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**Exploring the Experiences of
Individuals with Head and Neck
Cancer Using Online Support
Groups**

**A thesis submitted in fulfilment of the requirement
for the Degree of Doctor of Philosophy in Dentistry**

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
AJCC	The American Joint Committee on Cancer
ASR	Age Standard incidence Rate
AR	Attributable Risk
BDI	Beck Depression Inventory
BSNI	The Berkman-Syme Social Network Index
CBI	The Cancer Behaviour Inventory
CBI-B	The Cancer Behaviour Inventory-Brief version
CES-D	The Centre for Epidemiological Studies Depression Scale
CESD-R	The Centre for Epidemiologic Studies Depression Scale-revised
CG	Caregiver
CI	Confidence Interval
CMSG	Computer-Mediated Support Group
CT scan	Computed Tomography Scan
D/M	Number of Days of Using Online Support Groups Per Month
EBV	Epstein Barr virus
EOC	Emotion Oriented Coping
EORTC	The European Organization for Research and Treatment of Cancer
EORTC QLQ-C30	The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30
EORTC QLQ-H&N35	The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire -Head and Neck Cancer module 35
EPQ	The Eysenck Personality Questionnaire
EPS	The Empowering Processes Scale
FACT	The Functional Assessment of Cancer Therapy scale
FACT-G	The Functional Assessment of Cancer Therapy scale (General cancer)
FACT-HN	The Functional Assessment of Cancer Therapy scale (Head and Neck cancer)
GHQ	The General Health Questionnaire
H&N	Head and Neck
HADS	Hospital Anxiety and Depression Scale
HCP	Health Care Professional
HIV	Human Immunodeficiency Virus
HNCI	Head and Neck Cancer Inventory
HPV	Human Papilloma Virus
HR	Hazard Ratio

HRQoL	Health- Related Quality of Life
IARC	International Agency for Research on Cancer
ICD	The International Classification of Disease
ICT	Information and Communication Technology
LOT	The Life Orientation Test scale
LOT-R	The Life Orientation Test- Revised scale
MAC	The Mental Adjustment to Cancer
MCF	Mouth Cancer Foundation
MINI-MAC	The Mini-Mental Adjustment to Cancer
MOS-HIV	The Medical Outcome Study -Human Immunodeficiency Virus Health Survey
MOS-SSS	The Medical Outcomes Study Social Support Survey
MRI	Magnetic Resonance Imaging
MSN	The Microsoft Network
NRT	Nicotine Replacement Therapy
OCF	Oral Cancer Foundation
OR	Odd Ratio
OSG	Online Support Group
OSGs	Online Support Groups
PET	Positron Emission Tomography
POC	Problem Oriented Coping
PSS	Performance Status Scale
PSS-HN	Performance Status Scale for Head and Neck Cancer patients
Pwc	Person with cancer
QoL	Quality of Life
RCT	Randomised Control Trial
RR	Relative Risk
SEER (program)	Surveillance, Epidemiology, and End Results program
SES	Socioeconomic Status
SF (health survey)	The Short Form health survey
SSBC	The Social Support Behaviour Code
SSC	Squamous Cell Carcinoma
SUPPH	The Strategies Used by Patients to Promote Health
THANC	Thyroid Head and Neck Cancer Foundation
TNM (staging system)	Tumour, Node, Metastasis staging system
TsU	Times since Starting Using online support groups
UADT	Upper Aero-Digestive Tract
UCLA (loneliness scale)	University of California, Los Angeles loneliness scale
UICC	The Union for International Cancer control
UREC	University of Sheffield Research Ethics Committee

UW-QOL	University of Washington Quality of Life Questionnaire
WHO	World Health Organisation
WOC	The Worry Of Cancer
WOCC	The Ways of Coping Checklist

Abstract

Objectives: Head and neck (H&N) cancer is commonly cited as the most emotionally traumatic of all tumours with potentially severe impacts on quality of life (QoL). Social support is increasingly recognised as playing an important role in helping people cope with the diagnosis, progression, and outcomes of cancer, including H&N cancer. Using online support groups (OSGs) has been found to be associated with a range of positive psychosocial outcomes in relation to several health conditions. The aim of this thesis was three-fold; firstly, to assess the types of social support, sought and offered, within OSGs for H&N cancer. Secondly, to explore the relationship between using OSGs and QoL and examine the psychosocial factors that may influence this relationship and, thirdly, to explore, in depth, the OSGs experiences of people with H&N cancer.

Methods: Two studies are reported in this thesis: Study 1 was a content analysis of posted messages within H&N cancer-OSGs. A total of 312 support-offering messages and 87 support-seeking messages (in a one year period) were randomly selected from 18 H&N cancer OSGs. The content of the support-offering messages were analysed using a modified version of Social Support Behaviour Code and the content of the support-seeking messages were analysed using a modified version of the Coursaris and Liu coding scheme.

Study 2 was a cross-sectional study consisting of two parts; the first was an online questionnaire using six pre-validated measures for social network, self-efficacy, anxiety and depression, adjustment, empowerment and quality of life. In addition, socio-demographic as well as illness-related and OSGs-related information were collected. This questionnaire was completed by 199 persons with H&N cancer using four OSGs within a 6 month period. The second part of Study 2 was an unstructured online interview in which, 30 people from the previous 199 were interviewed synchronously online using Facebook, Email, Skype, Yahoo messenger and MSN, and a narrative thematic experience analysis was conducted on the data.

Results: The content analysis of Study 1 showed that the most frequently offered types of social support by members of OSGs were informational (43.4%) and emotional (32.4%), followed by esteem (15.65%) and network support (6.04%), whereas little tangible assistance was offered (2.47%). The content of messages seeking support included OSGs members sharing personal experience (31.52 %), with the most frequently sought support being informational support (25.54 %).

In the quantitative part of Study 2 a series of multiple linear regression analyses indicated that longer use of OSGs was related to better QoL ($p= 0.02$), and lower levels of depression and anxiety, lower endorsement of negative adjustment behaviour ($p = 0.00$ for each), greater self-efficacy ($p = 0.02$) and higher levels of empowerment ($p = 0.01$). Additional analysis of mediation effects suggested that depression and adjustment were direct mediators of the relationship between OSGs and QoL, whilst anxiety, self-efficacy and empowerment were indirect mediators. The narrative thematic analysis of the qualitative part of Study 2 showed that one main theme emerged (*Trust*) which included four subthemes: (1) distrust, (2) institutional trust, (3) identification based and relational trust (4) power relationships and normalisation.

Conclusion: The advantages of cancer related-OSGs appear to be inclusive; regardless of location, access, availability or user characteristics. The results of the studies tentatively suggest that OSGs could benefit H&N cancer patients by providing support and information related to their condition, enhance empowerment processes and patient's beliefs in their control over their H&N cancer, as well as reduce anxiety, depression, and negative adjustment behaviours and subsequently improve quality of life. Moreover, these results support previous research on other types of cancer in importance of trust in managing online relationships and further emphasises the complexity of online social relationships.

Chapter I: Introduction

1 Introduction

Despite extensive research regarding head and neck (H&N) cancer, which is a heterogeneous group of malignant neoplasms usually originate from the surface layer of the upper aerodigestive tract [UADT] with a wide range of pathological, biological, clinical and phenotypical behaviour (Haddad and Shin, 2008), the incidence of some types of this cancer remains high and many patients with H&N cancer throughout the world still experience a range of psychosocial consequences. The consequences of living with head and neck cancer negatively influence quality of life (QoL) and wellbeing (Rogers *et al.*, 2007; Penner, 2009; So *et al.*, 2012). The literature suggests that several factors may mitigate or aggravate the impact of cancer on psychological status (McDonough *et al.*, 1996). These factors include coping strategies, social support, social networks, self-efficacy, anxiety, and depression.

Recently, an increasing number of people have used the internet for support, information and advice related to many aspects of health, including cancer (Leimeister *et al.*, 2008). Online support groups (OSGs), which has been defined as “*a topic-specific electronic mailing list where narrative messages are exchanged by a usually cohesive set of individuals that typically share a common ailment, problem, or concern*” (Agnew, 2001. P: 4), are also used for many health conditions including H&N cancer. Several studies have investigated these groups and suggested that they have many advantages over conventional face-to-face support groups and can be beneficial to users; offering a range of social support, and enhancing empowerment (Mo and Coulson, 2010a). To date, no study has explored the role of OSGs for people with H&N cancer. Yet, such groups may be of particular importance to those with H&N cancer since many might not be able to use face-to-face groups for a number of physical and/or psychological reasons.

The main aim of the present research was: exploring online social support groups for people with head and neck cancer.

To address this aim, two studies were carried out using different methods. The first study was a content analysis of the different types of social support contained in

posted messages within H&N cancer-OSGs. The second study was a cross-sectional study consisting of two parts; the first part was a cross-sectional study utilising a range of pre-validated questionnaires to assess H&N cancer patient's quality of life, social network, self-efficacy, anxiety, depression, adjustment and empowerment. The second part was a qualitative exploration of people's experiences of using H&N cancer OSGs using unstructured online interviews.

The thesis is structured as follows: Chapter Two provides an overview of the literature related to H&N cancer including its definitions, risk factors, epidemiology, management, and outcomes.

Chapter 3 consists of three sub-sections; the first sub-section details literature on coping with H&N cancer. The second sub-section provides an overview of literature on social support including definitions, types of social support, social support theory, mechanisms, and dimensions. The chapter includes a review of literature on social support and health, with a particular focus on relationships between social support, cancer and H&N cancer specifically. The third and final subsection focuses on literature on the use of OSGs including users of OSGs, advantages and disadvantages of OSGs, mechanisms for their potential effects and concludes with a discussion of ethics of internet-based research.

Chapter 4 details the first study of the thesis which was a content analysis of types of social support contained in posted messages within H&N cancer-OSGs.

Chapter 5 details the second study of the thesis which included two parts. The first was a cross-sectional study which examined H&N cancer patient's quality of life in relation to their social network, self-efficacy, anxiety, depression, adjustment and empowerment. The second part was an exploration of patient's experience of using H&N cancer OSGs using unstructured online interviews.

Chapter 6 brings together the findings of the two studies, highlighting the key aspects of social support provided and sought through OSGs, the relationships between using OSGs and patient's quality of life, and patient's experiences of using OSGs. It then discusses recommendations and suggestions for future research.

Chapter II: Head and Neck Cancer-Overview

2 Head and neck (H&N) cancer- overview

2.1 Definition

There is significant variability in the definition of head and neck (H&N) cancers within the literature internationally (Davies and Welch, 2006). Head and neck cancer belongs to a heterogeneous group of malignant neoplasms with a wide range of pathological, biological, clinical and phenotypical behaviour (Haddad and Shin, 2008).

The term "head and neck cancer" is a collective term identified on topographical-anatomical foundations to illustrate malignant cancers in specific sites in the head and neck region (Dobrossy, 2005). These sites usually originate from the surface layer of the upper aerodigestive tract [UADT], which comprises of three major parts; the oral cavity, pharynx, and larynx.

Cancers of the oral cavity originate from the mucosa of mouth i.e. the palate, floor of the mouth, gum, tongue, base of the tongue, and the lip. Cancers of the pharynx include the nasopharynx, oropharynx, and hypopharynx and represent the superior part of the throat and respiratory system. The third region of H&N cancers is the larynx, which represents the main vocal area (CRD, 2004; Dobrossy, 2005; Locate *et al.*, 2007; Ragin *et al.*, 2007; Sturgis and Cinciripini, 2007; Marur *et al.*, 2010).

Cancer of other structures located in the H&N region such as salivary glands, parathyroid glands, paranasal sinus, bone, thyroid, nasal cavity, neurovascular bundle, ear, skin, scalp, and muscle have also been included under the classification of H&N cancer (Shah and Lydiatt, 1995; CRD, 2004; Adeyemi *et al.*, 2008; Yu *et al.*, 2008; Gil and Fliss, 2009; Marur *et al.*, 2010; Rad *et al.*, 2010).

The International Classification of Disease (ICD-10) uses separate codes to differentiate anatomical sub-sites for H&N cancers (World Health Organisation [WHO], 2007), see Table 1.

“

“Anatomical sites	ICD-10 codes
Lip and Oral cavity	C00 – C06
- Lip	- C00
- Base of tongue	- C01
- Other parts of tongue	- C02
- Gum	- C03
- Floor of mouth	- C04
- Palate	- C05
- Other parts of the mouth	- C06
Parotid	C07
Major salivary glands	C08
Tonsils	C09
Pharynx	C10 – C13
- Oropharynx	- C10
- Nasopharynx	- C11
- Sinus pyriformis	- C12
- Hypopharynx	- C13
- Other sites the lip, oral cavity and pharynx	- C14
Larynx	C32”

Table 1: International Classification of Diseases (Revision 10) locations of head and neck cancers (adapted from the WHO, 2007)”

Cervical oesophagus, thyroid and parathyroid glands, salivary gland, nose and paranasal sinus are less frequently listed within classification of H&N cancers. Malignant cancers originating from skin, haematopoietic tissue (lymphoma and leukaemia), mesenchymal tissue (blood vessels and muscles) and central and peripheral nervous system are generally excluded from the definition of H&N cancer (Locate *et al.*, 2007).

From the ICD10 as well as previous studies, for the purposes of this research, we have included malignant tumours arising from mucosa of upper aerodigestive tract [UADT] from nasopharynx to larynx including the oral cavity, i.e. pharynx, lip and oral cavity and larynx.

Given these differing definitions and types, in the following literature review, specific types of cancer are noted when they have been mentioned in the original study (e.g. oral cancer, pharyngeal cancer). However, where no specific type(s) have been referred to, the generic term ‘head and neck cancers’ has been used.

2.2 Risk factors

The causes of H&N cancer appear to be complex and multi-factorial, and epidemiological evidence has indicated that several different risk factors may be involved. Although they may not be direct casual factors, they are thought to have a relationship, individually or in combination, with an increased probability of developing H&N cancer (Dobrossy, 2005).

Although there are several factors implicated to be risk factors for H&N cancer, only few were classified as major risk factors such as smoking, alcohol and the use of Betel quid. The remaining were classified as emerging risk factors such as human papilloma virus (HPV) and diet, controversial factors with limited evidence such as ethnicity and pollution, and any other factors considered to be controversial because they present inconsistent evidence, for example hereditary factors or the use of marijuana (Warnakulasuriya, 2009b).

For example, tobacco is thought to be implicated in approximately one fourth of oral cancers (Hashibe *et al.*, 2007). The authors found that among never drinkers, Odd Ratio (OR) for ever versus never smoking = 2.13 (95% Confidence Interval (CI) = 1.52 to 2.98) which means that the odds of being diagnosed with oral cancer was 2.1 times higher for those that smoked compared to those that never smoked. In relation to oropharyngeal cancers, Blot *et al.* (1988) suggested that tobacco and alcohol consumption together were implicated in more than three quarters of cases in their study. In this case-control study, the measure of association between oropharyngeal cancer risk and tobacco and/or alcohol intake had an odds ratio of 37.7 (population-Attributable Risks “AR” were 80%). The relationship between smoking and H&N cancer has been widely indicated in the literature, for example, recently, a systematic review (Radoï and Luce, 2013) has been conducted on risk factors of oral cancer using PubMed database to access relevant articles published between 1980 and 2010. It included papers reporting quantitative data on the association between the cancer of the oral cavity and the following risk factors: alcohol drinking, tobacco smoking, smokeless tobacco, betel chewing, marijuana smoking, human papilloma virus and sexual behaviours, oral health, familial history of cancer and occupational exposures.

