnaire (UW-QOL V4) with the CES-D and HADS. *Head & neck*, 28(8), 697–704. doi:10.1002/hed
- Rogers, N.,S., Miller, R. D., Ali, K., Minhas, A. B., Williams, H. F., & Lowe, D. (2006). Patients' perceived health status following primary surgery for oral and oropharyngeal cancer. *International Journal of Oral and Maxillofacial Surgery*, 35(10), 913–919. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17008054>



- Rogers, N.,S., Lakshmiah, S. R., Narayan, B., Lowe, D., Brownson, P., Brown, J. S., & Vaughan, E. D. (2003). A comparison of the long-term morbidity following deep circumflex iliac and fibula free flaps for reconstruction following head and neck cancer. *Plastic and Reconstructive Surgery*, 112(6), 1517–1525; discussion 1526–1527. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/14578779>
- Rose, P., & Yates, P. (2001). Quality of life experienced by patients receiving radiation treatment for cancers of the head and neck. *Cancer nursing*, 24(4), 255–63. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11502033>
- Ruf, M., Büchi, S., Moergeli, H., Zwahlen, R. A., & Jenewein, J. (2009). Positive personal changes in the aftermath of head and neck cancer diagnosis: a qualitative study in patients and their spouses. *Head & neck*, 31(4), 513–20. doi:10.1002/hed.21000
- Scharloo, M., Baatenburg de Jong, R. J., Langeveld, T. P. M., van Velzen-Verkaik, E., Doorn-op den Akker, M. M., & Kaptein, A. a. (2005). Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer. *Head & neck*, 27(10), 857–63. doi:10.1002/hed.20251
- Scottish Intercollegiate Guidelines Network (SIGN), & Network, G. (2006). Diagnosis and management of head and neck cancer. (SIGN Guideline No 90).
- Shiraz, F., Rahtz, E., Bhui, K., Hutchison, I., & Korszun, A. (2014a). Quality of life, psychological wellbeing and treatment needs of trauma and head and neck cancer patients. *The British journal of oral & maxillofacial surgery*, 52(6), 513–7. doi:10.1016/j.bjoms.2014.03.019
- Skevington, S. M., Lotfy, M., & O’Connell, K. a. (2004). The World Health Organization’s WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A Report from the WHOQOL Group. *Quality of Life Research*, 13(2), 299–310. doi:10.1023/B:QURE.0000018486.91360.00
- Skevington SM, Lotfy M, O. K. (2004). The World Health Organization’s WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Qual Life Res*, 13, 299–310.
- Smith, A. J., P, F., & M, L. (2009). *Interpretative Phenomenological Analysis Theory, Method and Research*. London: SAGE Publications Ltd.
- Snaith, R. P. (2003). The Hospital Anxiety And Depression Scale. *Health and quality of life outcomes*, 1, 29. doi:10.1186/1477-7525-1-29
- Stenberg, U., Ruland, C., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19(10), 1013–1025. doi:10.1002/pon.1670.
- The WHOQOL Group. (1998). WHOQOL User manual. Unpublished document (pp. 1–88). Retrieved from [http://www.who.int/mental\\_health/evidence/who\\_qol\\_user\\_manual\\_98.pdf](http://www.who.int/mental_health/evidence/who_qol_user_manual_98.pdf)
- Van Der Schroeff, M. P., Derks, W., Hordijk, G. J., & De Leeuw, R. J. (2007). The effect of age on survival and quality of life in elderly head and neck cancer patients: a long-term prospective study. *European archives of otorhinolaryngology official journal of the European Federation of*

OtoRhinoLaryngological Societies EUFOS affiliated with the German Society for  
OtoRhinoLaryngology Head and Neck Surgery, 264(4), 415–422. doi:0937-4477; 0937-4477

- Van Nieuwenhuizen, A. J., Buffart, L. M., Brug, J., René Leemans, C., & Verdonck-de Leeuw, I. M. (2015). The association between health related quality of life and survival in patients with head and neck cancer: A systematic review. *Oral oncology*, 51(1), 1–11. doi:10.1016/j.oraloncology.2014.09.002
- Vartanian, J. G., & Kowalski, L. P. (2009). Acceptance of major surgical procedures and quality of life among long-term survivors of advanced head and neck cancer. *Archives of otolaryngology-- head & neck surgery*, 135(4), 376–9. doi:10.1001/archoto.2009.5
- Verdonck-de Leeuw, I M Erenstein, S. E., Van der Linden, M. H., Kuik, D. J., de Bree, R., & Leemans, C. R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope*, 117(2), 238–241. doi:10.1097/01.mlg.0000250169.10241.58
- Vickery, L. E., Latchford, G., Hewison, J., Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & neck*, 25(4), 289–96. doi:DOI: 10.1002/hed.10206
- Wehage, I. C., & Fansa, H. (2011). Complex reconstructions in head and neck cancer surgery: decision making. *Head & neck oncology*, 3(1), 14. doi:10.1186/1758-3284-3-14
- Weymuller, A. E., Yueh, B., Deleyiannis B F, Kuntz, A. L., Alsarraf, R., & Coltrera, M. D. (2000). Quality of life in patients with head and neck cancer: Lessons learned from 549 prospectively evaluated patients. *Archives of Otolaryngology–Head & Neck Surgery*, 126(3), 329–335. Retrieved from <http://dx.doi.org/10.1001/archotol.126.3.329>
- World Health Organisation. (2008). The global burden of disease: 2004 update (pp. 1–133). Retrieved from [http://www.who.int/healthinfo/global\\_burden\\_disease/2004\\_report\\_update/en/](http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/)
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215–228. doi:10.1080/08870440008400302
- Ybema, J. F., Kuijjer, R. G., Hagedoorn, M., & Buunk, B. P. (2002). Caregiver burnout among intimate partners of patients with a severe illness: An equity perspective. *Personal Relationships*, 9(1), 73–88. doi:10.1111/1475-6811.00005
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica Scandinavica*, 67(6), 361–70. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/6880820>
- Zwahlen, R. A., Dannemann, C., Grätz, K. W., Studer, G., Zwahlen, D., Moergeli, H., Jenewein, J. (2008). Quality of life and psychiatric morbidity in patients successfully treated for oral cavity squamous cell cancer and their wives. *Journal of oral and maxillofacial surgery : official journal of the American Association of Oral and Maxillofacial Surgeons*, 66(6), 1125–32. doi:10.1016/j.joms.2007.09.003



## **8 Appendices:**

## 8.1 BJOMS Publication

Shiraz, F., Rahtz, E., Bhui, K., Hutchison, I., & Korszun, A. (2014). Quality of life, psychological wellbeing and treatment needs of trauma and head and neck cancer patients. *British Journal of Oral and Maxillofacial Surgery*, 52(6), 513–517

Provided for non-commercial research and education use.  
Not for reproduction, distribution or commercial use.



This article appeared in a journal published by Elsevier. The attached copy is furnished to the author for internal non-commercial research and education use, including for instruction at the authors institution and sharing with colleagues.

Other uses, including reproduction and distribution, or selling or licensing copies, or posting to personal, institutional or third party websites are prohibited.

In most cases authors are permitted to post their version of the article (e.g. in Word or Tex form) to their personal website or institutional repository. Authors requiring further information regarding Elsevier's archiving and manuscript policies are encouraged to visit:

<http://www.elsevier.com/authorsrights>



Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

SciVerse ScienceDirect

British Journal of Oral and Maxillofacial Surgery 52 (2014) 513–517



BRITISH  
Journal of  
Oral and  
Maxillofacial  
Surgery

[www.bjoms.com](http://www.bjoms.com)

## Quality of life, psychological wellbeing and treatment needs of trauma and head and neck cancer patients

Farah Shiraz<sup>a,1</sup>, Emmylou Rahtz<sup>a,2</sup>, Kamaldeep Bhui<sup>a</sup>, Iain Hutchison<sup>b</sup>, Ania Korszun<sup>a,\*</sup>

<sup>a</sup> Centre for Psychiatry, Old Anatomy Building, Barts and the London School of Medicine and Dentistry, Charterhouse Square, London EC1M 6BQ, United Kingdom

<sup>b</sup> Bart's Health NHS Trust, 59 Bartholomew Close, St. Bartholomew's Hospital, West Smithfield, London EC1A 7BE, United Kingdom

Accepted 26 March 2014

Available online 29 April 2014

### Abstract

There is increasing evidence that patients treated for trauma or cancer of the head and neck may go on to experience psychological distress. We aimed to measure the impact of this on their quality of life (QoL) and to explore their willingness to be referred for psychological support. A total of 96 patients with facial injuries and 124 with cancer of the head and neck completed a self-reported questionnaire to identify psychological distress (Hospital Anxiety and Depression Scale (HADS) and the Acute Stress Disorder (ASD) Scale), quality of life (WHOQoL-BREF), satisfaction with treatment, and willingness to accept psychological support. Thirty-nine percent of patients showed high levels of depressive symptoms and 43% reported high levels of anxiety; 43% in the trauma group and 12% in the cancer group had high ASD scores. Patients with high scores on the HADS reported poorer QoL, and 40% of those with high levels of psychological distress were willing to consider psychological support. Despite the fact that patients report high levels of satisfaction with their medical and surgical care, many have psychological problems and have needs that are not being met. A large proportion would use psychological support services.