One hundred and two studies met the inclusion criteria. The results of this review indicated that smoked tobacco seems to be a stronger risk factor for oral cavity cancer than alcohol. The population -attributable risk (AR) related to smoked tobacco alone was approximately 25% for oral cavity cancer and 52% for larynx cancer. Among never drinkers, the risk of oral cavity cancer was 1.4–1.7 times higher in smokers than in never smokers. This relative risk was lower than that for pharyngeal (OR 1.9–3.1) and laryngeal cancers (OR 6.8–11.0). In addition, the International Agency for Research on Cancer (IARC) completed a review of the more than 100 chemicals, occupations, physical agents, biological agents, and other agents that it has classified as carcinogenic to humans. In this review smoking has been classified as a carcinogenic agent for all the sites of H&N cancer (oral cavity, pharynx and Larynx) (Cogliano *et al.*, 2011).

Alcohol alone is made up of many different chemicals and acids (see Appendix 1) and it may be that the interplay between these differing constituents is in itself a risk factor (Mosedale and Puech, 1998; Scalbert and Williamson, 2000). Heavy alcohol consumption, by itself, was found to be associated with the development of H&N cancers, especially for cancer of hypopharynx and mouth (Bagnardi *et al.*, 2001). Bagnardi and colleagues meta-analysis of case-control and cohort studies from 1966 to 2000 found that there was 25 case control and one cohort study which included 7954 cases of cancers of the oral cavity and pharynx. To analyse the modifying effect of tobacco, pooled estimates based on unadjusted and adjusted Relative Risks (RR) were compared for studies providing relevant information. Across these studies, the pooled RRs (95% Confidence Interval (CI) associated with alcohol intake was 1.75 (1.70, 1.82) for 25g day, 2.85 (2.70, 3.04) for 50g day and 6.01 (5.46, 6.62) for 100g day. Twenty of the case control studies also included 3759 cases of laryngeal cancer and showed that the pooled RR (and 95% CI) associated with alcohol intake was 1.38 (1.32, 1.45) for 25g day, 1.94 (1.78, 2.11) for 50g day and 3.95 (3.43, 4.57) for 100g day.

In relation to other risk factors, areca nut, which is the main constituent of betel quid (Merchant *et al.*, 2000) has been categorised by the International Agency for Research on Cancer (IARC) as another oral carcinogen (IARC, 2004), and an increased risk of developing oral cancer has been reported among users of the areca nut (vanWyk *et al.*,

1993; Merchant *et al.*, 2000). vanWyk and colleagues, in a retrospective study (1983-1989) of oral cancer and concomitant oral habits suggested that for chewing areca nut only, the odds ratio of oral cancer was 43.9 (AR = 89%). With tobacco, the odds ratio increased to 47.42 and the AR to 91%. Merchant *et al.*'s (2000) case-control study included 79 cases (people with oral cancer) and 149 controls (people who did not have a past or present history of any malignancy) and found that in the univariate analysis, cases were more likely than controls to have oral cancer (OR = 23.46; $p < 0.001$), to report ever using alcohol (OR= 2.70; $p = 0.036$), naswar "tobacco and lime" (OR = 3.42; $p = 0.011$), paan "areca nut and lime" with tobacco (OR = 12.45; $p < 0.001$) and paan without tobacco (OR = 5.17; $p < 0.001$).

In summary, the aetiology of H&N cancer appears complex and multi-factorial, and many different etiological factors are thought to work directly or indirectly, individually, or in combination, to increase the likelihood of developing H&N cancers.

2.3 Descriptive epidemiology

Reliable and high quality data concerning the incidence and mortality of H&N cancers are readily available from the cancer registries based on population and death certificates in developed countries such as Europe and Northern America. For global rates of H&N cancer, we need to take into account that incidence rates are merely estimates and directly related to the poor quality of reporting or absence of cancer registries in some other regions of the world (Dobrossy, 2005). Based on this, the trend of the worldwide incidence and mortality of H&N cancer is still difficult to determine with precision. However, the results of some research and cancer statistics appeared to be consistent with each other. For example, some research and cancer statistics showed that there has been a reduction in the overall percentage of laryngeal cancer with a corresponding increase in pharyngeal cancer (especially nasopharynx) whilst no dramatic changes to oral cancer rates have occurred worldwide (Ridge *et al.*, 2004; IARC, 2008; IARC, 2012). However, these trends can be different for specific countries, for example, it appears that there has been an increase in the incidence of oral cancer in the UK throughout the last few decades (Cancer research, 2013) (see Figure 1).

Other researchers (Chaturvedi *et al.*, 2013) suggest that there was a significant increase in the incidence of oral and oropharyngeal cancer between 1983 and 2002, mainly in developed countries. This increase appears to be consistent with data taken from UK Cancer Research statistics (Figure 1) in which the age-standardised incidence rates of oral cancer has steadily increased during 1975 to 2011. It seems that despite the dramatic development and progress in cancer therapies and management over recent years, the trends in some categories of H&N cancer (oral and pharyngeal) is still increasing, which might indicate that H&N cancer statistics have not significantly changed for the better.

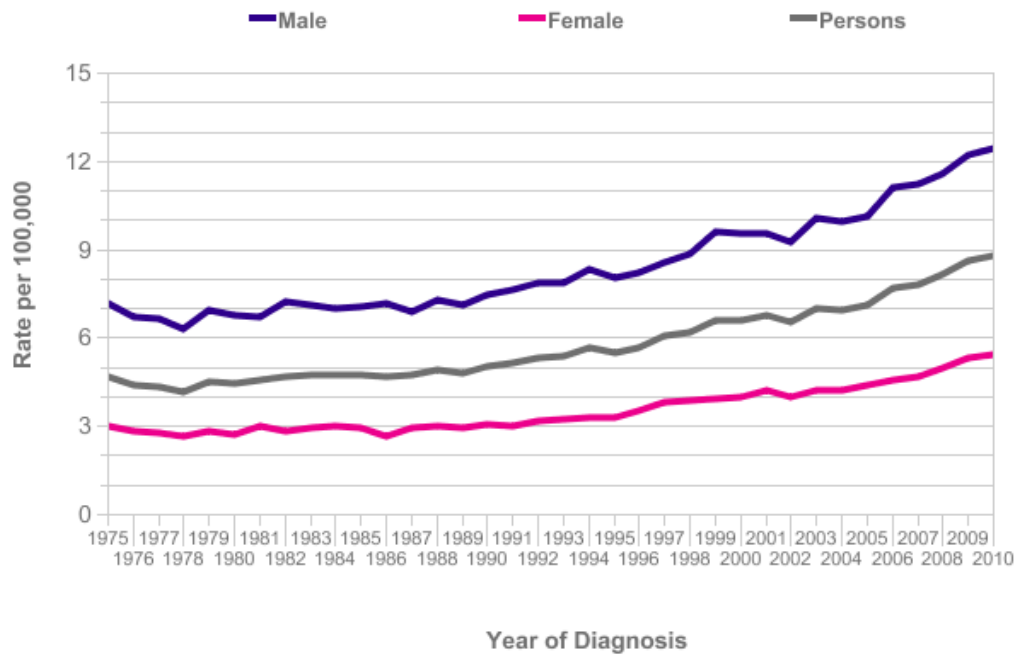


Figure 1: European age-standardised incidence rates of oral cancer per 100,000 populations, by Sex, UK (1971 – 2011) (Taken from Cancer Research, 2013)

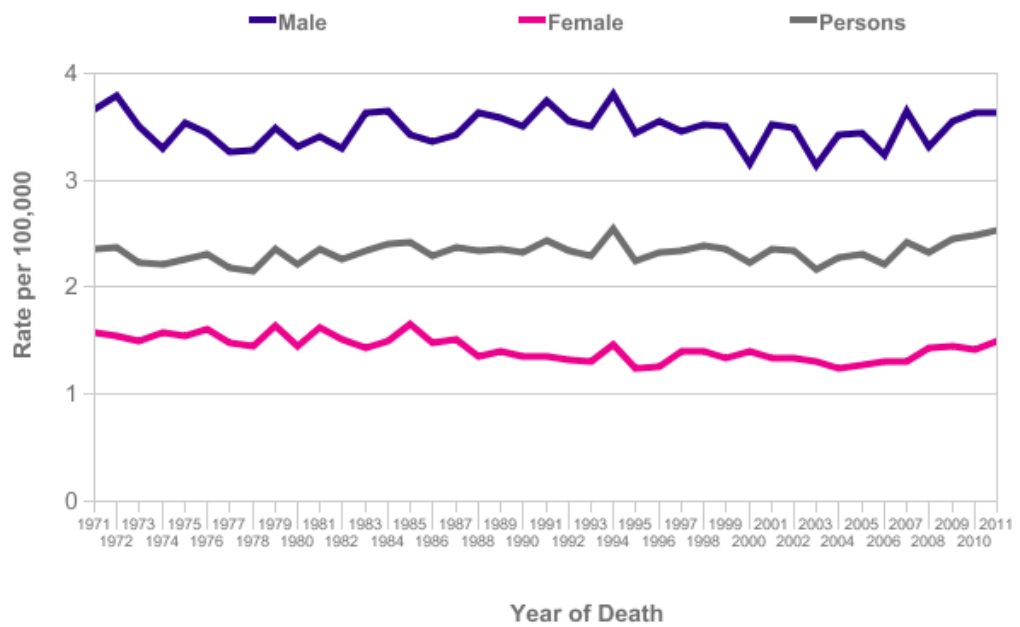


Figure 2: European age-standardised mortality rates of oral cancer per 100,000 populations, by Sex, UK (1971 – 2011) (Taken from Cancer Research, 2013)

The literature suggests that more than half a million new cases of H&N cancer are diagnosed each year (Fan, 2004; Dobrossy, 2005; Vermorken, 2005; Adeyemi *et al.*, 2008; Altumbabic *et al.*, 2008; Boyle *et al.*, 2008; Haddad and Shin, 2008; Marur and Forastiere, 2008; Pai and Westra, 2009; Michl *et al.*, 2010; Rad *et al.*, 2010) with approximately two thirds of these cases originating from developing countries. Head and neck cancers (oral and pharyngeal) are amongst the six most prevalent cancers in the world (Shah and Lydiatt, 1995; Fan, 2004; Dobrossy, 2005; Altumbabic *et al.*, 2008; Marur *et al.*, 2010; Rad *et al.*, 2010) and there is a high mortality rate from some types of this cancer (particularly Oropharyngeal cancer) (Price, 2010; Rad *et al.*, 2010).

The definition of head and neck cancer in this thesis comprises malignant tumours arising from mucosa of upper aerodigestive tract [UADT] (larynx, pharynx and oral cavity), and the most frequent histological type of cancer in this anatomical region, is squamous cell carcinoma (SSC), which represents 90% of cancers diagnosed with varying grades; from undifferentiated non keratinised to well differentiated keratinised (Shah and Lydiatt, 1995; Dobrossy, 2005; Vermorken, 2005; Sturgis and Cinciripini, 2007; Marur and Forastiere, 2008; Pai and Westra, 2009; Marur *et al.*, 2010; Polz *et al.*, 2010; Rad *et al.*, 2010).

2.3.1 Incidence by geography

There are broad disparities in the incidence of H&N cancers amongst different geographical regions in the world. These geographical disparities may reflect the differences in the frequency of aetiological factors between the different regions and countries (Bagnardi *et al.*, 2001; IARC, 1986).

More than sixty percent of oral and pharyngeal tumours occur in developing countries, since elevated incidence rates of cancerous tumours have been reported in the Indian subcontinent followed by tropical regions of South Africa and South America (Dobrossy, 2005).

The percentage of incidence of H&N cancer in the world in 2008 and 2012 for each anatomical sub-site can be seen in Figure 3, with cancer of the lip and oral cavity as

the most prevalent subcategory of H&N cancer in both years. While there was no significant change in the percentage of cancer of the lip and oral cavity and pharyngeal cancer (other than nasopharynx), there was a clear decrease in the percentage of cancer of the larynx, which may attributed to changes in patterns and exposure to tobacco and alcohol (Bosetti *et al.*, 2006) and a clear increase in the percentage of nasopharyngeal cancer. Some researchers attribute this change to variation in the data quality from divergent sources (Wei *et al.*, 2010); however, the exact reason is not clear. In contrast, the Age Standard incidence Rate (ASR) does not show significant changes between these two years, (see Table 2) which is probably related to the way the data was collected.

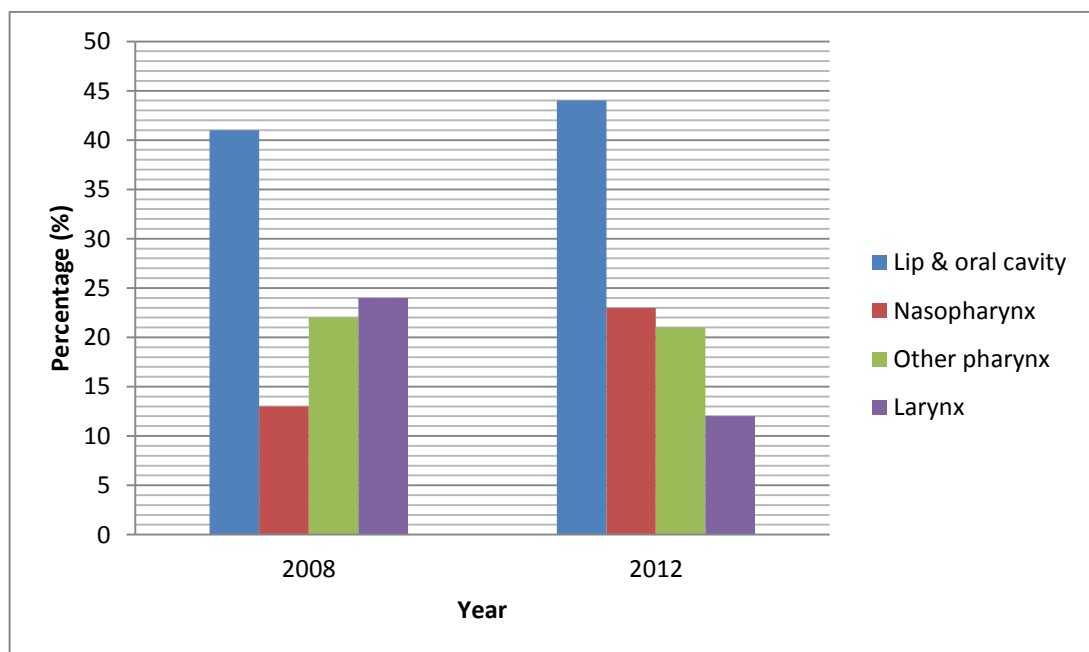


Figure 3: The percentage of each sub-site of head and neck cancer in the world, (data from IARC, 2008 and 2012)

Cancer	ASR (2008)	ASR (2012)
Lip, oral cavity	3.8	4.0
Nasopharynx	1.2	1.2
Other pharynx	2.0	1.9
Larynx	2.2	2.1

Table 2: Age Standard incidence Rates (ASR) of head and neck cancer in the world (data from IARC, 2008 and 2012)

2.3.2 Incidence by gender

In relation to H&N cancer specifically, Ridge (2004) reported that 66% to 95% of cases of H&N cancer occur in men. In addition, Warnakulasuriya (2009a) reported that the worldwide incidence of oral and oropharyngeal cancer is more prevalent in males than in females in the majority of countries. The ratio of males to females diagnosed with cancer, however, was about 1.5:1 for oral cancer and 2.8:1 for oropharyngeal cancer. The author attributed this difference to more exposure or participation of males in riskier habits than females, even though the incidence of oral cancer in males to that in females has dropped over the decades. However, the reasons for this are unclear at present given no existing studies examining the complex interplay of social, psychological and biological factors that may be implicated in the differential development of H&N cancer between sexes.