© 2014 The British Association of Oral and Maxillofacial Surgeons. Published by Elsevier Ltd. All rights reserved.

**Keywords:** Psychological; Quality of life; Head and neck cancer; Facial trauma; Depression; Anxiety; Psychological distress

### Introduction

Despite considerable advances in surgical restoration, which have resulted in improvements in cosmetic appearance, function, and survival after treatment for injuries and cancer of the head and neck, less attention has been given to patients' overall quality of life (QoL) and their psychological needs

after treatment. Studies report a wide range in the proportion of patients who have serious psychological problems.

Rogers et al. found that after 3–4 years, at least one in 10 patients who had had operations for cancer of the head and neck with no recurrence, was anxious or depressed.<sup>1</sup> Similar studies have shown that anxiety levels were highest at diagnosis, while depression was most common during treatment.<sup>2</sup> A cross-sectional study from Taiwan of patients with various stages of head and neck cancer found that 33% had clinically significant levels of depression,<sup>3</sup> and a UK study reported a 22% incidence of anxiety and depression.<sup>4</sup>

In an assessment, UK researchers found that patients with facial injuries had an increased risk of depression (odds ratio (OR) 9.2) and, to a lesser extent, anxiety (OR 2.68), when compared with a control group who were undergoing elective oral and maxillofacial operations.<sup>5</sup> They

\* Corresponding author: [a.korszun@qmul.ac.uk](mailto:a.korszun@qmul.ac.uk) (Professor Ania Korszun). Fax: +44 020 7882 5728.

E-mail addresses: [f.shiraz@qmul.ac.uk](mailto:f.shiraz@qmul.ac.uk) (F. Shiraz), [e.rahtz@qmul.ac.uk](mailto:e.rahtz@qmul.ac.uk) (E. Rahtz), [k.s.bhui@qmul.ac.uk](mailto:k.s.bhui@qmul.ac.uk) (K. Bhui), [Iain.Hutchison@bartshealth.nhs.uk](mailto:Iain.Hutchison@bartshealth.nhs.uk) (I. Hutchison).

<sup>1</sup> Tel: +44 20 7882 2045; fax: +44 20 7882 5728.

<sup>2</sup> Joint first author.

<http://dx.doi.org/10.1016/j.bjoms.2014.03.019>

0266-4356/© 2014 The British Association of Oral and Maxillofacial Surgeons. Published by Elsevier Ltd. All rights reserved.



also found that women were more likely to suffer negative psychological consequences. Another study found that 30% experienced depression or anxiety at baseline and one year later, which suggests that these reactions are not transient.<sup>6</sup>

Acute stress disorder (ASD) is a common outcome after traumatic events, including injury or diagnosis with cancer, and comprises distressing symptoms of intrusive reminders and anxiety about the event. High levels of acute stress are reported in patients with facial injuries and they are often accompanied by symptoms of depression.<sup>7</sup>

We know of little research that has included the diverse black and ethnic minority population in the UK. Studies on the coping styles of different ethnic groups of cancer patients in Britain reported that British Asian patients were more likely to disbelieve their diagnosis than those who were white (48% British Asian; 31% white British), and that denial was strongly associated with anxiety and depression.<sup>8</sup> South Asian patients also had a more fatalistic attitude towards their diagnosis than white patients.<sup>8</sup> Clearly, to develop future interventions that aim to improve the well-being of oral and maxillofacial patients, such findings raise questions that require further investigation. Little is known about the willingness of these patients to seek psychological support.

We aimed to examine levels of psychological distress (depression, anxiety, and symptoms of acute stress) in oral and maxillofacial patients based in everyday clinical settings, and to explore their willingness to be referred for psychological support. It is clinically useful to recognise psychological problems, as they can potentially be treated, and interventions can ameliorate dysfunction and improve QoL.

## Patients and methods

### Sample

Over a 3-month period (January 2012 to March 2012) we invited all patients attending oral and maxillofacial (OMF) outpatient trauma clinics at the Royal London Hospital and outpatient head and neck cancer clinics at St Bartholomew's Hospital, London, to complete questionnaires. This was part of a clinical effectiveness audit registered with the Clinical Effectiveness Unit for Barts Health NHS Trust (approved 8/12/11). Two research psychologists, who were supervised by a consultant oral and maxillofacial surgeon and a consultant psychiatrist, collected the data. Patients aged over 18 years were included, and those who did not speak English, or had psychotic symptoms or impaired cognitive function, were excluded.

### Standardised questionnaires

Symptoms of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS),<sup>9</sup> which is the most suitable measure of psychological distress in

Table 1  
Patients' details. Data are number (%).

	Outpatient clinic	
	Trauma (n = 96)	Head and neck cancer (n = 124)
Sex		
Male	83 (87)	76 (61)
Female	13 (14)	48 (39)
Age (years)		
18–35	57 (59)	16 (13)
36–65	33 (34)	64 (52)
66+	4 (4)	43 (35)
Not given	2 (2)	1 (<1)
Ethnicity		
White	58 (60)	70 (56)
Asian	18 (19)	31 (25)
Black	6 (6)	12 (10)
Other	10 (10)	3 (2)
Not given	4 (4)	8 (6)

people who are physically ill. Scores of 8 or above indicate anxiety or depression.<sup>9</sup>

Two QoL questions taken from the World Health Organization Quality of Life Questionnaire (Brief version) (WHOQoL-BREF),<sup>10</sup> which relate to overall quality of life and overall general health, were included. The WHOQoL-BREF is a validated and reliable measure with which to assess quality of life in different medical populations.

The Acute Stress Disorder Scale is a 19-item, self-reported inventory of ASD.<sup>11</sup> Scores range from 19 to 95, and those over 55 indicate psychological distress and post-traumatic stress disorder. It can be used effectively in people who have experienced traumatic civilian events.

### Questionnaire on treatment required

This questionnaire included questions devised by the authors to ascertain whether patients had previously sought help for emotional problems, who they had approached, and who they would be willing to see. It also included items designed to find out how satisfied they were with a range of clinical and emotional measures, and to find out in which areas they needed further support.

### Statistical analysis

A non-parametric test (Mann–Whitney *U*) was used to evaluate differences in QoL as data from the HADS and ASDS were not normally distributed.

## Results

In total, 96 patients with facial injuries and 124 with cancer of the head and neck were included. All the cancer patients participated but 9% (*n* = ?) of those injured refused.

Patients' details are shown in Table 1.



Table 2  
Number (%) of high scores for anxiety, depression, and acute stress.

	Depression $\geq 8$	Anxiety $\geq 8$	Acute stress $\geq 56$
Trauma	36/85 (42)	34/81(42)	39/91 (43)
Sex			
Male	31/73 (43)	29/69(42)	34/78 (44)
Female	5/12	5/12	5/13
Age (years)			
18–35	24/53 (45)	21/52(40)	25/55 (46)
36–65	9/27 (33)	10/25(40)	12/30 (40)
66+	2/3	2/4	1/4
Ethnicity			
White	16/51 (31)	16/48(33)	23/56 (41)
Asian	11/15	8/15	6/16
Black	2/6	4/5	3/6
Other	6/9	5/9	5/9
Not given	1/4	1/4	2/4
Cancer	37/101 (37)	46/104 (44)	10/84 (12)
Sex			
Male	23/61 (38)	27/64 (42)	6/73 (8)
Female	14/40 (35)	19/40 (48)	4/12
Age (years)			
18–35	5/14	5/14 (36)	0/9
36–65	22/52 (42)	28/53 (53)	9/48 (19)
66+	10/35 (29)	13/37 (35)	1/27 (4)
Ethnicity			
White	17/58 (29)	28/61 (46)	5/54 (9)
Asian	15/28 (54)	14/28 (50)	1/17
Black	3/7	3/7	2/14
Other	0/3	0/3	0/2
Not given	2/5	1/5	2/7
Overall	73/186 (39)	80/185 (43)	49/175 (28)

High scores classified as depression:  $\geq 8$ , anxiety:  $\geq 8$  on HADS, acute stress  $\geq 56$  on ASDS, are indicative of clinically relevant symptoms.

#### Prevalence of psychological distress in oral and maxillofacial patients

Of all OMFS patients, 39% ( $n = 73$ ) showed high levels of depression, 43% ( $n = 80$ ) had high levels of anxiety, and 28% ( $n = 49$ ) had high levels of acute stress (Table 2). The mean scores of patients who reported high levels of depression and anxiety (scores above 8), which indicate clinically relevant symptoms, were between 11 and 12. These scores are higher than those of the general population.<sup>12</sup> The mean scores for acute stress were particularly high in the trauma group (50.6 compared with 35.8 in the cancer group). There were no significant differences by age or sex.

#### Quality of life and psychological distress (depression, anxiety, and acute stress)

The median (SD) score of overall QoL for these patients was 3 (1–5).

Results show that QoL had an inverse correlation with scores for depression, anxiety, and acute stress in both groups. These differences were significant for depression (trauma group:  $z = -5.64$ ,  $p < .05$ ; cancer group:  $z = -3.39$ ,  $p < .05$ ), anxiety (trauma group:  $z = -3.82$ ,  $p < .05$ , cancer group:  $z = -3.02$ ,  $p < .05$ ), and acute stress (trauma group:  $z = -3.82$ ,

Table 3  
Mean and sum rank scores of overall quality of life (QoL) and levels of psychological distress.

Score	No. of patients	Mean rank of QoL	Sum of ranks score
Depression			
Trauma			
High	36	25.3	885.0
Low	48	54.2	2601.0
Cancer			
High	37	38.8	1434.0
Low	64	58.1	3717.0
Anxiety			
Trauma			
High	34	28.9	952.0
Low	46	48.0	2208.0
Cancer			
High	46	43.0	1978.5
Low	58	60.0	3481.5
Acute stress			
Trauma			
High	39	34.6	1350.0
Low	50	53.1	2655.0
Cancer			
High	10	24.0	240.0
Low	74	45.0	3330.0

WHOQoL-BREF: "How would you rate your overall quality of life?" 1 = poor, 2 = very poor, 3 = neither poor nor good, 4 = good, and 5 = very good.

$p < .05$ , cancer group  $z = -3.02$ ,  $p < .05$ ). This shows that patients with high levels of psychological distress are more likely to have a poorer QoL than those with low levels of psychological distress (Table 3).

#### Treatment needed

In total 29% ( $n = 61$ ) of patients reported that they had approached someone about their emotional needs since they began their treatment (trauma group 24%, cancer group 33%). Most had approached a friend or member of the family (33%) or their general practitioner (25%). Overall, 70% (trauma group  $n = 64$ ; cancer group  $n = 77$ ) in both groups were willing to see someone about their emotional needs if it was recommended by their treatment team. Patients were largely satisfied with the treatment they had been given (Figs. 1 and 2), but 29% overall ( $n = 47$ ) thought that their psychological needs had not been addressed. Among those with high levels of psychological distress (depression, anxiety, or acute stress), 38% ( $n = 36$ ) thought that their needs had not been met. Patients were asked about the areas in which they needed further support and 24% stated they needed help to cope with their condition emotionally ( $n = 20$  in the trauma group,  $n = 24$  in the cancer group). Among those with high levels of distress, 35% ( $n = 17$ ) in the trauma group and 40% ( $n = 21$ ) in the cancer group wanted more support in this area. In both groups, 17% of patients (trauma group  $n = 13$ ; cancer group  $n = 15$ ) felt that they needed more support to cope physically with their condition, and 20% in the trauma group

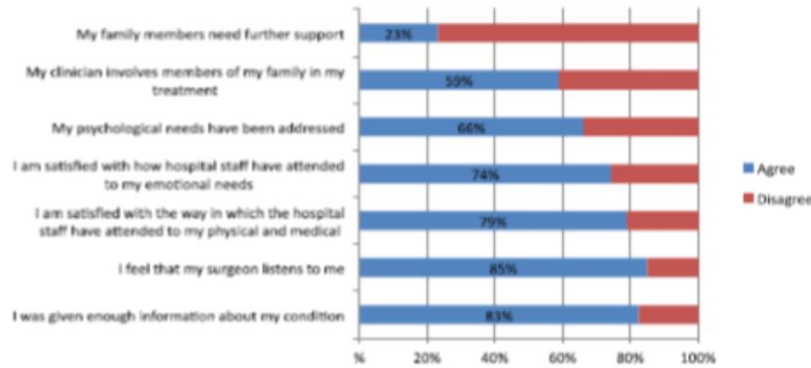


Fig. 1. Trauma group: satisfaction with treatment (blue = agree, red = disagree).

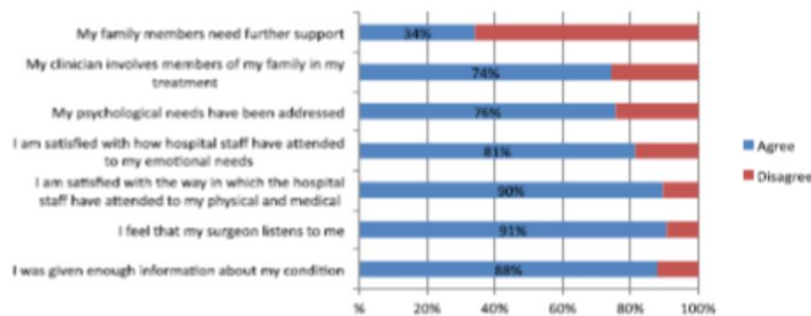


Fig. 2. Cancer group: satisfaction with treatment (blue = agree, red = disagree).

( $n = 19$ ) and 18% in the cancer group ( $n = 20$ ) felt the need for further financial support.

**Discussion**

*Prevalence of psychological distress in oral and maxillofacial patients with injuries and with cancer*

There were high levels of psychological distress in a cross-section of all the patients. The highest levels of depression were seen in South Asian participants (11/15 with trauma, and 15/28 with cancer). A poorer QoL was significantly associated with higher levels of psychological distress (HADS, ASDS).

Although satisfaction with surgical and medical treatment was high, the psychological needs of patients were not always addressed. A high proportion stated that they were willing to have psychological treatment although few had actively sought it. Many, including those who were most distressed,

reported that they had turned to members of the family for support during treatment, which indicates a potential burden for patients' families. The psychological impact on families may be considerable and future studies that examine this would be beneficial.

Our findings in South Asian patients are consistent with other reports in which Asian patients with cancer reported higher levels of depression on the HADS questionnaire than a white group.<sup>8</sup> However, to our knowledge, the present study is the first to measure the prevalence of psychological distress in South Asians with cancer of the head and neck, and further research on a larger sample is required.

The strength of this study is the inclusion of a diverse ethnic population, but because of language barriers we could include only a relatively small sample of ethnic minority patients (those who could read and write English). Our measures were simple to use in a clinical setting. Future research using standardised psychiatric interviews to verify results on the HADS and ASDS would make findings more robust.

The study was limited as it did not include details of the site of the cancer or injury, the treatment given, and the time since diagnosis or injury. The mechanism of injury, such as interpersonal violence or accident, was not taken into account and may influence outcomes. However, our aim was to explore levels of psychological distress and to establish which needs are not being addressed in OMFS patients. Future studies are needed to investigate predictors of outcome.

Coexisting illnesses such as depression and anxiety may complicate recovery and lead to poor adherence to treatment and a poorer QoL. However, there is a growing recognition amongst clinicians that patients require psychological support, and our findings highlight the need to identify those most at risk through appropriate screening so that early intervention can improve outcome. Obviously there are implications for services, as there is a substantial need for psychological screening and counselling. Before this can be done, more studies are needed to identify the risk factors for and the underlying causes of psychological distress.

#### Conflict of interest

None.

#### Ethical approval

This was carried out as part of a clinical effectiveness audit registered with the Clinical Effectiveness unit for Barts Health NHS Trust (approved 8/12/11).