2.3.3 Incidence by age

The incidence of H&N tumours (particularly oral cancer) appears to increase with age particularly after 50 years (SEER, 2004; Ries *et al.*, 2005; Chidzonga and Mahomva, 2006; Warnakulasuriya, 2009a). However, recently, research indicates that H&N tumours (particularly oropharyngeal cancer) do increasingly occur in young people (Ridge *et al.*, 2004; Dobrossy, 2005). Some investigators argue that the reason for this change in oropharyngeal cancer may be due to the increasing prevalence of Human papillomavirus (HPV) especially in developed countries, as well as the increased prevalence of oral sex and multiple sexual partners (Marur and Forastiere,

2008). However, caution needs to be exerted here because the exact factors and mechanisms in oropharyngeal cancer have yet to be fully identified.

2.3.4 Incidence by ethnicity

There have been some studies within the United States (Ridge *et al.*, 2004) which suggests that there is no predominance of H&N cancers by ethnicity and the incidence presents equally in white and black men. Others (Hayat *et al.*, 2007) suggest that the incidence rates for men with oral and pharyngeal cancer were higher for black than white men. It has also been reported that the survival rates associated with these cancers (oral and pharyngeal) among African Americans were lower than that of white populations for similar cancer stages (62.6% in white, 43.7% in African-Americans) (Du and Liu, 2010). However, the reason for these differences is still not well understood. It may be that differences in exposure to risk factors or participation in riskier habits, rather than genetic factors, might be implicated in observed disparities in populations and higher rates of H&N cancers in some ethnic groups (Warnakulasuriya, 2009b).

2.4 Management

2.4.1 Control and primary prevention

Increasing trends, especially in developing countries, and a simultaneous rise in the worldwide incidence in some types of H&N cancer (particularly oral and pharyngeal cancer), has resulted in a call for making this disease a high priority (Boyle, 1993; IARC, 2008; IARC, 2012). Given that there may be a relationship between H&N cancer, tobacco smoking, and alcohol consumption, then theoretically, control of these risk factors may contribute to prevention of these tumours. However, incidence reduction through a primary prevention agenda such as health promotion and health education is likely to be a long term task and may not be very promising (Horowitz *et al.*, 1996; Petersen *et al.*, 2005). There may also be other determinants that perpetuate the proliferation of H&N cancer when joined with other risk factors such as excessive use of alcohol and tobacco. This complexity creates uncertainty when addressing the issue and trying to implement health promotion.

2.4.1.1 Potentially malignant disorders

The working group of WHO have classified ‘precancer’ into ‘lesions’ and ‘conditions’ since four decades ago with following definitions (WHO, 1973):

- A precancerous lesion is “*a morphologically altered tissue in which oral cancer is more likely to occur than in its apparently normal counterpart*”
- A precancerous condition is “*a generalized state associated with a significantly increased risk of cancer*”.

At that time, it was considered that the origin of a malignancy in the oral cavity of a patient known to have a precancerous lesion would correspond with the site of precancer. On the other hand, in precancerous condition, cancer may arise in any anatomical site of the mouth or pharynx. It is now known that even the clinically ‘normal’ appearing mucosa in a patient harboring a precancerous lesion may have dysplasia on the contralateral anatomic site (Thompson, 2002) or molecular aberrations in other oral mucosal sites suggestive of a pathway to malignant

transformation and that cancer could subsequently arise in apparently normal tissue (Bremmer *et al.*, 2005).

The current Working Group of WHO (2005) did not favor subdividing precancer to lesions and conditions and the consensus view was to refer to all clinical presentations that carry a risk of cancer under the term ‘potentially malignant disorders’ (PMD) and elimination of the term ‘precancer’ to reflect their widespread anatomical distribution (Warnakulasuriya *et al.*, 2007). The latest WHO monograph on head and neck tumors (2005) uses the term ‘epithelial precursor lesions’ (Barnes *et al.*, 2005) and defined it as “*altered epithelium with an increased likelihood for progression to squamous cell carcinoma*”.

2.4.1.2 Screening

The previous thought that most oral cancers are preceded by a lesion that can be detected clinically (WHO, 1984) appeared to support the justification for their early detection by screening although it has been found that many of the oral cancers can arise de novo "from the beginning" (Scully and Bagan, 2009; van der Waal, 2009).

Screening programmes for the most common tumours such as cervical and breast tumours have effectively reduced mortality rates and helped in decreasing their incidence (Sasieni *et al.*, 2003; NHSBSP, 2006). This would appear to suggest that screening may be important in reducing mortality rates for some types of H&N cancers which have not altered for fifty years (Comprehensive Cancer Centre, 2011).

Whilst some studies have recommended regular examination of the oral mucosa by dental clinicians throughout the course of their daily work as a primary screening method that might identify pre-cancerous lesions (Parkin *et al.*, 1985; Field *et al.*, 1995), studies on other H&N cancers (i.e. larynx and pharynx) have produced scant evidence on the possibility and efficacy of screening (Alho *et al.*, 2006). This is because the majority of laryngeal and pharyngeal lesions cannot be detected by visual examination. This inconsistency in detection means that organised population based screening is seen as impractical as a public health measure for some types of H&N cancer (Boyle, 1993, Speight *et al.*, 2006).

Given the high incidence and mortality rates related to oral cancer, it is important to assess the effectiveness of screening, particularly as there has been detailed debate about its introduction. A systematic review by Downer *et al.* (2006) was conducted to investigate measures of effectiveness in screening for oral cancer and precancer in primary care. In this review, nine databases were searched for studies reporting a range of measures on the effectiveness of screening for oral cancer and precancer. Criteria for considering studies for the review covered types of studies, participants, interventions and outcome measures. Ninety full text articles have been screened and only 28 were included after applying the exclusion criteria. There was a substantial heterogeneity between the studies regarding study objectives, design, setting and location as well as characteristics and numbers of participants, screening personnel, procedures of recruitment and types of data collected. Only one randomised controlled trial, from the India, has been reported: interim results showed 14.9% of intervention subjects died after 3 years compared with 56.3% of non-intervention controls. The review generally produced no evidence for or against the potential benefits of an oral cancer screening programme, since there was insufficient available data to make an unequivocal determination as to the effectiveness of oral cancer screening programmes at that time.

Another systematic review by Kujan and colleagues (2003), updated three times (Kujan *et al.*, 2006; Brocklehurst *et al.*, 2010; Brocklehurst *et al.*, 2013) aimed to assess the effectiveness of current screening methods in decreasing oral cancer mortality. The latest update of the review (Brocklehurst *et al.*, 2013) used electronic databases including MEDLINE via OVID (up to July 2013) CANCERLIT via PubMed (up to July 2013), the Cochrane Central Register of Controlled Trials (The Cochrane Library 2013, Issue 6), The Cochrane Oral Health Group Trials Register (up to July 2013) and EMBASE via OVID (up to July 2013) and incorporated randomised controlled trials of screening for oral cancers and precancerous oral lesions using common screening methods such as visual examination, toluidine blue, brush biopsy or fluorescence imaging.

The review did not find a statistically significant difference in the oral cancer mortality rates for the screened group and the control group (RR= 0.88; 95% CI= 0.69

to 1.12) and there also was no statistically significant difference in incidence rates. However, regarding specific groups, the results revealed that the mortality rate of oral cancer in high- risk groups (those who use tobacco or alcohol or both) was reduced (RR= 0.76; 95% CI= 0.60 to 0.97), and a statistically significant reduction in the number of individuals diagnosed with stage III or worse oral cancer was found for the screened group (RR= 0.81; 95% CI =0.70 to 0.93). In addition, the survival rate among the whole population was improved (five-year survival rate = 55.5% for screened group and 43.4% for the control; $p = 0.003$) through a population based screening strategy (visual examination). However, these findings were based on one study (four reports) (Sankaranarayanan *et al.*, 2000; Ramadas *et al.*, 2003; Sankaranarayanan *et al.*, 2005; Sankaranarayanan *et al.*, 2013) which included 191,873 apparently healthy adults from 13 clusters divided into intervention (7 clusters, 96,517) and control (6 clusters, 95,356) in Kerala, India. The consequence of cluster randomisation was not taken into account in the analysis which may lead to risk of bias. The review could not find any strong evidence to support the use of toluidine blue, fluorescence imaging or brush biopsy as a screening tool to reduce oral cancer mortality due to lack of randomised controlled studies associated with brush biopsy and fluorescence imaging, and the poor methodology for the study that investigated toluidine blue.

The only RCT included in the systematic review was conducted in a developing country (India) with high incidence and mortality rates of H&N cancer (WHO and IARC, 2008). To date, there have been no RCTs conducted in developed countries or countries with low incidence and mortality rates.

Despite the lack of RCTs in the area, there have been suggestions that opportunistic screening by a general dental or medical practitioner for high risk groups through oral examination could be a cost-effective screening strategy (Speight *et al.*, 2006). In this study, the authors used a decision analysis model to simulate the cost-effectiveness of oral cancer screening programmes in a number of primary care settings by conducting hypothetical screening programmes in these settings and comparing eight strategies; (one “No screening” three “invitational screening”; two “opportunistic screening” and two “opportunistic high risk screening”) in both general medical and general dental

practices. The main outcome measures were Quality-adjusted Life years (QALYs), life time cost and incremental cost effectiveness ratios (ICERs). The result suggested that the cheapest option seen in “No screening strategy” and none of the invitational screening was cost effective. However, for the opportunistic strategies, the ICER for the whole population (age 49–79 years) ranged from £15,790 to £25,961 per QALY. Modelling a 20% reduction in disease progression always gave the lowest ICERs. The authors concluded that there were difficulties with the use of the simulation model because of a lack of available data, as the model does not allow for the potential negative effects of screening and cannot allow for possible positive psychosocial effects of screening.

2.4.1.3 Diagnosis of frank malignancy

While some categories of H&N cancer (e.g. nasopharynx) have no symptoms at the early stages (Wei *et al.*, 2010), others (e.g. oral and pharyngeal) often do have early symptoms (Cancer.net, 2013; NHS, 2014; ADA, 2014). Thus, the stage at which the diagnosis takes place appears crucial in treatment decision-making and prognosis, since more complicated treatments and a poorer prognosis is expected in the advanced stages, while easier treatment and better prognosis is expected in the initial stages (Moor and Durden, 2010).

Head and neck cancer symptoms often appear as changes in upper aero-digestive tract including changes in speech, swallowing, respiration and hearing (Ridge *et al.*, 2004). Table 3 shows symptoms that a patient may be aware of.

-
- Dysphagia (swallowing difficulty)
 - Odynophagia (painful swallowing)
 - Hoarseness of voice
 - Epistaxis (nosebleeds)
 - Otagia (earache)
 - Epiphoria (excessive tear production)
 - Hemoptasis (coughing up of blood from the larynx, trachea, or lungs)
 - Oral ulceration
 - Trismus (restriction in opening the mouth)
 - Changes in ability to form words
 - Chronic sore throat
 - Nasal obstruction
 - Headache
 - Numbness of the face
-

Table 3: Presenting symptoms for upper aero-digestive tract (adapted from Ridge *et al.*, 2004; Lokker *et al.*, 2010)

A detailed history that reviews risk factors, signs and symptoms of all H&N cancers should be taken from the patient and a thorough physical examination performed on the H&N region including eyes, nose, cranial nerves, skin, ears, oral cavity and neck, (CDC, 2011). Diagnostic imaging such as plain x-ray, angiography, Magnetic Resonance Imaging (MRI), Computed Tomography (CT scan) or Positron emission Tomography (PET), direct and indirect laryngoscopy and endoscopy can be helpful for some types of the cancer, but definitive diagnosis requires biopsy (Ridge *et al.*, 2004; CDC, 2011). In addition, early presentation and early diagnosis seems to be one of the most important factors in improving cure rates of cancer, and prognosis of cancer depends greatly on early diagnosis and immediate treatment (Alsos, 1960; Rich and Radden, 1984).

The inaccessibility of many abdominal and intrathoracic tumours creates practical difficulties (Oishi *et al.*, 2004; Immanuel, 2011), and similar difficulties can be found

in the case of pharyngeal and laryngeal cancer, whereas many sites of oral cancer are readily accessible (Ensley, 2003). Head and neck cancers tend to stay localised in their tissue of origin for a long time and even after metastasis, they remain limited to the lymphatic tissue of H&N area for months (Shaw, 1976). This can facilitate the early diagnosis and theoretically the eradication of many H&N tumours, although some sites such as the nasopharynx, base of tongue and palatine tonsils exhibit difficulty in detection because in the early stages they can be tiny and hidden in folds of mucosa or the crypts of lymphoid tissue (Lore, 1995). What is not possible to account for is whether H&N cancers are primary or secondary sites, and even with early diagnosis and eradication of the tumours, the patient may still die.

It is easy to assume that a delay in diagnosis leads to more advanced cancer and a decrease in survival. For example, some researchers (McGurk *et al.*, 2005; Kokat, 2010) have reported five year survival rates for initial H&N cancers (particularly oral cancer) of up to 80%, whereas survival rates show a decline to 30% for more advanced stages. Yet, delay in diagnosis can be due to the patient, professional or both (Dimitroulis *et al.*, 1992; Jovanovic *et al.*, 1992; Kerdpon and Sriplung, 2001b).

2.4.2 Treatment

Surgery and radiotherapy were the main treatment for H&N cancer in the period between 1960 and 1980 (Marur and Forastiere, 2008). Single treatment modality or combined treatment (surgery and radiotherapy) were used according to the severity and stages of cancer and, in spite of this approach, recurrences occur in 60% of patients, 20% with metastasis and risk of secondary sites (Al-Sarraf and Hussein, 1995).

Systemic chemotherapy was introduced as part of combination therapy (Al-Sarraf, 1988; Al-Sarraf and Hussein, 1995). Chemotherapy has been used in cases of recurrent or metastatic H&N tumours and its role was mainly palliative for alleviation of symptoms rather than survival (Jacobs *et al.*, 1992; Clavel *et al.*, 1994). The positive impact of chemotherapy on the survival rate has become clear after three decades of research on the combination of radiation therapy with chemotherapy (radio-chemotherapy) (Munro, 1995; Browman *et al.*, 2001a).

Chemotherapy is used either as a single modality or as concurrent (chemo-radiotherapy) according to the stage and operability of cancer. For example, single modality was used for those with metastatic and/or recurrent cancers but it can also be used for treatment of locally advanced tumours, while concurrent chemotherapy was used in cases of inoperable or unresectable locally advanced H&N tumours (Al-Sarraf, 1988; Al-Sarraf and Hussein, 1995; Vokes *et al.*, 2000; Argiris, 2002; Manam and Al-Sarraf, 2002). Table 4 indicates the suitability of each treatment for different stages and types of H&N cancer.