#### References

1. Rogers SN, Rajlawat B, Goru J, et al. Comparison of the domains of anxiety and mood of the University of Washington Head and Neck Questionnaire (UW-QOL V4) with the CES-D and HADS. *Head Neck* 2006;28:697–704.
2. Hammerlid E, Ahlner-Elmqvist M, Bjordal K, et al. A prospective multicentre study in Sweden and Norway of mental distress and psychiatric morbidity in head and neck cancer patients. *Br J Cancer* 1999;80:766–74.
3. Haisfield-Wolfe ME, McGuire DB, Soeken K, et al. Prevalence and correlates of depression among patients with head and neck cancer: a systematic review of implications for research. *Oncol Nurs Forum* 2009;36:107–25.
4. Hutton JM, Williams M. An investigation of psychological distress in patients who have been treated for head and neck cancer. *Br J Oral Maxillofac Surg* 2001;39:333–9.
5. Islam S, Ahmed M, Walton GM, et al. The association between depression and anxiety disorders following facial trauma—a comparative study. *Injury* 2010;41:92–6.
6. Sen P, Ross N, Rogers S. Recovering maxillofacial trauma patients: the hidden problems. *J Wound Care* 2001;10:53–7.
7. Auerbach SM, Laskin DM, Kiesler DJ, et al. Psychological factors associated with response to maxillofacial injury and its treatment. *J Oral Maxillofac Surg* 2008;66:755–61.
8. Roy R, Symonds RP, Kumar DM, et al. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer* 2005;92:1393–7.
9. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:361–70.
10. Skevington SM, Lotfy M, O'Connell KA, WHOQOL Group. The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Qual Life Res* 2004;13:299–310.
11. Bryant RA, Moulds ML, Guthrie RM. Acute Stress Disorder Scale: a self-report measure of acute stress disorder. *Psychol Assess* 2000;12:61–8.
12. Crawford JR, Henry JD, Crombie C, et al. Normative data for the HADS from a large non-clinical sample. *Br J Clin Psychol* 2001;40:429–34.

## **8.2 Patient and Caregiver, information sheet, Consent form and sample questionnaires**

### **8.2.1 Patient information sheet**



## Wellbeing in Patients with Cancer

### Participant Information

Before you decide whether you wish to take part in this study it is important for you to understand why the research is being carried out and what it will involve. Please take the time to read the following information carefully. If you wish, you can discuss the information with others and our research staff will also be happy to help you. Please ask us if there is anything that is not clear, or you would like more information, and take your time in deciding whether or not you wish to take part.

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

- **The purpose of the study is to investigate how the emotional wellbeing of patients undergoing treatment for cancer can be improved.**
- Some people who have treatment for certain cancers – may go on to experience problems such as distress about changes to their appearance and problems with social and functional adjustment.
- We will be focusing on the effects of social support and relationships on patients' treatment outcome and quality of life as well as the effects on partners and family members.
- If you live with a partner, we may also ask you to invite your partner to take part in the study, so that we can get their perspective of living with someone who has undergone treatment for cancer. However if you do not have a partner, or they do not wish to be included, you can still take part in the research.
- We may also invite a family member of your choice to take part in the study, again to get their perspective of having a family member with Cancer.
- What we learn from this study will be used to help develop treatments to improve the wellbeing of patients undergoing treatment for cancer.

#### Do I have to take part?

- There is no obligation for you to take part in this study.
- If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form.
- You will be able to withdraw from the study without giving a reason at any time while we are collecting information from participants.

#### What if my partner or family member does not want to take part?

- If you are willing to take part and your partner or family member does not wish to participate, you will still be able to take part in the research. If you do not wish your partner or family member to participate, you will still be able to take part in the research.

#### What will happen to me if I decide to take part?

- If you choose to take part in this study, you will be asked to complete a series of questionnaires and take part an interview.

#### **What questions will the questionnaires ask?**

- The questionnaires include questions about your thoughts and feelings about your cancer treatment, your experiences before and after the treatment, and how other people have helped you during this experience. If you find any of these questions upsetting or prefer not to answer certain questions it is fine to leave them out. If the questionnaire raises any issues you would like to discuss please let us know.

#### **When do I complete the questionnaires and how long will the questionnaires take?**

- Questionnaires will be completed at 3 time points (before or soon after your treatment, 3 months after your treatment and 6 months after treatment) which will usually fit in with your normal clinic appointments.
- You may receive several questionnaires at each time point which can take between 30- 45 minutes to complete. If you require help filling in any of the questionnaires someone will be available to help.
- Your questionnaires do not all need to be completed at the same time, they can be filled in at home or at the clinic, whichever you find most convenient. If completed at home all postage will be paid by us.

#### **What are the photographs for?**

- We are interested in how you feel about your appearance, and how this relates to any changes to your appearance after your cancer treatment.
- We will take a photograph of you within a few weeks of treatment. When you take part in the follow-up in three months and six months' time, you can send us a photo, by email or by post.

#### **Do I have to be photographed?**

- No. You can choose not to be photographed or to submit photos and still take part in the rest of the study.

#### **When does the interview take place?**

- 3 months after your treatment you will be asked to take part in an interview. This will be at a time and place of your choice and will take about one hour of your time.
- Interviews can take place at the clinic or on the phone; if you would prefer to come to us then we will reimburse you for travel expenses.
- The interview will be conducted by a trained member of the research team and will include questions related to your past and present health and wellbeing.
- **The interviews will be conducted separately, and partners or family members will not be present during your interview.**
- The interview will be audio recorded to assist with future analysis. If you require a copy of your own interview this can be provided upon request.



**Why is the interview recorded?**

- As we are interested in your personal experience the interview will be audio recorded to ensure we don't miss any important information for the analysis.
- All information will be kept confidential and no one apart from the research team will have access to the recordings.
- Once the recordings have been analysed they will be destroyed.

**Will my partner or family member see the answers to my questionnaires or interview?**

- **No – all answers to the questionnaires and the interview will be kept confidential.**
- The information gathered in this trial will be coded so that no one will be able to identify you from the data that will be used in the analyses.
- Only the people involved in this study will have access to the data.

**What will happen to the data collected?**

- The results from your questionnaires and the interview will be stored under a code number that does not contain any of your personal details. Only the research team will be able to link all of your data for the purpose of analysing your results.
- All of the data will be stored in locked filing cabinets, or kept on password protected computers.
- **No one but the people involved in this study will have access to your data.**

**What are the possible disadvantages of taking part?**

- There are no risks in taking part in the study.

**What are the possible benefits of taking part?**

- There is no direct benefit to you. The purpose of the study is to find out more about your experiences of being treated for cancer and how we can improve future treatment for people with cancer.

**What happens when the research study stops?**

- Your data may be used for further analysis after you have finished participating in the study.

**What will happen to the results of the research study?**

- The results from the study will be published in medical and scientific journals.
- **You will not be identified in any report or publication arising from this study.**
- There may also be a presentation at Saving Faces or other service user groups to which you will be invited to attend.

**Who is organising and funding the research?**

- Researchers at Queen Mary University of London are organising the research together with the surgeons at participating clinics.



- The doctors and surgeons will not receive any special or additional payment if you agree to participate in the study.
- This research is funded by Saving Faces.

**Who has reviewed the study?**

- This study was given a favourable ethical opinion for conduct in the NHS by Camberwell and St Giles research ethics committee.

**Please note that as we are a teaching hospital, medical students may be present in the clinics and may be involved in the research project. Please let the researcher know if you prefer that they should not be present during your involvement in the research project.**

**Contacts for further information**

If you have any questions or concerns about this study please contact your consultant or one of the research staff based at Queen Mary's.