Treatment	Cancer
Multimodality with surgery or radiotherapy Concurrent chemotherapy	Early-stage tumour Locally advanced unresectable tumour <ul style="list-style-type: none"> - Nasopharyngeal carcinoma - Unresectable H&N cancer (not site specified) - Locally advanced laryngeal tumour (for larynx preservation). - High risk post-operative H&N cancer (not site specified).
Palliative chemotherapy with combination to cytotoxic chemotherapy.	Recurrent and metastatic disease <ul style="list-style-type: none"> - Brief response in about one third of the patients. - No survival benefits over single patient.

Table 4: Suitability of different treatment for different stages and sites of head and neck cancer (adapted from Marur and Forastiere, 2008)

The choice of treatment for patients with H&N cancer depends on varying factors related to the cancer, patient and physician. The most important cancer factors appear

to be the site and stage of the disease. For example, for cancers of the oral cavity whether the tumour is located anteriorly or posteriorly are important, as the anterior tumour can be easily detectable and accessible (Shah and Lydiatt, 1995; Al-Sarraf, 2002).

Patient factors that influence the choice of treatment include age and general physical health of the patient. These factors can influence the ability of patients to tolerate optimal treatment. Other factors such as socioeconomic status, acceptance, occupation and compliance are believed to play a role in treatment selection for specific cancers (Shah and Lydiatt, 1995; Al-Sarraf, 2002).

Physician or health care provider's factors include optimal skills in medical oncology, radiotherapy and oncologic surgery. In addition, certain cancers require rehabilitation skills such as prosthodontics and other prosthesis. This may mean complex dentures that replace not only teeth but parts of the mouth structure, or eyes, or other parts of the facial structures and for successful results it would appear crucial to provide support services for emotional, psychological and occupational rehabilitation (Shah and Lydiatt, 1995). Social support for H&N cancer patients is discussed in detail later in the thesis (see Chapter 3).

The need for a wide range of specialist support services is generally accepted and although there is agreement that dieticians (Flynn and Leighty, 1978; Piquet *et al.*, 2002), speech and language therapists (Minear and Lucente, 1979; Lehmann and Krebs, 1991) and specialist nurses (Seikaly *et al.*, 2001) can play critical roles, the poor quality of previous studies in this area and the lack of definitive conclusions limits the strength of the evidence to date.

Recent systematic reviews (Glenny *et al.*, 2010; Furness *et al.*, 2011; Oliver *et al.*, 2011) reviewed the different treatment modalities available for H&N cancer and associated survival rates. Regarding surgical treatment, Oliver *et al.*, (2011) found only weak evidence that elective neck dissection (removal of neck nodes that influenced by cancer) at the time of removal of the primary cancer resulted in reduced cancer recurrence (RR = 0.42; 95% CI = 0.18 to 0.96). In addition, they could not find sufficient evidence that this strategy increased overall or disease free survival and

could not find evidence that radical neck dissection increased overall survival compared to conservative neck dissection surgery.

Glenny *et al.*, (2010) review of studies relating to radiation therapy suggested that altered fractionation radiotherapy was associated with an improvement in overall survival in patients with oral and oropharyngeal cancers (Hazard Ratio (HR) of mortality = 0.86, 95% CI = 0.76 to 0.98). Furness *et al.*, (2011) review of chemotherapy treatment suggested that chemotherapy, in addition to radiotherapy and surgery, were associated with improved overall survival in patients with oral cavity and oropharyngeal cancers (HR of mortality= 0.84; 95% CI = 0.72 to 0.98, $p = 0.03$). However, both Glenny *et al.*, and Furness *et al.*'s reviews could not find sufficient evidence as to which regimen was associated with better overall survival rates.

2.4.3 Side effects of treatments

2.4.3.1 Complications of surgery for head and neck cancer

Surgical treatment for H&N cancer may also produce complications which are usually divided into surgical and medical complications and for medicine most of them are temporary and correctible (Zabrodsky *et al.*, 2004; Paydarfar and Birkmeyer 2006) as seen in Table 5.

Surgical complications	Medical complications
<ul style="list-style-type: none">- Flap re-exploration- Haemorrhage- Wound dehiscence- Infection- Fistula formation- Seroma (pocket of clear serous fluid)- Skin necrosis	<ul style="list-style-type: none">- Respiratory tract infection- Gastric or duodenal ulcers- Cardiac insufficiency

Table 5: The most common complications of surgery for head and neck cancer

Head and neck tumours and their treatment can have profound effects on the main functions of life including difficulty in respiration, speech, eating, and mastication (Sakai *et al.*, 2008). It has been reported that several post-surgical complications such as flap necrosis and fistula formation have been found to be more common after surgery followed by radiation therapy than in cases of surgery alone (Sassler *et al.*, 1995; Sarkar *et al.*, 1990). Other factors such as blood loss, operation time (Girod *et al.*, 1995) and the use of chemotherapy (Corey, 1986) may have role in the development of post-surgical complications, which may increase the period of hospitalisation and in turn reduce quality of life (QoL) for patients.

The general incidence of H&N cancer-related post-operative complications has been found to be 39.4% (Sakai *et al.*, 2008) and the incidence of each complication observed is shown in Table 6.

Complication	%
Wound infection	14.1
Fistula formation	9.9
Hematoma	4.2
Necrosis of free flap	4.2
Skin necrosis	18.3
Serous retention	1.4

Table 6: Incidence of complications of surgery for head and neck cancer (adapted from Sakai *et al.*, 2008)

2.4.3.2 Side effects of radiation and chemotherapy

In spite of the development of radiation and chemotherapy treatments, numerous patients still experience debilitating side effects that significantly influence their quality of life (QoL) (Heron, 2005). Many side effects are common with both radiation therapy and chemotherapy, and the side effects of each treatment alone and the combination of both treatments are briefly summarised below.

2.4.3.2.1 Side effects of radiotherapy

Although the beams of radiotherapy usually target the cancer site as accurately as possible, and the quality has improved with advances in technology (Bucci *et al.*, 2005), radiotherapy frequently harms the normal tissues that surround the site of the cancer inadvertently restricting the dose of radiation that would be used to devastate tumour cells effectively (Heron, 2005).

Macmillan Cancer Support (2010) reported that the side effects of radiation treatment for H&N cancer (all types) can differ in severity according to the length of treatment and dose of radiotherapy, and generally become noticeable two weeks from treatment onset. Table 7 shows the possible side effects of radiotherapy.

General side effects	Local side effects	Long-term side effects
<ul style="list-style-type: none"> - Loss of appetite - Tiredness - Drowsiness 	<ul style="list-style-type: none"> - Mouth effects (sore, dry) - skin effects (sore, dry or itchy) - Loss of taste - Dental decay - Hair loss - Nausea - Trismus (restriction in opening the mouth) - Bad breath - Voice change - Endocrine problems - Osteoradionecrosis (necrosis of bone as a result of radiation) 	<ul style="list-style-type: none"> - Disturbed growth and development - Uneven development of muscle of the neck - Asymmetrical face

Table 7: The side effects of radiotherapy for head and neck cancer

Although the majority of these side effects appear to be temporary, it has been argued that some of them may remain for months after the end of treatment, or may be permanent as in the case of osteoradionecrosis, which is where the bone dies and there is a ‘dead area’ which may prove difficult to repair because the cells, blood supply and nerves may be too badly damaged (Clatterbridge Centre for Oncology, 2009). It has been suggested that some of these side effects such as dental decay, trismus, osteoradionecrosis and endocrine problems may not appear until after a relatively long term of treatment (Addenbrooke’s Hospital, 2006).

2.4.3.2.2 Side effects of chemotherapy

The side effects of chemotherapy for H&N tumours can be debilitating (Honor Cancer Nursing, 2011; Master, 2011) as seen in Table 8.

General side effects	Local side effects	Long-term side effects
<ul style="list-style-type: none">- Loss of appetite- Malaise- Fatigue- Anaemia- Diarrhoea- Constipation- Increase susceptibility to infection- Allergic and dermatological reaction	<ul style="list-style-type: none">- Sore mouth (mucositis)- Loss/ change of taste- Hair loss- Nausea- vomiting	<ul style="list-style-type: none">- Fertility problems- Hearing problems

Table 8: The common side effects of chemotherapy for head and neck cancer

A biomedical explanation of some of these side effects is that chemotherapy usually destroys all actively growing cells such as bone marrow, hair follicle and digestive tract (Honor Cancer Nursing, 2011).

2.4.3.2.3 Side effects of radio-chemotherapy

It has been suggested that the primary side effects of radio-chemotherapy for H&N tumours might include acute dermatitis (inflammation of skin), acute mucositis (inflammation of mucous membrane), dysphagia (difficulty in swallowing) and xerostomia (dry mouth) (Elsbruch, 2011).

There is no fixed list of the side effects of radio-chemotherapy for H&N cancer, indicating that there may be differences in recording methods of the side effects between clinicians or researchers or there might be many factors determining their development. It is not clear whether these side effects are caused by radiation therapy or chemotherapy or they appear as a result of the combination of both treatments.

Table 9 demonstrates the incidence of side effects in patients with H&N cancer treated with radiochemotherapy.

Side effect	%
- Mucositis	92.3
- Hematologic toxicity	59.6
- Neurotoxicity	26.9
- Severe nausea and vomiting	26.9
- Severe dehydration or malnutrition	26.0
- Pneumonia	25.0
- Severe fever	18.3
- Trismus	7.7
- Osteoradionecrosis	3.8
- Treatment-related death	1.9

Table 9: The incidence of side effects in patients with head and neck cancer treated with radiochemotherapy (adapted from Givens *et al.*, 2009)

Table 9 suggests that the majority of patients had mucositis and more than half had hematologic toxicity. However, the study from which these results were taken is limited by incomplete data resulting from the retrospective nature of the study. As medical reports were used, inconsistency of the results are to be expected, since numerous methods for reporting these side effects have been developed, and this may result in inconsistencies in reporting between different staff (Fromme *et al.*, 2004).

A combination of chemotherapy and radiotherapy for H&N cancer may cause changes in swallowing and nutritional intake that might have long-term consequences (Morphy, 2006). Impaired swallowing may occur as a result of tissue loss, fibrosis and inflammatory changes, while the nutritional disruption may take place as a consequence of xerostomia (dry mouth), altered taste, mucosal sensitivity or pain, problems with the dentition, and altered swallowing sensation (Morphy, 2006).

2.5 Outcomes

Survival rates for H&N cancer vary, and as can be seen from the previous sections, many survivors may be left with persistent problems that can have an impact on their QoL. This section discusses the prognosis of H&N cancer, the possible physical and psychosocial consequences, and their potential influence on QoL.

2.5.1 Prognosis

Cancer stage is thought to be an important factor in determining prognosis (Nicolson, 1986; Patel, and Shah, 2005). The staging systems for H&N cancer have been established by consensus panels in Europe (the Union for International Cancer control "UICC") (Hermanek and Sobin 1987) and America (the American Joint Committee on Cancer "AJCC") (Beahrs *et al.*, 1992). These staging systems try to set standard criteria for research and to establish prognostic categories for cancer (Iro and Waldfahrer, 1998).

The staging system for many types of cancers including H&N cancer is called the Tumour, Node, Metastasis (TNM) staging system, where T- refers to the features of cancer at primary location and usually based on size or site of the cancer or both of them; N- refers to the extent of regional lymph node involvement and M- indicates the presence and absence of distant metastases. The stages of cancer are produced as result of combination of T, N and M features (Iro and Waldfahrer, 1998; Deschler and Day, 2008).

The TNM staging system is effective in evaluating the basic features of the tumour such as size, regional distribution and distant metastasis (Brown *et al.*, 1998; Costa *et al.*, 2002). Advanced TNM stage (stage III and stage IV) are usually associated with poor prognosis in patients with oral cancer (Nicolson, 1986), and it is suggested that patients with oral cancer with a bilateral metastasis of the cervical ganglia have a poorer prognosis than those with unilateral metastasis (Kerdpon and Sriplung, 2001a).

Another important prognostic factor is the level of lymph node inclusion, since multiple contra-lateral involvement of lymph node can significantly reduce patient survival (Woolgar and Scott, 1995; Iro and Waldfahrer, 1998). The advanced stages (III and IV) of oral carcinoma are usually associated with lymphatic and neural involvement. This is why patients with stage IV usually appear with active or recurrent cancer and a low survival rate (Dib *et al.*, 1994; Numata *et al.*, 2000), while those with stage I and II usually survive after 5 years follow-up (Araujo Junior *et al.*, 2006). Figure 4 shows an overview of H&N cancer survival by stages measured within 10 years from 1992 to 2001. The more extensive cancers (stages 3 and 4) appear to have a poorer survival rate.

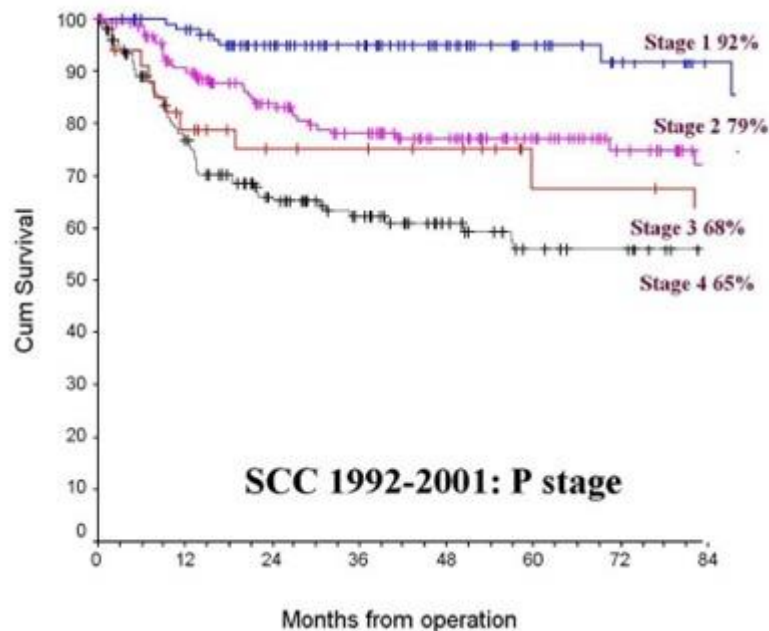


Figure 4: Head and neck cancer survival by stage (taken from Merseyside Regional Head and Neck Cancer Center, 2014)

Anatomical site of cancers can also be viewed as a prognostic measure, because cancers have different behaviours in different anatomical sites (Urist *et al.*, 1987; Martinez-Conde *et al.*, 2001). For example, tongue cancer has a tendency to recur and has a high risk of metastasis because of its proximity to the cervical lymph nodes, and these cancers usually have a high histological malignancy score (Martinez-Conde *et al.*, 2001; Costa *et al.*, 2005).

Whilst many studies suggest that there is a significant correlation between TNM classification and prognosis in association with the different anatomical sites of oral cancer (de Araujo *et al.*, 2008), other studies suggest a number of additional predictive factors for survival in oral and pharyngeal cancers (Ping *et al.*, 2007). Factors include ethnic group, age at diagnosis, period of diagnosis, anatomical location, gender, morphological type and treatment. For example, some studies suggest racial disparities in survival for patients with H&N tumours (details of these studies are available in Appendix 2).