**Research staff – Farah Shiraz**  
Phone no. 020 7882 2045  
Email [f.shiraz@qmul.ac.uk](mailto:f.shiraz@qmul.ac.uk)

Research staff – Emmylou Rahtz  
Phone no. 020 7882 2026  
Email [e.rahtz@qmul.ac.uk](mailto:e.rahtz@qmul.ac.uk)

Chief Investigator – Prof Ania Korszun – Honorary Consultant Psychiatrist  
Phone no. 020 7882 2026 / 020 7882 2045  
Email [a.korszun@qmul.ac.uk](mailto:a.korszun@qmul.ac.uk)

Consultant Surgeon and Clinical Director – Prof Iain Hutchison  
Phone no. 07889 473 916

For impartial information on patient research please contact:  
Patient Advisory Liaison Service (PALS). Tel: 020 359 42040/42050 or email [pals@bartsandthelondon.nhs.uk](mailto:pals@bartsandthelondon.nhs.uk)

Saving Faces has an expert patient helpline talk to other patients who have experienced the same condition or gone through similar surgery. Tel: 07792 357972 or email: [helpline@savingfaces.co.uk](mailto:helpline@savingfaces.co.uk)

If at any point you wish to make a formal complaint you may contact:

Jarrard O'Brien  
Quality Development  
Barts and The London NHS Trust  
Healthcare Governance Directorate  
3<sup>rd</sup> Floor, Prescott Street  
020 7480 4857, [Jarrard.obrien@bartsandthelondon.nhs.uk](mailto:Jarrard.obrien@bartsandthelondon.nhs.uk)

**Thank you for reading this**

## **8.2.2 Patient Consent form**

## Wellbeing in Patients with Cancer PATIENT CONSENT FORM

Names of Researchers: Farah Shiraz, Prof Ania Korszun, Prof Kam Bhui, Prof Iain Hutchison, and Emmylou Rahtz

		Please initial box
1. I confirm that I have read and understand the information sheet Version 3. 26.07.12 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time up to the point of complete data collection, without giving any reason, without my medical care or legal rights being affected.		<input type="checkbox"/>
3. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from Barts and The London, Queen Mary's School of Medicine and Dentistry, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.		<input type="checkbox"/>
4. I agree to take part in the questionnaire assessments in the above study.		<input type="checkbox"/>
5. I understand that my interview will be audio recorded and agree for this to take place		<input type="checkbox"/>
6. I agree for my partner and or family member to be approached for the study		<input type="checkbox"/>
7. I understand that I will be photographed and agree for this to take place. I can also submit photographs three months and six months from now.		<input type="checkbox"/>
Name of Patient _____	Date _____	Signature _____
Name of Person taking consent _____	Date _____	Signature _____

### **8.2.3 Caregiver information sheet**

## Wellbeing in Cancer Patients Participant Information Leaflet

Before you decide whether you wish to take part in this study it is important for you to understand why the research is being carried out and what it will involve. Please take the time to read the following information carefully. If you wish, you can discuss the information with others and our research staff will also be happy to help you. Please ask us if there is anything that is not clear or you would like more information and take your time in deciding whether or not you wish to take part.

### What is the purpose of the study?

- The purpose of the study is to investigate how the emotional wellbeing of patients undergoing treatment for Cancer can be improved.
- Some people who have had treatment for Cancer — may go on to experience problems such as distress about changes to their appearance and problems with social and functional adjustment.
- We will be focusing on the effects of social support and relationships on patients' treatment outcome and quality of life, as well as the effects on partners and family members.
- What we learn from this study will be used to help develop treatments to improve the wellbeing of patients undergoing treatment for Cancer.

### Why am I being asked to take part?

- We are interested in your perspective of living with someone undergoing treatment for Cancer.

### Do I have to take part?

- There is no obligation for you to take part in this study.
- If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form.
- You will be able to withdraw from the study without giving a reason at any time while we are collecting information from participants.

### What will happen to me if I decide to take part?

- If you choose to take part in this study, you will be asked to complete a series of questionnaires and take part in an interview.

### What questions will the questionnaires ask?

- The questionnaires include questions about your thoughts and feelings about your partner's or family member's treatment and how people have helped you during this experience.



**What will happen to the data collected?**

- The results from your questionnaires and the interview will be stored under a code number that does not contain any of your personal details. Only the research team will be able to link all of your data for the purpose of analysing your results.
- All of the data will be stored in locked filing cabinets, or kept on password protected computers.
- **No one but the people involved in this study will have access to your data.**

**What are the possible disadvantages of taking part?**

- There are no risks in taking part in the study.

**What are the possible benefits of taking part?**

- There is no direct benefit to you. The purpose of the study is to find out more about your experiences of being treated for cancer and how we can improve future treatment for people with cancer.

**What happens when the research study stops?**

- Your data may be used for further analysis after you have finished participating in the study.

**What will happen to the results of the research study?**

- The results from the study will be published in medical and scientific journals.
- You will not be identified in any report or publication arising from this study.
- There may also be a presentation at Saving Faces or other service user groups to which you will be invited to attend.

**Who is organising and funding the research?**

- Researchers at Queen Mary University of London are organising the research together with the surgeons at participating cancer clinics.
- The doctors and surgeons will not receive any special or additional payment if you agree to participate in the study.
- This research is funded by Saving Faces.

**Who has reviewed the study?**

- This study was given a favourable ethical opinion for conduct in the NHS by Camberwell and St Giles research ethics committee

**Please note that as we are a teaching hospital, medical students may be present in the clinics and may be involved in the research project. Please let the researcher know if you prefer that they should not be present during your involvement in the research project.**

- If you find any of these questions upsetting or prefer not to answer certain questions it is fine to leave them out. If the questionnaire raises any issues you would like to discuss please let us know.

**When do I complete the questionnaires and how long will the questionnaires take?**

- Questionnaires will be completed at 3 time points (before or after patient's treatment, 3 months after treatment and 6 months after treatment).
- You may receive several questionnaires at each time point which can take between 30- 45 minutes to complete. If you require help filling in any of the questionnaires someone will be available to help.
- Your questionnaires do not need to be completed at the same time, they can be filled in at home or at the clinic, whichever you find most convenient. If completed at home all postage will be paid by us.

**When does the interview take place?**

- 3 months after the cancer treatment you will be asked to take part in an interview. This will be at a time and place of your choice and will take about one hour of your time.
- Interviews can take place at the clinic or on the phone; if you would prefer to come to us then we will reimburse you for travel expenses.
- The interview will be conducted by a trained member of the research team and will include questions related to your past and present health and wellbeing.
- **The interviews will be conducted separately, and partners and family members will not be present during your interview.**
- The interview will be audio recorded to assist with future analysis. If you require a copy of your own interview this can be provided upon request.

**Why is the interview recorded?**

- As we are interested in your personal experience the interview will be audio recorded to ensure we don't miss any important information for the analysis.
- All information will be kept confidential and no one apart from the research team will have access to the recordings.
- Once the recordings have been analysed they will be destroyed.

**Will my partner or family member see the answers to my questionnaires or interview?**

- **No – all answers to the questionnaires and the interview will be kept confidential.**
- The information gathered in this trial will be coded so that no one will be able to identify you from the data that will be used in the analyses.
- Only the people involved in this study will have access to the data.

#### **8.2.4 Caregiver consent form**



## Wellbeing in Patients with Cancer Participant CONSENT FORM

Name of Researchers: Farah Shiraz, Emmylou Rahtz, Prof Ania Korszun, Prof Kam Bhui, and Prof Iain Hutchison,

Please put your initials in each box					
1. I confirm that I have read and understand the information sheet dated. 26.07.12, version 3 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		<input type="checkbox"/>			
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.		<input type="checkbox"/>			
3. I agree to take part in the questionnaire assessments in the above study.		<input type="checkbox"/>			
4. I understand that my interview will be audio recorded and agree for this to take place		<input type="checkbox"/>			
<table style="width: 100%; border: none;"> <tr> <td style="width: 33%; border-bottom: 1px solid black; border-top: 1px solid black;">Name of Participant</td> <td style="width: 33%; border-bottom: 1px solid black; border-top: 1px solid black;">Date</td> <td style="width: 33%; border-bottom: 1px solid black; border-top: 1px solid black;">Signature</td> </tr> </table>	Name of Participant	Date	Signature		
Name of Participant	Date	Signature			
<table style="width: 100%; border: none;"> <tr> <td style="width: 33%; border-bottom: 1px solid black; border-top: 1px solid black;">Researcher</td> <td style="width: 33%; border-bottom: 1px solid black; border-top: 1px solid black;">Date</td> <td style="width: 33%; border-bottom: 1px solid black; border-top: 1px solid black;">Signature</td> </tr> </table>	Researcher	Date	Signature		
Researcher	Date	Signature			