Briefly, the most common example is the disparity between African Americans and white Americans. Whilst some researchers attribute these disparities to the differences in access and use of health services (Shavers *et al.*, 2003; Shiboski *et al.*, 2007; Goodwin *et al.*, 2008) others relate the issue to quality of health care, incidence of co-morbid conditions and diet (Goodwin *et al.*, 2008), or suggest that exposure to risk factors or carcinogens and genetic factors are implicated (Ho *et al.*, 2007; Goodwin *et al.*, 2008). In contrast, Molina *et al.*, (2008) argue that significant disparities by race and socio-economic status are not completely explained by under-treatment, co-morbid conditions or demographics, suggesting that the issue is far more complex.

There appear to be broad disparities in the mortalities and survival rates related to H&N cancer among different geographical regions in the world. These disparities might be related to differences in case mix of anatomical sub-sites (Berrino *et al.*, 1998), since the anatomical site of cancer has been recognised as one of the prognostic factors (Urist *et al.*, 1987; Martinez-Conde *et al.*, 2001). After adjusting for distribution of different sub-sites, disparities are found to still exist. This is possibly because of delayed diagnosis and/or delayed referral (Berrino *et al.*, 1998; McGurk *et al.*, 2005), differences in the quality of health care, poor accessibility of patients to well commissioned treatment between countries (Berrino *et al.*, 1998; Goodwin *et al.*, 2008), and the persistence of genetic or other risk factors (Ho *et al.*, 2007; Goodwin *et al.*, 2008).

2.5.2 Physical and psychosocial consequences

Beside the physical impact, cancer has psychological and social effects on patients (Goldberg and Cullen, 1985; Pruyn *et al.*, 1986; Penner, 2009). A range of psychosocial consequences experienced by H&N cancer patients can be seen in Table 10.

Physical problems	Psychosocial problems
<ul style="list-style-type: none"> - Swallowing difficulties - Chewing difficulties - Impaired speech - Problems in physical appearance - Loss of sense of smell - Mucous discharge - Problems related to coughing - Problems related to blowing nose - Having colds more frequently - Breathing difficulty 	<ul style="list-style-type: none"> - Anxiety - Depression - Fear of relapse - Feeling embarrassed by physical appearance - Uncertainty about the future - Loss of self-esteem - Sorrow - Isolation from friends - Social and sexual tension within family - Difficulty in re-employment - Financial affairs - Feelings of shame - Feelings of less attractiveness - Feelings of uselessness - Irritability - Suicidal thoughts

Table 10: Physical and psychosocial problems reported to be experienced by head and neck cancer patients (adapted from Pruyn *et al.*, 1986; Penner, 2009)

Patients with advanced stages of H&N cancer may experience intensive changes to physical and fundamental characteristics of life and these changes might have effects on their psychosocial care (Penner, 2009). In the next section, the most common physical and psychosocial problems are explored.

2.5.2.1 Physical appearance

Treatment for H&N cancer (particularly oral cancer) frequently leads to an alteration in the patient's facial appearance because of surgery and/or other treatment modalities or as result of the tumour itself (Rathmell *et al.*, 1991; Gamba *et al.*, 1992). A cross-sectional study (Katz *et al.*, 2003) included a sample of 112 H&N cancer patients (most of them with oral cancer) and found that higher level of depression, measured by Centre for Epidemiologic Studies-Depression Scale (CES-D) (Radloff, 1977), was experienced by patients with greater facial impairments (measured by Observer-Rated Disfigurement Rating Scale (Katz *et al.*, 2000) ($B = 0.25$; $p < .01$). This study also suggested gender differences in the level of depression with women reporting higher levels than men. This difference was statistically significant ($t [80] = -2.308$, $p < .024$).

2.5.2.2 Speech and communication problems

Complex communication impairments may arise in patients with H&N cancer and is dependent upon a range of factors such as surgery (Logemann *et al.*, 1993; Pauloski *et al.*, 1993). In these studies, speech and swallowing performance was assessed pre-operatively and one and three months post-operatively. Speech tasks included an audio recording of a brief conversation and of a standard articulation test (The Fisher Logemann Test of Articulation Competence); swallowing function was examined using videofluoroscopy. The results suggested that patients demonstrated a significant ($P < 0.05$) impairment in speech and swallowing after surgery.

In other studies it has been found that a tracheostomy or post-operative laryngeal or oral swelling can lead to impaired speech (Jianga and Morrison, 2003; Rodriguez *et al.*, 2006). Surgical removal of oral cancer and its subsequent repair may alter the oral anatomy and interfere with the patient's original communication style. Verbal articulation in particular could be impaired or lost in patients who have undergone a laryngectomy (Penner, 2009).

Although it seems that impaired speech or loss of verbal expression is distressing for patients, some researchers suggest that permanent loss of speech is not necessarily

interpreted as a chief disadvantage for the life style of patients and may not be their main determinant of QoL (Ramirez *et al.*, 2003; Semple *et al.*, 2008). This is possibly because of numerous possible methods recently available for voice rehabilitation after laryngectomy (Penner, 2009).

2.5.2.3 Swallowing and chewing

More than half of patients with H&N cancers experience difficulties in eating and drinking after treatment, especially those with advanced stages of cancer (Pauloski *et al.*, 2000, Hanna *et al.*, 2004). For example, one of the side effects of treatment can be sticky viscous saliva, which can lead to difficulty controlling food in the mouth, initiating swallowing, coughing, and frequent bouts of pneumonia (List *et al.*, 2002; Becker *et al.*, 2006). There is also the issue of a limited diet because some foods will be impossible to eat as a direct result of reduced or extremely sticky saliva (Teichgraeber *et al.*, 1986; List *et al.*, 1997; Huguenin *et al.*, 1999).

Swallowing difficulties have multiple impacts on the patient's life and on their families (Penner *et al.*, 2007). For example, difficulties with food and eating is further influenced by alteration in the social, physical and emotional aspects of the normal routines because patients may need longer to eat, choose food that they can eat, and experience impaired physical ability to chew food adequately (McQuestion *et al.*, 2006). Some patients report altered taste sensations or may need a specific texture of diet, which limits the enjoyment that is normally coupled with eating and drinking, both at home and socially (Larsson *et al.*, 2003; McQuestion *et al.*, 2006).

2.5.2.4 Employment

Cancer has an impact on the everyday lives of patients, particularly when they are in employment. Complex treatment modalities for H&N tumours usually interfere with the daily activities of patients, and may result in physical discomfort, changes in appearance, general fatigue, stopping or changing employment, and early retirement (Short *et al.* 2005; Liu 2008). This may then create a significant financial burden because the inability to work may persist for a long time after treatment completion (Taylor *et al.*, 2004).

Indeed, patients treated with chemotherapy are reported to be 3.5 times likely to experience the inability to work and those who have experienced a neck dissection are twice as likely to lose or leave employment (Taylor *et al.*, 2004).

2.5.2.5 Sexual performance

The psychological and physical influences of H&N tumours can critically influence patient's sexual relationships. For example, radiotherapy can contribute to erectile dysfunction and chemotherapy can cause loss of libido for both males and females and vaginal dryness in women (American Cancer Society, 2010; Iliades, 2010; American Cancer Society, 2011). In addition, loss of sexual libido in H&N cancer patients may also contribute to psychological concerns around appearance changes including surgical scars, hair loss, depression and stress (Iliades, 2010).

Approximately 20% of patients who have undergone laryngectomy report serious problems with sexual performance (De Boer *et al.*, 1999a; Gritz *et al.*, 1999). Patients undergoing surgery for hypopharyngeal or laryngeal tumours frequently experience reduced sexual enjoyment and libido (Singer *et al.*, 2008). In spite of the importance and prevalence of reports about this issue, it is rarely investigated in clinical practice and only a few studies appear to have been carried out (Penner, 2009).

2.5.2.6 Psychological distress

Head and neck cancer is commonly cited as the most emotionally traumatic of all tumours (Dropkin, 2001). This may be because facial appearance can alter dramatically, and as previously discussed, pleasure in eating and drinking may be significantly impaired (reference). In addition, treatments for H&N cancer are often prolonged and highly invasive creating a multidimensional impact on patients' lives (List *et al.*, 2002; Elani and Allison, 2011).

Psychological distress experienced by H&N cancer patients may also be related to a number of other factors including low socioeconomic status (with associated lack of resources), and poor social networks with diminished support (Breitbart and Holland,

1988). Psychological distress may also be related to some physical factors resulting from the cancer itself or from the side effects of the treatment or both, as some side effects and complications of treatment are chronic and visible. These may include dry mouth, permanent impairments or scarring and partial loss of some functions such as eating and taste (Bjordal and Kaasa, 1995). In Bjordal and Kaasa's study, 204 H&N cancer patients (mainly laryngeal and oral cancer) completed a questionnaire 7 to 11 years after treatment. The questionnaire consisted of the General Health Questionnaire (GHQ), and the EORTC Core Quality of Life Questionnaire (EORTC QLQ-C30). The authors found significant relationships between psychological distress and physical factors resulting from H&N cancer and its treatment such as dry mouth ($p = 0.002$), problems in taste ($p = 0.004$), swallowing ($p < 0.001$) and mucous production ($p < 0.001$).

Changes in physical appearance, impaired speech and communication, eating and drinking problems as well as employment problems may induce feeling of sadness, vulnerability and fear, with many patients worrying about tumour recurrence (Semple *et al.*, 2008; Penner, 2009). Semple *et al.*, (2008), for example, employed semi-structured interviews with 10 patients who had completed treatment 6–12 months for H&N cancer (oral, pharyngeal and laryngeal). Following the thematic analysis, five themes emerged which covered areas of change and challenges to participant's lifestyles after treatment. These were: physical changes, work and day-to-day tasks, concerns about cancer, social functioning and interpersonal relationships. Physical changes experienced as a result of treatment for H&N cancer included nine subthemes, namely appearance, eating and drinking, saliva, speech, taste, chewing, shoulder movement, sense of smell and drooling. For many interviewees, the diagnosis and treatment of H&N brought about major changes to their normal sphere of work and ability to do day-to-day tasks; however some were still able to maintain normality.

Kissun *et al.* (2006) aimed to evaluate the timing of outpatient review appointments in relation to tumour recurrence by retrospectively reviewing 278 consecutive previously untreated persons with oral and oropharyngeal cancer between 1995 and 1999. Information on the recurrence time, presentation, site, treatment and outcome was

collected and the study suggested that recurrence of these cancers had been experienced by 19% of patients especially within the first two years.

The 5 year survival rate for patients with advanced stages of some types of H&N tumours is still poor and relatively not improved during the last few decades, despite extensive research conducted on treatment modalities for H&N cancer (Jemal *et al.*, 2008; Merseyside Regional Head and Neck Cancer Center, 2014) (see Figure 4 which illustrates H&N cancer survival by stage). Jemal *et al.* (2008), in their study, collected data on 5-year relative survival rates for different cancers in USA from the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute (SEER, 2007) covering the period from 1975 – 2003. They found that trends in 5-Year Relative Survival Rates for Laryngeal cancer during that time had declined from 67% (1975-1977) to 66% (1984-1986) to 64% (1996-2003).

Recent research also suggests that fear of cancer recurrence dramatically influences the psychological morbidity of patients (Humphris *et al.*, 2003, Hodges and Humphris, 2009). Humphris and his colleagues were aimed to evaluate fear of recurrence and psychological morbidity in patients with oro-facial cancer in two samples (87 and 100) of participants using a single question item to assess fear of recurrence as well as Hospital Anxiety and Depression Scale (HADS). The results of their study suggested that there was a significant positive association between fears of recurrence and psychological morbidity at the majority of data collection points (3, 7 and 24 months). In addition, for anxiety and depression at 3 months ($p= 0.008$ and 0.009) respectively. However, only anxiety was significant at 7 months and follow up ($p= 0.006$ and $p= 0.003$ for the two points respectively). More recently, Hodges and Humphris (2009) conducted a study to systematically investigate illness and distress concerns among H&N cancer patient-carer dyads in a sample of 202 participants (101 patients and 101 carers) using two questionnaires (HADS and the Worry Of Cancer (WOC). The results indicated that fear of cancer recurrence was reported in both patients and carer groups. However, significantly higher recurrence concerns were recorded among carers than among patient group ($p < 0.001$).

It has been suggested that people with H&N cancer experience levels of debilitating distress such as depression and anxiety (Archer *et al.*, 2008; Haman, 2008). Depression and anxiety are reported to be more prevalent in patients with H&N tumours than in patients with other types of cancer (Zabora *et al.*, 2001; Massie, 2004) and may have a negative impact on the treatment and rehabilitation of the patient (Zwahlen *et al.*, 2008).

Some types of head and neck cancers are thought to be associated with psychiatric problems (Chaturvedi *et al.*, 1996), such as symptoms of depression which have been reported in 86% of H&N cancer patients (de Leeuw *et al.*, 2001) and the general prevalence rates of depression in these patients are reported to be ranging between 13 and 57% (Massie, 2004; Haisfield-Wolfe *et al.*, 2009). This percentage was estimated in some studies to be 46% of patients (Zabora *et al.*, 2001; Duffy *et al.*, 2002; Duffy *et al.*, 2007). The difference in the results may be attributed to differences in method of assessment or to the cancer type.

Some researchers interpret this high frequency of depression as a response to cancer therapy (Faberow *et al.*, 1971; Davies *et al.*, 1986). Others conclude that the high rates of depression might be linked to lack of social support (Baile *et al.*, 1992). Other factors such as discomfort, pain, and nutritional deficits because of the alteration in diet, may also play a role in the onset of depression (Chaturvedi *et al.*, 1996).

It appears that after six months of diagnosis, anxiety and depression scores tend to improve, although symptoms can still be reported in approximately 80 % of patients up to 3 years later (Karnell *et al.*, 2006). A number of factors were related to continuity of these symptoms in H&N cancer patients including larger cancer mass at diagnosis, smoking, young age, male gender, single, lower level of education and reduced level of physical activity Haisfield -Wolfe *et al.*, (2009).

Several studies dealt with H&N cancer survivors in the early stage of adjustment when the trauma of the surgery, chemotherapy, or radiotherapy, as well as inability to attend the treatment, were the most common features in the findings (Blank *et al.*, 1989). The first three months were the most stressful and were different from the later stages (Weisman and Worden, 1977; DeHaes and Van Kippenberg, 1985). For example, studies on the long-term effects of cancer in patients show that stress decreased in the

few weeks after diagnosis (Manuel *et al.*, 1987) but that mental health declined after longer periods (Ell *et al.*, 1989) and a range of problems occurred (Holland, 1986; Baider *et al.*, 1988).

2.5.2.7 Social distress

Head and neck cancer patients may also encounter alteration in social relationships such as stigma related avoidance from others because of their altered physical appearance, or a reduction in their ability to be able to communicate effectively (Rogers *et al.*, 1999; Terrell *et al.*, 1999). These changes may in turn, influence their capacity to cope with the unpleasant side effects of cancer (List *et al.*, 2002).

Compared to other cancers, it could be argued that patients with H&N cancers justify special consideration, since these cancers are located in a prominent visible region of the body, and for many cultures the face is one of the sites of identity, and acts as the conduit for communication with others through facial expressions as well as audible speech (Dropkin, 2001).