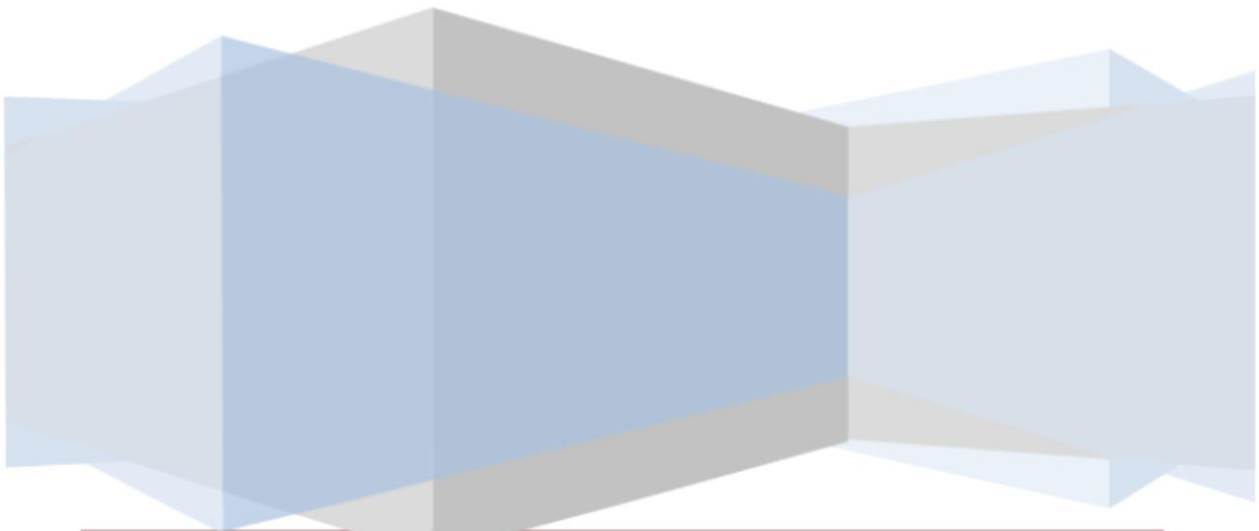
|

**8.2.5 Example of wellbeing questionnaire which included the HADS, WHOQOL-BREF and Demographics.**

Name:  
DOB:  
Gender:  
Participant Number:  
Date:

# Wellbeing Questionnaire

Your answers are confidential. Nobody other than the research team will know what your answers are. If you have any queries, please let us know



---

Please return to Farah Shiraz, Old Anatomy Building, [Barts](#) and The London School of Medicine and Dentistry, Charterhouse Square, London. EC1M 6BQ

Please answer the following questions with respect to how you have felt in the last two weeks. Tick ONE answer only.

1	I feel tense or 'wound up'		I feel as if I am slowed down	8
	<input type="checkbox"/> Most of the time. <input type="checkbox"/> A lot of the time. <input type="checkbox"/> From time to time, occasionally. <input type="checkbox"/> Not at all.		Nearly all the time <input type="checkbox"/> Very often <input type="checkbox"/> Sometimes <input type="checkbox"/> Not at all <input type="checkbox"/>	
2.	I still enjoy the things I used to enjoy		I get a sort of frightened feeling like 'butterflies' in the stomach	9
	<input type="checkbox"/> Definitely as much. <input type="checkbox"/> Not quite so much. <input type="checkbox"/> Only a little. <input type="checkbox"/> Hardly at all.		Not at all <input type="checkbox"/> Occasionally <input type="checkbox"/> Quite often <input type="checkbox"/> Very often <input type="checkbox"/>	
3.	I get a sort of frightened feeling as if something awful is about to happen		I have lost interest in my appearance	10
	<input type="checkbox"/> Very definitely and quite badly. <input type="checkbox"/> Yes but not too badly. <input type="checkbox"/> A little, but it doesn't worry me. <input type="checkbox"/> Not at all.		Definitely <input type="checkbox"/> I don't take as much care as I should <input type="checkbox"/> I may not take quite as much care <input type="checkbox"/> I take as much care as ever <input type="checkbox"/>	
4.	I can laugh and see the funny side of things		I feel restless as if I have to be on the move	11
	<input type="checkbox"/> As much as I always could. <input type="checkbox"/> Not quite so much now. <input type="checkbox"/> Definitely not so much now. <input type="checkbox"/> Not at all.		Very much indeed <input type="checkbox"/> Quite a lot <input type="checkbox"/> Not very much <input type="checkbox"/> Not at all <input type="checkbox"/>	
5.	Worrying thoughts go through my mind		I look forward with enjoyment to things	12
	<input type="checkbox"/> A great deal of the time. <input type="checkbox"/> A lot of the time. <input type="checkbox"/> Not too often. <input type="checkbox"/> Very little.		As much as I ever did <input type="checkbox"/> Rather less than I used to <input type="checkbox"/> Definitely less than I used to <input type="checkbox"/> Hardly at all <input type="checkbox"/>	
6.	I feel cheerful		I get sudden feelings of panic	13
	<input type="checkbox"/> Never. <input type="checkbox"/> Not often. <input type="checkbox"/> Sometimes. <input type="checkbox"/> Most of the time.		Very often indeed <input type="checkbox"/> Quite often <input type="checkbox"/> Not very often <input type="checkbox"/> Not at all <input type="checkbox"/>	
7	I can sit at ease and feel relaxed		I can enjoy a good book or radio or television programme	14
	<input type="checkbox"/> Definitely. <input type="checkbox"/> Usually. <input type="checkbox"/> Not often. <input type="checkbox"/> Not at all.		Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Not often <input type="checkbox"/> Very seldom <input type="checkbox"/>	

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question

	Very poor	Poor	Neither poor nor good	Good	Very good
<sup>1</sup> How would you rate your quality of life	1	2	3	4	5
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<sup>2</sup> How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the **last two weeks**

	Not at all	A little	A moderate amount	Very much	An extreme amount
<sup>3</sup> To what extent do you feel that physical pain prevents you from doing what you need to do	1	2	3	4	5
<sup>4</sup> How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
<sup>5</sup> How much do you enjoy life	1	2	3	4	5
<sup>6</sup> To what extent do you feel your life to be meaningful	1	2	3	4	5
	Not at all	A little	A moderate amount	Very much	Extremely
<sup>7</sup> How well are you able to concentrate?	1	2	3	4	5
<sup>8</sup> How safe do you feel in your daily life?	1	2	3	4	5
<sup>9</sup> How healthy is your physical environment?	1	2	3	4	5

The following questions ask **how completely** you experience or were able to do certain things in the **last two weeks**

	Not at all	A little	Moderately	Mostly	Completely
<sup>10</sup> Do you have enough energy for everyday life?	1	2	3	4	5
<sup>11</sup> Are you able to accept your bodily appearance?	1	2	3	4	5
<sup>12</sup> Have you enough money to meet your needs?	1	2	3	4	5
<sup>13</sup> How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
<sup>14</sup> To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
	Very poor	Poor	Neither poor nor good	Good	Very Good
<sup>15</sup> How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the **last two weeks**

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18. How satisfied are you with your capacity for work?	1	2	3	4	5
19. How satisfied are you with yourself?	1	2	3	4	5
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with your sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
25. How satisfied are you with your mode of transportation?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the **last two weeks**

	Never	Seldom	Quite Often	Very Often	Always
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

The following questions are concerned with your personal beliefs, and how these affect your quality of life. These questions refer to the **last two weeks**

	Not at all	A little	A moderate amount	Very much	An extreme amount
27. Do your personal beliefs give meaning to your life?	1	2	3	4	5
28. To what extent do your personal beliefs give you the strength to face difficulties?	1	2	3	4	5
29. To what extent do your personal beliefs help you understand difficulties in life?	1	2	3	4	5



<b>1. Marital status (please circle)</b>	Single <sup>1</sup>	Living with partner <sup>2</sup>	Married <sup>3</sup>	Separated <sup>4</sup>	Divorced <sup>5</sup>	Widowed <sup>6</sup>
<b>2. Ethnicity (please circle)</b>	White / White British	White British <sup>1</sup>	White Other <sup>2</sup>	Any other white background <i>Please specify:</i> <sup>3</sup>		
	Black/ Black British	British African <sup>4</sup>	British Caribbean <sup>5</sup>	Caribbean <sup>6</sup>	African <sup>7</sup>	
	Asian / Asian British	British Indian <sup>8</sup>	British Pakistani <sup>9</sup>	British Bangladesh <sup>10</sup>	British Chinese <sup>11</sup>	
		Indian <sup>12</sup>	Pakistani <sup>13</sup>	Bangladeshi	Chinese <sup>15</sup>	
	Mixed / Multiple ethnic Groups	White and black Caribbean <sup>16</sup>	White and black African <sup>17</sup>	White and Asian <sup>18</sup>	Other <sup>19</sup>	
Other (please specify)						
<b>3. Is English your first language</b>	Yes <sup>1</sup>	No <sup>2</sup>	If No <i>please specify other languages spoken:</i>			
<b>4. How well do you speak English?</b>	<sup>1</sup> Very well	<sup>2</sup> Well	<sup>3</sup> Not well			
<b>5. What is your religion?</b>	<sup>1</sup> No religion	<sup>2</sup> Christian	<sup>3</sup> Buddhist	<sup>4</sup> Hindu	<sup>5</sup> Jewish	<sup>6</sup> Muslim <sup>7</sup> Sikh
	Other (please state)					
<b>6. Highest level of education</b>	None <sup>1</sup>	GCSE / 'O' level <sup>2</sup>	'A' level (or equivalent) <sup>3</sup>	Diploma (or equivalent) <sup>4</sup>	Degree or higher degree (or equivalent) <sup>5</sup>	
	<sup>9</sup> Other qualification – <i>please specify</i>					

## **8.3 Qualitative Study appendices**



### 8.3.1 Step by step process of IPA stages of analysis:

The following section presents a step by step process of IPA analysis as recommended by Smith and colleagues (2009). **Table 34** presents a summary of the six steps.