The proximity of vital structures such as tongue, salivary glands, tonsils, teeth, and throat in this relatively small area, means that the necessity of surgery as treatment of choice of advanced stages may be radical, such as mandibulectomy which is resection of any portion of the mandible (Shah, 1992; Dubner and Heller, 1993; Shah and Lydiatt, 1995). The more radical the approach implies a possible increase in the negative social and personal experiences of H&N cancer (Chaturvedi *et al.*, 1996; Van Cann *et al.*, 2005). Overall QoL (see Sub-section 2.5.3 below) can be reduced due to these negative occurrences resulting in withdrawal from social interaction, and coupled with loss of verbal communication for some individuals, may impact greatly on personal and social relationships (Chaturvedi *et al.*, 1996; Van Cann *et al.*, 2005). These experiences, alongside the potential for permanent speech and facial impairments means that people with H&N cancers may have numerous unique psychosocial impacts in social situations (Dropkin, 2001).

2.5.3 Effect of head and neck cancer on quality of life (QoL)

QoL is a vague and difficult concept to define and measure. Nevertheless, it is becoming widely used within the cancer field as a key patient-reported outcome. It is outside the scope of this PhD to review the quality of life literature. Rather, the PhD will use the definition of QoL from a recent systematic review of H&N cancer quality of life assessment instruments which was “*a multi-dimensional construct of an individual’s subjective assessment of the impact of an illness or treatment on his or her physical, psychological, social, and somatic functioning and general well-being*” (Ojo *et al.*, 2012. P: 923).

Head and neck cancers may have a negative influence on QoL (Morton and Izzard, 2003). This group of cancers usually originate from the oral cavity, pharynx and larynx, which are all anatomically complex and functionally critical areas for vital activities such as swallowing and speech and may also affect facial integrity and appearance (Murphy *et al.*, 2004). Patients with H&N cancers may also be more susceptible to psychosocial crisis as a result of the impact on emotions and social interaction, which in turn have a negative impact on the patient's QoL (Kazi *et al.* 2007).

Concerns about the immediate and late consequences of H&N cancer and its different treatment modalities have provided a driver for the increase in studies assessing QoL in patients treated for H&N cancer (Moore *et al.*, 2014). However, many studies in the area have been limited by their method; for example, they are often cross-sectional and retrospective or used small sample sizes (Sayed *et al.*, 2009). This has been further complicated by the absence of a consensus on a fixed definition for QoL and the use of inconsistent measures to evaluate such outcomes in patients with H&N cancer (Farguhar, 1995; Murphy *et al.*, 2007). For example, a plethora of health-related quality of life (HRQoL) instruments have been used to measure HRQoL in patients with H&N cancer. Murphy *et al.*, (2007) have categorised these instruments under four main classes: symptom specific, disease specific, treatment specific and generic. However, it appears that there is little consensus as to which instrument is the most reliable.

Regardless of which measure has been used, generally, QoL of patients treated for H&N cancer appears to decrease after treatment, and then it improves gradually over time to

reach baseline levels. For example, a cross-sectional study conducted by Hammerlid *et al.*, (2001) investigated HRQL of patients with H&N cancer from diagnosis until three years post-diagnosis, using a sample of 232 patients to complete a set of questionnaires including:

- The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30) (Aaronson *et al.*, 1993).
- The EORTC QLQ-Head and Neck Cancer module (QLQ-H&N35) (Bjordal *et al.*, 1994)
- The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).

The findings of this study suggested that the greatest change in HRQoL for patients with H&N cancer were observed within one year after diagnosis, with a major decrease just after treatment stopped. After that, QoL and anxiety and depression return to pre-treatment levels.

A recent study (Moore *et al.*, 2014) aimed to systematically review the literature describing quality of life (QoL) outcomes and support needs in patients with oral cancer along the cancer trajectory. The following electronic databases were searched; Cochrane, PubMed, Embase, Scopus, CINAHL, PsycINFO and Web of Science and articles were included if they described patient-reported QoL outcomes that were translatable to support needs in patients with oral cancer. Data were extracted and synthesized according to the identified support needs and their relative influence on QoL. Methodological quality was evaluated using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool. This review included studies that described patient-reported QoL outcomes that were translatable to support needs in patients with oral cancer as well as studies reporting QoL findings from heterogeneous H&N cancer samples that include oral cancer. Thirty-one studies met the inclusion criteria, most of them were of cross-sectional design (n = 21), followed by smaller number of longitudinal or prospective designs (n = 7). Two studies were designed as case-control, and one study used a retrospective chart review methodology. In this review, anxiety, depression and malnutrition were recognised as having a significant influence on QoL. However, most of the included studies were cross sectional in design and no RCT included. Furthermore, the systematic review included no detail or information on the statistics, for example, odds ratios or significance levels.

2.5.3.1 Demographic and clinical factors which influence quality of life in people with H&N cancer

Murphy *et al.*, (2007) suggested several possible demographic and clinical factors influencing QoL outcomes in patients with H&N cancer as can be seen in Table 11.

Patient features	Tumour related features	Treatment related features
Age	Stage	Extent of surgery use
Gender	Site	Adjuvant chemotherapy
Race		Radiation therapy
		Neck dissection

Table 11: Possible predictive factors for quality of life outcomes in patients with head and neck cancer (adapted from Murphy *et al.*, 2007)

In addition to those factors above, Terrell *et al.* (1997 and 2004) indicated that introducing feeding tubes and presence of co-morbid disease are also major predictors of QoL outcomes. They implied that patients with these tubes might have incomplete nutrients, which may result in weakness, and some symptoms such as leakage, nausea, and vomiting are frequently associated with tube feeding which in turn impacts on QoL.

It seems that variability in these demographic and clinical factors might influence QoL differently. However, the mechanism through which H&N cancer and its treatment exerts an impact on the QoL of the patients can be seen from the influence of the cancer on some functional and psychological aspects as can be seen below.

2.5.3.2 Effect of functional issue and symptoms control on quality of life

There is a limited amount of current data on assessing patient's priorities, experiences, and perceptions, although researchers and clinicians set a great significance on functional outcomes for patients with H&N cancer (Murphy *et al.*, 2007). Some studies suggested that eating and speech are independently linked to QoL and that psychosocial outcomes may have greater importance for the patient than clinical

outcomes (Karnell *et al.*, 2000, Rogers *et al.*, 2002). In addition, some factors such as symptom intensity, time course and intrinsic patient related factors influence the relationship between functional issues/ symptom control and QoL (Murphy *et al.*, 2007) (See below for examples).

2.5.3.2.1 Dysphagia

Patients with advanced stages of H&N cancer may experience continuous swallowing difficulties and social disturbances despite the type of treatment received (El-Deiry *et al.*, 2005). Although the impact of swallowing difficulty on QoL is uncertain and usually based at the point in the disease course on which the evaluation was performed (Murphy *et al.*, 2007), patients with moderate to severe swallowing difficulty may experience or report a dramatically lower QoL than those with mild or reduced difficulty (Nguyen *et al.*, 2005).

Campbell *et al.* (2004) evaluated the relationship between QoL and swallow function/weight change in 62 patients who had been originally treated for H&N cancer at least 5 years prior to entry to the study. Different types of measures were used; three objective measures such as weight history, and four subjective measures, for example the University of Washington QOL questionnaire “UWQOL”. The outcomes of this study suggest that there is a strong relationship between aspiration and questions related directly to swallowing in most of the subjective measures.

2.5.3.2.2 Speech and communication

The relationship between speech and QoL has been explored in several studies (Meyer *et al.*, 2004; Low *et al.*, 2009; Flapper *et al.*, 2011). Some studies (Meyer *et al.*, 2004) suggest a strong correlation between word and sentence intelligibility and QoL (questions of speech from University of Washington Quality of Life Questionnaire (UW-QOL) (Hassan and Weymuller, 1993; Weymuller *et al.*, 2001; Rogers *et al.*, 2002) and Performance Status Scale for H&N cancer patients (PSS-HN) (List *et al.*, 1996). Such that lower word intelligibility and sentence intelligibility scores were related to reduced self-perceived Speech (on UWQOL) and understandability of Speech (on PSS-HN).

However, this correlation did not exist in patients who had undergone a laryngectomy, which might be attributed to an alteration in the expectation of a greater functional decline for this group of patients. The authors could not find any association between speech intelligibility and QoL when measured by the Functional Assessment of Cancer Therapy scale (General cancer “FACT-G” or H&N cancer “FACT-HN”) (Cella *et al.*, 1993; Cella *et al.*, 1994), which may indicate a difference in the methods of assessment of QoL (Smith *et al.*, 2006; Ferrans, 2007).

2.5.3.2.3 Other oral symptoms

Oral symptoms such as dry mouth, which has a huge impact on eating and speaking (Silverman, 1993; List *et al.*, 1997; de Graeff *et al.*, 1999a; de Graeff *et al.*, 1999b; Epstein *et al.*, 1999), taste change, mucosal sensitivity and dental decay that result from treatment of H&N cancer may influence the general QoL of patients (Epstein *et al.*, 1999; Epstein *et al.*, 2001; Duke *et al.*, 2005).

2.5.3.2.4 Neck and shoulder dysfunction

Neck dissection for patients with H&N cancer often leads to several late effects such as reduced range of neck and shoulder movements as well as neck and shoulder pain (Murphy *et al.*, 2007; Dedivitis *et al.*, 2011).

For example, in a prospective study conducted by Laverick *et al.* (2004) to evaluate the impact of selective surgery on neck function and QoL, 278 patients were treated surgically for cancers of oral cavity or oropharynx. Patients completed the UWQOL four times with six months duration between each assessment. Outcomes of the study suggested that patients who underwent extensive neck dissection had a significant decrease in QoL when compared to those who did not have "or had limited" neck dissection. Similar results have been observed in other studies (Kuntz and Weymuller, 1999; Shah *et al.*, 2001).

2.5.3.2.5 Psychological effects

Psychological effects such as anxiety, depression, avoidance and social phobia have been recognised as important psychological problems in some groups of patients with H&N cancer (de Leeuw *et al.*, 2001; Massie, 2004; Archer *et al.*, 2008; Haman, 2008; Haisfield -Wolfe *et al.*, 2009).

Recent research suggests that fear of recurrence reduces QoL in patients (Humphris *et al.*, 2003; Mellon *et al.*, 2006; Hodges and Humphris, 2009). Although the majority of the research reports symptoms of depression as measured by standard psychiatric tests and depression symptoms might be brought about by the tumour or its associated treatment (Murphy *et al.*, 2007), some studies suggest that depression and anxiety have an adverse effect on QoL (Kohda *et al.*, 2005; Zwahlen *et al.*, 2008).

Patients may have several concerns about their cancer and ensuing treatments, leading them to experience a reduction in QoL. These concerns range from the routine daily functional activities such as communication, chewing and eating, to more subjective concerns such as dependence and self-esteem (Chaturvedi *et al.*, 1996). The commonest concerns recorded amongst patients with H&N cancers were worries about the future, finances, subjective evaluations of their physical appearance, being upset, and ability to communicate (Vidhubala *et al.*, 2006).

Whilst it is clear that H&N cancer and its treatments can have a significant impact on QoL for the patient in different ways, some researchers suggest that patients with H&N cancer do not necessarily experience depression and reduced QoL, which raises questions as to the consistency and reliability of the measurements and indicates the possibility of other factors being important (Garzaro *et al.*, 2007).

A numbers of studies have investigated the psychological distress of H&N cancer; these studies have been reviewed by a number of researchers (Frampton, 2001; Luckett *et al.*, 2011; Lang *et al.*, 2013; Semple *et al.*, 2013).

Frampton (2001), for example, suggested that there is an increased incidence of psychological distress in patients with H&N cancer as a result of the cancer itself or its

treatment. This review suggests a list of factors to be related to psychological distress in patients with H&N cancer including; social stresses, premorbid factors, pain, change to body image, treatment, prognosis, addiction to tobacco and alcohol, and history of psychiatric disease. In addition to this list, the review implicates a number of co-existing factors, for example, a high frequency of depression (40%) reported in people with H&N cancer was not necessarily the result of the cancer or its treatment but might have been related to other factors such as nutritional insufficiencies and lack of social support.

The above review also reveals that psychological distress is usually underdiagnosed and undertreated probably because patients do not disclose openly to their doctors particularly the emotional symptoms of distress. In general, the review recommended that in order to diminish the impact of H&N cancer, and improve QoL, psychological support for patients and their caregivers is essential from diagnosis and throughout treatment.

Three recent systematic reviews have been conducted on the psychological distress of H&N cancer patients; one reviewed the experience of people with H&N cancer (Lang *et al.*, 2013) and two investigated the effectiveness of psychosocial interventions for this group of people (Lockett *et al.*, 2011; Semple *et al.*, 2013) (see Table 12 for details).

Lang *et al.* (2013) suggests that individuals with H&N cancer experience excessive disruption to their ordinary daily activities, because of the emotional and physical effects of H&N cancer and its treatment. The review indicates that daily challenges were linked to existential and social changes and a physical loss of the person's sense of self and perception of the future which is influenced by their views of life having changed by the experience of cancer.

Although Lockett *et al.* (2011) in their systematic review suggest that it may be possible to recruit individuals with H&N cancer to psychological interventions and to use repeated-outcome measures to assess their progress. However, evidence for interventions is restricted due to the small number of studies (9), poor comparability and methodological problems. Two studies were designed as RCT whereas the

remaining used pre and post measures with or without controls. Samples included in these studies were patients with various H&N cancer diagnoses and the interventions used were; education/psycho-education, stress management training, cognitive-behavioural therapy, behavioural therapy, communication skills training, supportive-expressive group therapy, cognitive therapy, support group, family therapy/counselling, problem-solving therapy. Intervention delivery has been carried out by a nurse (67%), psychologist/therapist (22%) and multi-disciplinary team (22%).

In contrast, another systematic review (Semple *et al.*, 2013) failed to find any evidence that psychosocial interventions enhance QoL for people with H&N cancer. There was also no significant change in levels of depression and anxiety after the intervention. This review had a small number of studies (7 studies) but all of them were RCTs. Samples included in these studies were patients with any type or stage of H&N cancer and psychosocial interventions (individual or group interventions) included were; cognitive behavioural training, psycho-educational, psychotherapy and supportive interventions. These interventions were delivered by lay or trained personnel.

Author /date	Aim	Study design	Sample	Country	Method	Result
Luckett <i>et al.</i> (2011)	To review the evidence of psychological interventions for individuals with H&N cancer	Systematic review	9 studies	Sydney/ Australia	<ul style="list-style-type: none"> - Searching CENTRAL, Medline, PsycINFO, Embase and CINAHL - From conception until December 2009 	<ul style="list-style-type: none"> - The studies that been included in the review suggested that is possible to recruit individuals with H&N cancer to psychological interventions and to assess their conditions through repeated- measures of the outcome.
Lang <i>et al.</i> (2013)	To review patients' experiences of H&N cancer by examining the results of the available qualitative studies	Systematic review	29 studies	Dundee / UK	<ul style="list-style-type: none"> - Searching CINAHL, MEDLINE, Embase, ASSIA, Citation Index, Social Science, PsycINFO and the British Nursing Index and Archive (BNI) - From conception until September 2011. - Included qualitative studies only 	<ul style="list-style-type: none"> - Six themes emerged — disruption to daily life, uncertainty and waiting, making sense of the experience, the diminished self, finding a path and sharing the burden.
Semple <i>et al.</i> (2013)	To explore the value of psychosocial interventions to improve QoL for people with H&N cancer.	Systematic review	7 studies	Belfast/ UK.	<ul style="list-style-type: none"> - Searching the Cochrane; the Cochrane Central Register of Controlled Trials (CENTRAL); EMBASE; PubMed; CINAHL; Cambridge Scientific Abstracts; Web of Science; BIOSIS Previews; ICTRP and other sources for published and unpublished trials. - From conception to 17 December 2012. - Included randomised controlled trials and quasi-randomised controlled trials of psychosocial interventions for adults with H&N cancer. 	<ul style="list-style-type: none"> - No evidence to advocate that psychosocial intervention encourages QoL for people with H&N cancer after an intervention - The five functional scales of the (EORTC QLQ-C30) which are physical, cognitive, social, role and emotional, did not show evidence that psychosocial intervention offers a medium-term or immediate improvement on any of these five functional scales - no significant change in levels of depression or anxiety after intervention

Table 12: Systematic reviews about psychological distress in H&N cancer

Given the increased attention paid to quality of life (QoL) outcomes among patients with H&N cancer (Gotay and Moore, 1992; Elani and Allison, 2011), it is not surprising that there has also been research into the factors which may mitigate or aggravate the impact of the disease on patient's psychological wellbeing (McDonough *et al.*, 1996). Coping is one of these mediating variables that have been found to have a critical influence on a range of health outcomes (Sherman *et al.*, 2000).

People who live with H&N cancer and experience the different consequences of this cancer and its treatment tend to use varying coping strategies (Rogers *et al.*, 1999; Vidhubala *et al.*, 2006; Elani *et al.*, 2009). Social support is widely considered to be the most significant factor implicated in coping and some studies have suggested that social support seeking behaviours represent the highest component (25%) of the whole coping effort for people with H&N cancer (List *et al.*, 2002).

In more recent years, the literature suggests that using online support groups (OSGs) may be associated with a variety of positive psychosocial outcomes including better health, a reduced feeling of social isolation, better management of the disease and better use of active coping strategies (Fogel *et al.*, 2002; Kalichman *et al.*, 2005). The next chapter will overview in more detail the role of coping, social support and OSGs in H&N cancer.

Chapter III: Coping, Social Support and Online Support Groups

3 Coping, social support and online support groups

3.1 Coping with head and neck cancer

Since H&N cancer is commonly cited as the most emotionally traumatic of all tumours (Dropkin, 2001) and a relatively high percentage of patients report a range of physical and psychosocial consequences, this raises challenges in investigating QoL outcomes among patients with this cancer and factors which influence QoL. One factor which has been shown to have a critical influence on health outcomes generally is coping (Sherman *et al.*, 2000).

One well known theoretical framework for coping is that by Lazarus and Folkman (1984) who define coping as "*constantly changing cognitive and behavioural efforts to manage specific external and/ or internal demands that are appraised as taxing or exceeding the resources of the person*" (Lazarus and Folkman, 1984, p.141).

According to Lazarus and Folkman (1984), coping comprises of two principal strategies; one is problem-focused coping strategies, which are based on altering or managing the problem or the situation causing distress. These are comprised of social skills and problem-solving. The other is emotion-focused coping strategies that are based on regulating the physical and emotional responses to stress (Lazarus and Folkman, 1984). Since their original work, more than 500 coping strategies have been identified and the taxonomy of these schemes has become more complex. Yet, common differentiations exist such as emotion-focused versus problem-focused; behavioural versus cognitive and engagement versus disengagement. More recently, Weiten and Lloyd (2008) have supplied a useful review of three broad categories of coping strategies; problem-focused (adaptive behavioural), emotion-focused and appraisal-focused (adaptive cognitive).

Problem-focused strategies occur when individuals try to adjust to the cause of their crisis, for example by learning new skills or looking for information to cope with the problem. In general, these types of coping strategies are aimed at eliminating or changing the source of the stress.

Emotion-focused strategies include the release of pent-up emotions, managing hostile feelings, distracting oneself and meditating or employing regular relaxation procedures. Generally, this type of coping is directed toward administrating the emotions associated with the perception of stress (Brannon and Feist, 2009).

Appraisal-focused strategies happen when people modify the way they think about the problem; for example, utilizing distancing or denial oneself from the issue. Some individuals may modify their way of thinking about an issue by altering their values and goals, such as the use of humour, which has been believed to have a role in moderating stress (Worell, 2001).

In general, people appear to use a mixture of all types of coping schemes, and their coping skills usually modify with time. Although all coping techniques can be useful, some researchers claim that people using problem-focused strategies will adjust better and may lead people to have greater perceived control over their crisis, whilst emotion-focused coping may occasionally lead to a decrease in perceived control; often termed maladaptive coping (Taylor, 2006). This suggestion was supported by other studies which indicated that problem-focused coping leads to better adjustment and subsequently better QoL for cancer patients (Chaturvedi *et al.*, 1996), whilst, emotion-focused coping appears to be related to higher depression and anxiety levels and poorer QoL (Lazarus and Folkman, 1984; Burgess *et al.*, 1988; Friedman, 1988; Classen *et al.*, 1996). Although problem-focused strategies deal with the root source of the problem and may provide a longer term solution, they are not always the best as they work effectively only when the individual can control the cause of stress. It is not a productive method for all persons. For example, individuals with low self-esteem usually use emotion-focused strategies (Lazarus and Folkman, 1984; Lazarus, 1991).

The ability to utilise successful coping strategies may affect emotional wellbeing (e.g. anxiety and depression) and adjustment (Endler and Parker, 1990). For example, using a specific coping strategy has been found to frequently link with a decrease in perceived stress and enhancement in psychological adjustment (Petrosky and Birkimer, 1991; Dunkel-Schetter *et al.*, 1992). On the other hand, behaviours such as heavy smoking and alcohol consumption, which are the most important risk factors for

H&N cancer, have been associated with maladaptive coping strategies and failure to adjust habitual behaviours (Dropkin, 1989).

A great deal of attention has been paid to coping with cancer and better adjustment to the disease has been observed in patients who use problem-focusing strategies or who reach a level of acceptance in relation to their disease (McGoldrick, 2001). Coping has been investigated among patients with different cancers especially breast cancer (Stanton *et al.*, 2000; Petticrew *et al.*, 2002) and has been found to be significantly related to HRQoL (Ell *et al.*, 1989; Carey *et al.*, 1993), distress (Carver *et al.*, 1993; Stanton and Snider, 1993; Stanton *et al.*, 2000) and sometimes immune activity (Lutgendorf *et al.*, 1999) and survival (Greer *et al.*, 1990; Molassiotis *et al.*, 1997; Petticrew *et al.*, 2002). Coping has been suggested to be a stronger predictor of QoL outcomes than medical factors such as degree of disease or treatment type (Stanton and Snider, 1993; Manne *et al.*, 1994; Sherman *et al.*, 2000).

It has been indicated that patients with breast cancer use various coping strategies to adjust to their illness (Stanton *et al.*, 2000). For example, women with breast cancer using emotional expression; such as talking about their negative emotions to a significant other were found to exhibit lower degrees of psychological distress (Stanton *et al.*, 2000). However, the quality of the relationship with the significant other may also play an important part in the reduction of psychological distress. Reviewing the literature showed that people with H&N cancer also use several coping strategies to adjust to their disease. Table 13 shows the results of research conducted to investigate how people with H&N cancer deal with symptoms and invasive treatments or how coping influences adjustment.

Author/ date	Aim	Study design	Sample	Country	Method	Result
Demadda lena, and Zenner (1991)	To understand the conditions that cause anxiety, coping with anxiety, reaction to anxiety, and anxiety-reinforcing conditions in H&N cancer patient	Cross - sectional	50 patients	Germany	- The COPE Inventory (<i>Carver et al., 1993; Carver et al., 1989</i>). - HADS (<i>Zigmond and Snaith, 1983</i>)	- Higher levels of anxiety was related positively to the coping strategies "giving up" and "intake of nicotine, alcohol and medication, "
Chaturve di etal (1996)	To investigate the coping mechanisms and concerns of patients with H&N cancer and assess their QoL	Cross - sectional	50 patients	Bangalore/ India	- Interviewed using a coping and concerns checklist and a semi structured interview - HADS (<i>Zigmond and Snaith, 1983</i>)	- Concerns about the future were the most common concerns (64%), followed by subjective physical evaluation (60%), finances (56%), being upset (54%), communication (54%), current illness (52%) and inability to do things (50%). - Helplessness and fatalism were the most commonly used coping strategies.
de Leeuw <i>et al.</i> (2000)	To assess whether pre-treatment factors can be used to predict depression at 6 and 12 months later in patients with H&N cancer	Cross - sectional	155 patients	Utrecht/ The Netherlands	- Social Support List Interactions (<i>Van Sonderen, 1991</i>) - The Inventory of Socially Supportive Behaviours (<i>Barrera et al., 1981</i>) - The Social Provisions Scale (<i>Cutrona and Russel, 1987</i>) - The Utrecht Coping List (<i>Komproe and Rijken, 1995</i>) - The Cancer Locus of Control Scale (<i>Pruyn et al., 1988; Watson et al., 1990</i>)	- The result suggested that it predicting patients who would have symptoms at 6 (81%) and 12 months (67%) after treatment may be possible using 5 factors (emotional support, physical symptoms, extent of the social network, avoidance coping and depressive symptoms) - Example: more depressive symptoms at follow-up were related to more avoidance coping before treatment.

					<ul style="list-style-type: none"> - Center for Epidemiologic Studies—Depression scale (<i>Eaton et al., 2004</i>). - European Organization for Research and Treatment of Cancer QoL Core Questionnaire C30+3 (<i>Aaronson et al., 1993</i>) 	
Sherman <i>et al.</i> (2000)	To explore coping patterns among H&N cancer patients at different stages of disease	Cross-sectional	120 patients	Arkansas/ USA	<ul style="list-style-type: none"> - The COPE questionnaire (<i>Carver et al., 1993 ; Carver et al., 1989</i>) - Profile of Mood States (<i>McNair et al., 1992</i>) - Impact of Events Scale (<i>Horowitz et al., 1979</i>) 	<ul style="list-style-type: none"> - Use of specific coping responses differed among the groups. - Behavioural disengagement (giving up or withdrawing), Denial, suppression of competing activities and emotional ventilation were most characteristic of patients who were treated for H&N cancer
List <i>et al.</i> (2002)	To identify how patients cope with the debilitating and exhaustive treatment and the functional and physical residual effects of H&N cancer	Cross-sectional	79 patients	Chicago/ USA	<ul style="list-style-type: none"> - The Functional Assessment of Cancer Therapy-H&N (<i>Cella et al., 1993 and 1994</i>) - The Performance Status Scale for H&N Cancer Patients (<i>List et al., 1996</i>) - The Ways of Coping-Cancer Version (<i>Dunkel-Schetter et al., 1992</i>) 	<ul style="list-style-type: none"> - There are many of coping strategies used by people with H&N cancer. - Social support seeking behaviours representing the highest percentage of total coping (25%). - The use of both behavioural and escape avoidant coping strategies was related to worse QOL.
Aarstad <i>et al.</i> (2005)	To study self-reported coping style and the association to received treatment, TNM stage, and HRQoL in a people with successfully	Cross-sectional	122 survivors	Bergen/ Norway	<ul style="list-style-type: none"> - The European organization for research and treatment of cancer QoL questionnaire (<i>Aaronson et al., 1993</i>) - The COPE questionnaire (<i>Carver et al., 1993 ; Carver et al., 1989</i>) 	<ul style="list-style-type: none"> - In survivors of H&N cancer, degree of problem focused coping strategy was linked to neck radiotherapy and the T stage. - Score of avoidance coping was negatively linked to HRQoL. - Score of emotional coping was

	treated H&N cancer					linked to HRQoL in a complex manner
Kohda <i>et al.</i> (2005)	To identify factors affecting the QoL in people undergoing radiation therapy for H&N cancer	Cross-sectional	35 patients	Tokyo/ Japan	<ul style="list-style-type: none"> - Full psychiatric interviews - Functional Assessment of Cancer Therapy [General and H&N] (FACT-G and H&N) (<i>Cella et al., 1993, 1994</i>) - The Hospital Anxiety and Depression Scale (HADS) (<i>Zigmond and Snaith, 1983</i>) - the NEO-Five Factor Inventory (NEO-FFI) 	<ul style="list-style-type: none"> - QOL was related to an emotional part of a coping - Interventions including physical management of pain and psychiatric management of depression appear to be essential for preserving QOL of people with H&N cancer
Vidhubal a, <i>et al.</i> (2006)	To evaluate the coping preferences of patients with H&N cancer.	Cross-sectional	176 patients	Chennai/ India	<ul style="list-style-type: none"> - Jalowiec coping preference scale (<i>Jalowiec et al., 1981</i>) - The variables chosen were treatment, site, education, survival, age and gender 	<ul style="list-style-type: none"> - Patients with H&N adapt both problem oriented (POC) and emotional oriented coping (EOC) throughout the course of the decrease - Males, literate patients, and patients subjected to different types of treatment preferred more POC of compared to others.
Becker <i>et al.</i> (2006)	To investigate the role of religion in coping with disease symptoms and treatment-related side effects in people with H&N cancer who are currently under radiotherapy.	Cross-sectional	105 patients	Freiburg/ Germany.	<ul style="list-style-type: none"> - EORTC QLQ-H&N35 (<i>Bjordal et al., 1994</i>) 	<ul style="list-style-type: none"> - Believers felt better for all types of side effects before, during and after therapy. - Religious faith appeared to play an significant role in coping style of patients treated with radiotherapy
Aarstad <i>et al.</i> (2008)	To explore to what extent choice of coping and personality predicted	Cross-sectional	96 patients	Bergen/ Norway	<ul style="list-style-type: none"> - The European Organization for Research and Treatment of Cancer Quality of life Questionnaire (EORTC-QLQ) 	<ul style="list-style-type: none"> - Low QoL was directly predicted by coping by problem solving, coping by humor and high neuroticism. While neuroticism

	self-reported QoL in successfully treated H&N cancer patients				<ul style="list-style-type: none"> - C30/HN35 (Aronson <i>et al.</i>, 1993) - The Eysenck Personality Inventory (Eysenck and Eysenck, 1964) - The COPE questionnaire (Carver <i>et al.</i>, 1993 ; Carver <i>et al.</i>, 1989) 	was also related to QoL through avoidance coping.
Elani <i>et al.</i> (2009)	To explore the relationship between levels of depression and anxiety and different coping strategies in patients with H&N cancer	Cross-sectional	157 patients	Montreal/ Canada	<ul style="list-style-type: none"> - HADS (Zigmond and Snaith, 1983) - The Ways of Coping Checklist (WOCC) (Folkman and Lazarus, 1980). 	<ul style="list-style-type: none"> - 71.3% of the participants had a low levels of and depression anxiety - 7% had a high levels of depression and anxiety - The most frequently used coping by the whole participants was Problem focused coping” - head and neck cancer - patients use a variety of coping strategies to deal with their disease and that their level of anxiety and depression is related to the type of coping strategies they use
Agarwal <i>et al.</i> (2010)	To assess the common coping strategies used by African American H&N cancer survivors and to examine them in relation with QoL	Cross-sectional	50 patients	North Carolina/ USA	<ul style="list-style-type: none"> - Coping questionnaire - QoL Questionnaire 	<ul style="list-style-type: none"> - The most commonly used coping styles were seeking support from God, helping others and seeking emotional support from family and friends, - These coping styles had strongest relationship with QoL and relationship well-being.
Horney <i>et al.</i> (2011)	To explore whether depression and anxiety are related to	Cross-sectional	103 patients	Sussex/ UK	<ul style="list-style-type: none"> - HADS (Zigmond and Snaith, 1983) - SF12v2 Health Survey (Ware <i>et al.</i>, 2002) 	<ul style="list-style-type: none"> - QoL explained a great percentage of the variance in pre-treatment depression and anxiety.