This step by step guide presents an example of how “it doesn’t shine as bright as it once did” became a superordinate theme.

#### Six stages of IPA analysis

**Table 34 Six stages of IPA analysis**

Stage of Analysis	Description of analysis
<b>Step 1:</b>	<b><u>Reading and re reading</u></b> The first transcript is read and re-read and examined a number of times. Reflection at each reading was recorded to allow active engagement with the data. At each read the text was annotated with comments.
<b>Step 2:</b>	<b><u>Initial noting</u></b> With each reading, the text was annotated with initial comments. Examination of semantic content and language was also analysed.  The aim was to provide a detailed set of notes and comments on the data. Descriptive comments focussed on describing the content of what the participant had said. Linguistic comments focussed on the use of specific language. Conceptual comments focused on engaging at a more interrogative and engaging level. (These three concepts are referred to as interpretive noting)
<b>Step 3:</b>	<b><u>Developing emergent themes</u></b> Transforming the comments into emergent themes that capture succinctly the essential features of initial reading.  Mapping the interrelationships, connections and patterns between explanatory notes.
<b>Step 4:</b>	<b><u>Searching for connections across emergent themes</u></b> The emergent themes were listed and connecting themes were sought, with those related being clustered under appropriate <sup>53</sup> super-ordinate conceptual headings – this is known as abstraction.  During this data organisation process continuous referral to interview transcripts were made to ensure themes selected were representative of individuals’ personal accounts. The themes reflected the most salient meanings within the participants’ narrative.
<b>Step 5:</b>	<b><u>Moving to next case</u></b> Repeating procedure for each case. Each case was treated on its own terms, with new themes incorporated within analysis.
<b>Step 6:</b>	<b><u>Looking for patterns across cases</u></b> The resultant framework showed the emergence of the three super-ordinate themes, with sub themes within each cluster. The themes were corroborated via an independent ‘auditor’ who checked the themes against the data (see appendix 3).

<sup>53</sup> A superordinate theme involves putting like with like and developing a new name for the cluster

## STEP 2: Initial noting taking

Table 35: Step 2 initial note taking, extract from case study 2

<b>Step 2: Initial noting taking</b>				
<p>With each reading, the text was annotated with initial comments. Examination of semantic content and language was also analysed. The aim was to provide a detailed set of notes and comments on the data. Descriptive comments focussed on describing the content of what the participant had said. Linguistic comments focussed on the use of specific language. Conceptual comments focused on engaging at a more interrogative and engaging level.</p>				
Language	Interview extract	Descriptive comments	Interpretation/ conceptual	Page and line number
<p><i>Will</i> <i>Chop chop</i>  <i>Let it all out</i></p>	<p>When I was having radiotherapy, I used to sit there in the morning and say 'I don't want to go; I don't want to go today.' "You will go, you'll be fine, chop chop" But <b>I didn't want him to let me cry, but sometimes I would've liked him to have said 'cry today. Let's just let it all out.'</b></p>	<p>Probing a reaction out of partner-for him to show he cares? Or wanting him to show his emotions?</p> <p>Increase in conflict, patient feeling partner was not allowing her to be upset. Wanting to share the experiences with him- and for him to allow her to be upset.</p>	<p>Craving the emotional attention from partner resulting in behaviours which she wants him to react to- acting out behaviour- regressing to adolescent- parent role.</p> <p>Wanted her to 'let it all out' suggesting she was exhausted with keeping her emotions and feeling in. Internalising these feelings was leading to increased resentment and increase in conflict within their relationship.</p>	<p>P9 194-196</p>
<p><i>Row</i></p>	<p><i>We had a row and he said 'Don't you think I have thoughts of your funeral, the future without you' and I said 'I'm actually you said that, because thank God you did have those fears which are normal, I needed to hear them.'</i></p>	<p>Fears of her dying (partner didn't disclose this in interview)</p> <p>Reaction patient wanted- which showed that he does care but also normalising his feelings.</p>	<p>Needing reassurance, highlighting patient's insecurities about the relationship but also confirmed her anxieties and potentially fuelled the guilt she felt about being a burden to family and partner.</p>	<p>P10 210-211</p>

## STEP 3: Developing emergent themes

Table 36: Step 3: Developing emergent themes

<b>Step 3: Developing emergent themes</b>					
Transforming the comments into emergent themes that capture succinctly the essential features of initial reading. Mapping the interrelationships, connections and patterns between explanatory notes.					
Emergent themes	Language/ Linguistic	Interview extract	Descriptive comments	interpretation/ conceptual	Page and line number
Relationship discord  Lack of open communication related to cancer	<i>Will</i> <i>Chop chop</i>  <i>Let it all out</i>	When I was having radiotherapy, I use to sit there in the morning and say 'I don't want to go; I don't want to go today.' "You will go, you'll be fine, chop chop" But <b>I didn't want him to let me cry, but sometimes I would've liked him to have said 'cry today. Let's just let it all out.'</b>	Probing a reaction out of partner-for him to show he cares? Or wanting him to show his emotions?  Increase in conflict, patient feeling partner was not allowing her to be upset. Wanting to share the experiences with him- and for him to allow her to be upset.	Craving the emotional attention from partner resulting in behaviours which she wants him to react to- acting out behaviour- regressing to adolescent- parent role.  Wanted her to 'let it all out' suggesting she was exhausted with keeping her emotions and feeling in. internalising these feelings was leading to increased resentment and increase in conflict within their relationship.	P9 194-196
Increased conflict	<i>Row</i>	<i>We had a row- and he said 'Don't you think I have thoughts of your funeral, the future without you' and I said 'I'm actually you said that, because thank God you did have those fears which are normal, I needed to hear them.'</i>	Fears of her dying (partner didn't disclose this in interview)  Reaction patient wanted- which showed that he does care but also normalising his feelings.	Needing reassurance, highlighting patient's insecurities about the relationship but also confirmed her anxieties and potentially fuelled the guilt she felt about being a burden to family and partner.	P10 210-211

## STEP 4: Searching for connections cross emergent themes

### Step 4: Abstraction leading to the development of a super-ordinate theme “it doesn’t shine as bright as it once did”

#### Searching for connections across emergent themes

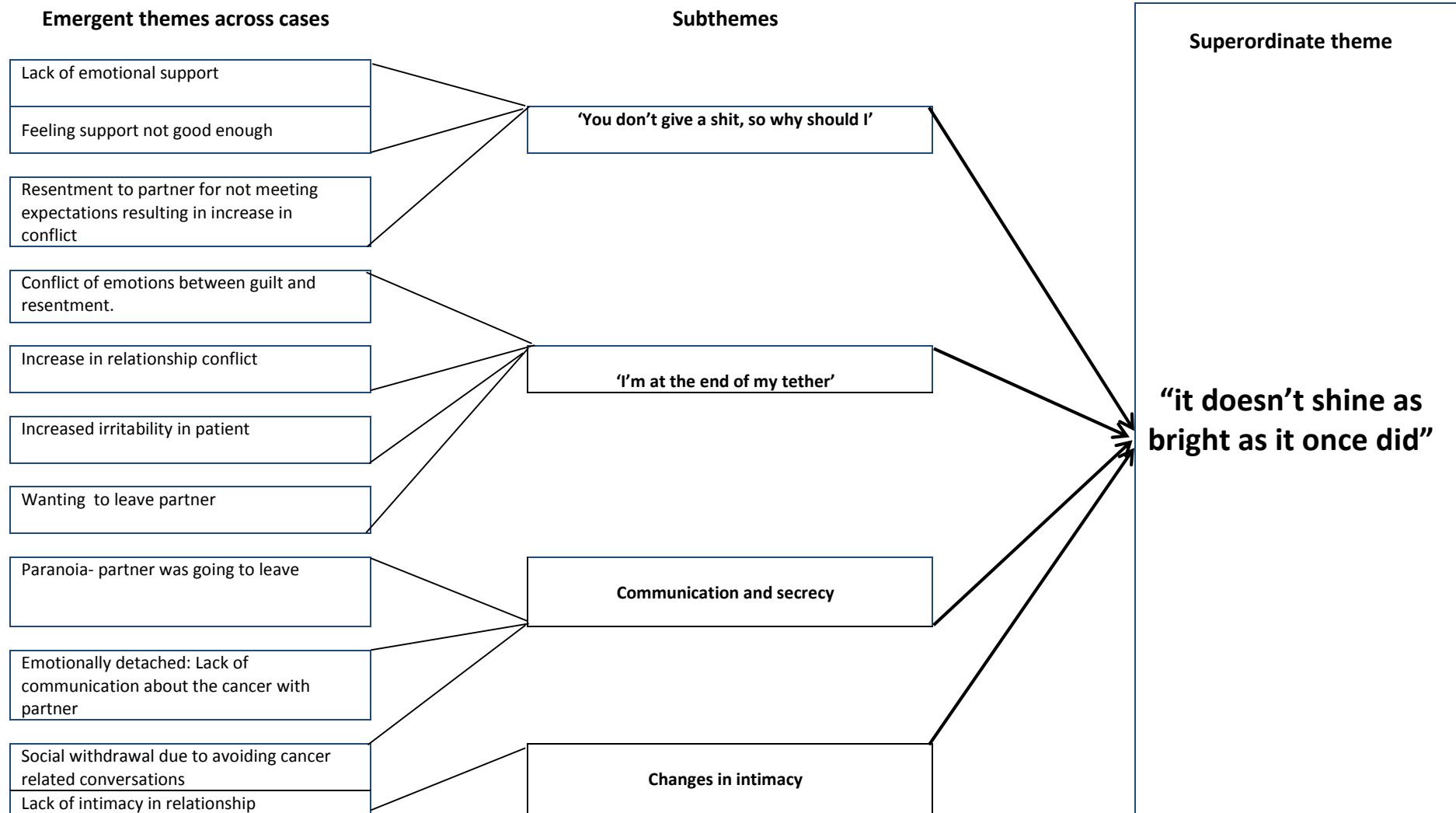
The example shows how the theme of “it doesn’t shine as bright as it once did” became the superordinate theme

The emergent themes were listed and connecting themes were sought, with those related being clustered under appropriate super-ordinate conceptual headings.

During this data organisation process continuous referral to interview transcripts were made to ensure themes selected were representative of individuals’ personal accounts. The themes reflected the most salient meanings within the participants’ narrative.

**Table 37 Searching for connections across themes “it doesn’t shine as bright as it once did”**

**STEP 4 continued: Searching for connections across emergent themes**



## Step 5 and Step 6: Moving to next case and repeating procedure for each case.

Step 5: Comparing emergent themes across cases, moving to next case.

Repeating procedure for each case. Each case was treated on its own terms, with new themes incorporated within analysis.

(Emergent themes within “it doesn’t shine as bright as it once did”

Case 1	Partner	Patient
	Closed communication about cancer	Emotionally detached: Lack of communication about the cancer with partner
	Not attending appointments	Perceives wife as loving and caring, expectations of wives role - cancer wife
	Communicating about cancer	Positive support he receives from his wife indicating little conflict- opposite to what wife feels.
	Patient choosing hide the cancer from others	Not sharing the emotional impact with partner
	Patient emotional reaction to diagnosis	Protective husband role?
	Anger at patients behavioural reaction to cancer	Belief of having strong relationship **Opposite to what partner reports
	Perception of impact of cancer on husband	Change in gender role having to do ‘female role’, cooking etc.
	Hiding emotions from patient	
	Social expectations of being the ‘cancer wife’	
	‘Cancer wife’- social expectations	
	Husband unsupportive for her needs	
	Lack of intimacy	
	Impact of cancer on relationship	
	Conflict of own emotions	
	Increase in Marital conflict	
<b>Case 2</b>		
	Moving on following diagnosis	Increase in conflict
	Cancer partner role	Expectations of perfect cancer partner- supportive, partner unavailable for emotional support
	Changes in relationship – not the same since cancer	Resentment to partner for not meeting expectations- resulting in increase in conflict
	Increase in marital conflict	Wanting to leave partner
	Feeling support not good enough	Lack of intimacy in relationship
	Resentment when patient not behaving as perfect patient	Paranoia- partner was going to leave
	Internalising / hiding own emotions	Increase worry for partner- conflict of emotions between guilt and resentment.
	Wanting to leave relationship	Anger at self for making everyone else feel better-wanting to be cancer patient’
	Needing respite	
	No emotional support from her family	
	Social support from friends	

	Anger, resent, anxiety	
<b>Case 3</b>		
	Cancer partner role- 'positive' fighting spirit	Positive support from partner
	Changes in roles, increased responsibilities	Feelings of guilt as partner experiencing stress related physical symptoms
	Frustrations in change to lifestyle- making sacrifices for husband.	Increasing worry in patient
	"we"- secondary patient- hospital visits, attending treatment	
	Social withdrawal- due to avoiding cancer related conversations	
	Increased irritability in patient	

## Master table of themes from qualitative analysis

Table 38 Master table of themes including description of each theme and subtheme

<b>Master table of themes from qualitative analysis</b>	
<b>Superordinate theme</b>	<b>Description of theme</b>
<b>1. “We got cancer”</b>	The superordinate theme of “we got cancer” reflected the reciprocal effects of the cancer experience highlighted by the HNC couples.
Coping with the bad news:	<i>This subtheme</i> described the HNC couples’ emotional and behavioural reactions to the diagnosis
Being the perfect cancer partner	<b>Being the perfect cancer partner and being the perfect cancer patient</b> were the self-defined identities patients and partners felt represented their changes in roles.
Being the perfect cancer patient	
<b>2. “It doesn’t shine as bright as it once did”</b>	The second superordinate theme “it doesn’t shine as bright as it once did” reflected the negative changes within HNC couples’ relationships since the cancer diagnosis. Partners in particular reported how they found the transition from treatment to ‘resuming normal life’ particularly challenging.
<i>“You don’t give a shit, so why should I</i>	<b>You don’t give a shit, so why should I’</b> : Partner’s indicated the lack of appreciation from patients for the support they were providing which led to increased hostility towards the patient.
<i>‘I’m at the end of my tether’</i>	<b>‘I’m at the end of my tether’</b> : Highlighted the increased relationship conflict reported by HNC couples since the cancer diagnosis.
<i>Communication and secrecy</i>	<b>Communication and secrecy</b> : revealed the difficulties HNC couples showed in communicating about the cancer to one another
<i>Changes in intimacy</i>	<b>Changes in intimacy</b> : HNC couples gave examples of the changes in the quality of their relationship following treatment
<b>3. What would’ve helped</b>	The final superordinate theme; “what would have helped” highlighted patients’ and partners’ perceptions of care received, and introduced views and recommendations to what was felt would have helped during their cancer experience. Each couple revealed various stages of the cancer that they found most difficult and highlighted the support and



	types of support that would have been beneficial during these difficult periods.
<i>Willingness to accept emotional support</i>	This subtheme revealed partners reluctance to accept emotional support.
<i>'Fear of the unknown'</i>	This subtheme highlighted a need for better emotional support for patients but also for the partner and family, particularly during time of increased emotional distress i.e. diagnosis, and treatment.
<i>What can we do?</i>	These were suggestions and recommendations for the type of support patients and partners would be willing to accept.

The images used in this thesis were produced by Mark Gilbert during a three year period as artist-in-residence in the Department of Oral and Maxillofacial Surgery at St. Bartholomew's and the Royal London Hospital. The paintings portray the faces of patients before, after and in some cases actually during their Head and neck cancer surgery.

Initiated and sponsored by surgeon Iain Hutchison, the paintings were conceived as a way of conveying to the public the possibilities of today's facial surgery whilst at the same time communicating the strength of spirit which can enable people with facial disfigurements and trauma to lead full and happy lives. Portraits of the patients are displayed in the exhibition which was launched in spring 2002 at the National Portrait Gallery and has since toured extensively in the UK, Europe and the USA.