	dispositional optimism, coping styles and QoL in H&N cancer patients				<ul style="list-style-type: none"> - Brief COPE (<i>Carver, 1997</i>) - The Revised Life Orientation Test (<i>Scheier and Carver, 1987</i>) 	<ul style="list-style-type: none"> - Using negative coping strategies was associated with high levels of anxiety - Low levels of optimism were associated with higher levels of depression.
Elani and Allison (2011)	To investigate how patients with H&N cancer 6-12 months after diagnosis cope with their illness and how their coping strategies are related to their levels of depression and anxiety	Cross-sectional	157 patients	Montreal/Canada	<ul style="list-style-type: none"> - Ways of Coping Checklist (<i>Folkman and Lazarus, 1980</i>) - HADS (<i>Zigmond and Snaith, 1983</i>) 	<ul style="list-style-type: none"> - There was a relationship between anxiety and depression levels and the type of the used coping method - People with higher levels of depression and anxiety used more "wishful thinking", "blamed self", and "avoidance" coping methods
Haisfield-Wolfe <i>et al.</i> (2012)	To explain coping among people with oropharyngeal and laryngeal cancer during definitive radiation with or without chemotherapy.	Cross-sectional (qualitative)	21 patients		<ul style="list-style-type: none"> - Interviews with open-ended questions 	<ul style="list-style-type: none"> - Patients cope to deal with the uncertainties of psychological and physical aspects of their issues - Patients commonly used family and friends support as a common coping strategy
Aarstad <i>et al.</i> (2012)	To explore to what extent personality, choice of coping, TNM stage, mood, treatment level and HRQoL scores predicted distress as measured by general health questionnaire in patients with H&N	Cross-sectional	96 patients	Bergen/Norway	<ul style="list-style-type: none"> - The Eysenck personality inventory (<i>Eysenck and Eysenck, 1964</i>) - The COPE questionnaire (<i>Carver et al., 1993 ; Carver et al., 1989</i>) - EORTC QLQ questionnaire (<i>Aaronson et al., 1993</i>) - Beck depression inventory (BDI) (<i>Beck, 1972</i>) 	<ul style="list-style-type: none"> - Low mood, low QoL, high neuroticism, high alcohol consumption, coping by problem solving directly, and by avoidance, predicted worse distress.

	cancer who are successfully treated					
Beisland <i>et al.</i> (2013)	To explore distress stability and HRQoL as related to choice of coping response and neuroticism in patients with H&N cancer during a 4 years period follow-up	Cross-sectional	162 patients	Bergen/Norway.	<ul style="list-style-type: none"> - The general health questionnaire (GHQ) (<i>Goldberg and Williams, 1988</i>) - The EORTC QLQ-C30 (<i>Aaronson et al., 1993</i>) - The Eysenck Personality Questionnaire (EPQ) (<i>Eysenck and Eysenck, 1964</i>) - The COPE Inventory (<i>Carver et al., 1993 ; Carver et al., 1989</i>) 	<ul style="list-style-type: none"> - Neuroticism, smoking history, T stage and avoidant coping pattern, these factors predicted the scores, HRQoL, and distress

Table 13: Studies on coping and H&N cancer

Sherman *et al.* (2000) suggest that patients who were treated for H&N cancer or were less than 6 months post-treatment used more inhibition of competing actions, rejections and behavioural disengagement as coping methods compared with those who were more than 6 months post-treatment or had not commenced their treatment yet. This study led Sherman and colleagues to argue that whilst Lazarus and Folkman (1984) interpret coping as a dynamic process that undergoes alteration over the course of disease, the stages of disease may be vital in shaping patients' reactions to invasive diseases, and patients use various coping strategies according to stage of treatment (Sherman *et al.*, 2000).

In relation to QoL, a cohort study by Kohda *et al.* (2005) investigating the QoL of H&N cancer patients who were only treated by radiotherapy, identified a positive relationship between emotion-oriented coping and patients' general HRQoL. However, the study sample was relatively small (only 35 patients) and used different cancer sites and stages which may have different influences on the outcomes of the study.

One suggestion is that teaching coping strategies for patients with H&N cancers may lead to an improvement in social and physical functioning and overall QoL, and decrease in sleeping disturbances, fatigue and depression, leading to more positive outcomes for the patient (Friedman, 1988).

Head and neck cancer patients were found to use a series of coping strategies during their cancer journey. These strategies can be categorised as emotion or problem-focused coping (Rogers *et al.*, 1999; Vidhubala *et al.*, 2006). Although some studies suggest that generally problem focused coping was the most frequently used strategy by the H&N cancer patients (Elani *et al.*, 2009), other studies identify specific coping strategies to be the most commonly used by this cohort of patients. For example, whilst Chaturvedi *et al.* (1996) found that helplessness and fatalism were the commonest coping mechanisms used by H&N cancer patients and thought that these unsuccessful emotion-focused coping strategies result in deficient resolution of the most common concerns recognised in this cohort of patients, Sherman *et al.* (2000) suggest that denial, focusing on the illness, emotional ventilation, and behavioural disengagement such as giving up or withdrawing were most characteristic of these

patients. More recently, Agarwal *et al.* (2010) suggest that helping others, seeking emotional support from friends and family, and coping through support from God were the most commonly used strategies. However, these studies used different methodologies and different participant samples which may explain the difference in results.

Some researchers tried to explore the relationship between different coping strategies and levels of depression and anxiety in H&N cancer patients; indicating that the type of coping strategy used is related to the level of anxiety and depression experienced by the person with cancer (Elani *et al.*, 2009; Elani and Allison, 2011). However, the nature of these studies (cross-sectional) does not allow directional inferences for this relationship. Indeed, negative coping strategies such as "giving up" and "intake of alcohol, nicotine and medication" were positively related to higher levels of anxiety (Demaddalena, and Zenner, 1991; Horney *et al.*, 2011). In addition, "avoidance", "blamed self" and "wishful thinking", coping strategies were noticed to be used by patients with higher levels of anxiety and depression (Elani and Allison, 2011; Beisland *et al.*, 2013). Avoidance coping seems to exert longer term influence, since more avoidance coping before treatment was found to be associated with more depressive symptoms at follow-up (de Leeuw *et al.*, 2000a), this negative coping strategy was also found to be associated with reduced QoL in more than one study (List *et al.*, 2002; Aarstad *et al.*, 2005; Aarstad *et al.*, 2008; Aarstad *et al.*, 2012; Beisland *et al.*, 2013).

Positive coping strategies such as being strong, self-reliant, engaging in distracting activities with others such as family and friends, having emotional support, seeking help from God, assistance from church, and helping others, were associated with increased QoL and well-being (Agarwal *et al.*, 2010). Indeed, some studies suggested that social support seeking behaviours represent the highest component (25%) of the whole coping efforts in people with H&N cancer (List *et al.*, 2002) and social networks play an increasingly important role in coping as family support could enhance the coping ability of the patient by enabling concentration on problem-focused coping strategies (Relic *et al.*, 2001). In addition, others conclude that the high rates of depression reported in people with H&N cancer may be linked to lack of social support (Baile *et al.*, 1992). In spite of these few studies on coping with H&N

cancer which suggest that patients with this type of cancer adjust using both emotion and problem focusing strategies during the cancer journey, to date no study has investigated in depth the role and mechanisms of social support and coping for people with H&N cancers. Therefore, the next section includes details about social support; definitions, types, theories, mechanisms and dimensions, as well as the relationship of social support and social networks with cancer in general and with H&N cancer.

3.2 Social Support

As can be seen from the previous section, people with H&N cancer use a series of strategies to cope with their conditions with social support representing the highest component (25%) of the whole coping efforts (List *et al.*, 2002). Social networks appear to play an increasingly important role by enhancing the coping ability of the patient (Relic *et al.*, 2001). In the same way, the higher rates of depression reported in people with H&N cancer have been linked to lack of social support (Baile *et al.*, 1992). This chapter will provide more details about social support, social networks and their relationships with cancer, and particularly H&N cancer.

3.2.1 Definition

Although the idea of social support has become, to some extent, a standardised concept used to assess the impact of social surroundings on health-related areas over the past four decades, there is no consensus concerning its meaning, and there are a variety of debates about the nature of social support and its dimensions.

Cohen and Mckay (1984) identify social support as the mechanisms by which interpersonal relationships may buffer an individual against stressful situations, whilst Friis and Seller (1999) have identified the concept of social support as the supportive relationships that develop with the person and family members, friends or with another individual. Similarly, Kim (2010, P: 255) argues that “*the term of social support refers to positive reinforcing attitudes generated by individuals in social relations to each other*”. However, both of the definitions raise more questions than they answer, because the failure to adequately define what is meant by ‘social relations’ and this leaves the area open to interpretation.

One suggestion is that although supportiveness appears to occupy the core of the concept, it has been used synonymously with ‘social bond’, ‘social network’ and ‘social integration’ in many studies leading to chaos in the theoretical definition of social support (Kim, 2010). This lack of clarity arising from the phrase ‘nature of support’, which is used interchangeably with ‘source of support’ (social network and

social relation), means that some researchers view social support as the degree to which an individual is integrated into the social networks in which he/she is a member (Antonovsky, 1979). Social support is also conceived as the availability of people for an individual to confide in (Miller and Ingham, 1976) or the depth of social relationships (Cassel, 1976). In addition, Lynch (1977) conceptualise social support as human relationships and Henderson (1980) present the concept as a social bond, while Mueller (1980) and Norbeck (1981) view it as social network. All of these concepts have been used to establish inferences about social support, but do not actually give concrete definitions about the constructs of social support.

Schwarzer and Rieckmann (2002) suggest that the concept of social support can be used both in a broad and narrow sense. In the narrowest sense, social support has been recognised in a variety of ways. For example, it may be viewed as coping assistance; resources supplied by others or as reciprocity of resources. However, when it is used in a broad sense the term social support includes social networks and social integration, although the three concepts are internally different. They suggest that social networks denote the objective base for social support and social integration. The latter two are viewed as theoretical constructs and refer to the extent to which people are socially surrounded, have a sense of intimacy and belonging and meet their tangible needs. They also differentiate social support and social integration in that social integration represents the quantity and structure of social relationships including density and size of networks and rate of the interaction. Nevertheless it sometimes refers to a subjective perception of embeddedness. In contrast, social support represents the quality and function of social relationships including perceived availability of assistance or actually obtained support. Social support appears to be established through an interactive process and can be linked to sense of obligation, altruism and the perception of reciprocation (Schwarzer and Leppin, 1989; Schwarzer and Leppin, 1991; Schwarzer and Leppin, 1992).

Social support has previously been defined in terms of information which divides into three types; information of worthiness (being valued and esteemed, or being viewed with positive regard), affective information (being loved and cared for) and information of partisanship (belonging to mutually influenced social relations) (Cobb 1976, Turner 1981). In a similar manner, social support has been defined as the extent

to which a person exhibits the need for trust, security, affection, succour, intimacy, affiliation, belongingness and approval (Kaplan *et al.*, 1977). Whilst other definitions take a more social approach and look at what society can provide the individual in terms of social ties to others, groups, and society as a whole (Lin *et al.*, 1979). Therefore, the concept is defined in terms of the extent of social relations, participation, and the stages of social adjustment.

3.2.2 Subtypes of social support

Social support has three distinctive subtypes and each one exhibits a different relationship with health. The three subtypes are; enacted support, perceived support and social integration (Barrera, 1986). Perceived support refers to a subjective judgment from the recipient that providers will supply (or have supplied) useful assistance during difficult times. Enacted support, sometimes called received support, refers to particular supportive activities such as reassurance or advice supplied by providers during difficult times, while social integration is the degree to which a recipient is tied inside a social network such as friends, family relations, organisation and club membership. It should be noticed that these three subtypes of social support are not strongly associated to each other, and each correlate differently with health, personal relationships and personality (Barrera, 1986, Uchino, 2009). For example, social integration has been related to physical health such as heart disease and mortality and not related to improved mental health, which is has been linked to perceived support (Barrera, 1986, Uchino, 2009). Contrastingly, enacted support has not been related consistently to either mental or physical health (Barrera, 1986, Uchino, 2009), instead, it has been related to a decline in mental health (Bolger *et al.*, 2000).

3.2.3 Causes of perceived support

Perceived support appears as a result of three major types of causes; provider influences, recipient trait influences and relational influences (Lakey *et al.*, 1996; Lakey, 2010).

Provider influences consider disparities amongst providers and reflect the recipients' agreement that providers differ in their supportiveness. In other words, provider influences reflect the degree to which providers are supportive objectively, according to recipient agreement. Recipient influences reflect disparities among recipients in their perception towards providers. For example, some recipients might perceive providers to be more supportive than other observers. As some providers are being rated by recipients, average disparities between recipients do not accurately reflect providers' characteristics. Instead, these disparities rather reflect the trait-like recipients' personality characteristics. Relational influences reflect organised disagreement between recipients on the providers' relative supportiveness. For example, a recipient may perceive a specific provider as more supportive than another provider, but another recipient may perceive the second provider as more supportive than the first one.

As regards the strength of each type of causes, it has been suggested that 60% of perceived support accounts for relational influence and about 25% for recipient trait influence, but only 5 -10% account for provider influence (Lakely , 2010). So, the personal tastes of recipients are reflected by the largest portion of perceived support. However, only a small portion reflects the recipients' personality.

Sometimes, social support is viewed as available support and perceived support; available support is represented by the availability of someone to offer the level of support required by the respondents. Perceived support refers to the quantity of support people feel. This measure can be more accurate than available support in relation to the amount of support the respondent receives (Komproe *et al.*, 1997). However, in cross sectional studies, there is a probability that it may measure support obtained as a consequence of ill health rather than support, or the absence of support leading to ill health (Marmot and Wilkinson, 2006).

3.2.4 Theories of social support

Numerous theories have been suggested to explain the link between social support and health. The commonest theories are stress and coping theory (Cohen and Wills, 1985)

which clarifies the buffering effects of stress; life span theory (Uchino, 2009) which is designed to show the link between trait-like aspect of social support and physical health; and relational regulation theory (Lakey and Oreheck, 2011) which deals with the relational side of perceived support and is designed to illustrate the major effect between mental health and perceived support.

Stress and coping social support theory (Cohen and Wills, 1985; Barrera, 1986; Thoits, 1986, Cutrona and Russel, 1990) strengthens research on social support. This theory hypothesises that social support protects people from poor health resulting from the stress of harmful events and is related to how people cope with and think about these effects. Lazarus and Folkman (1984) present stress and coping as a result of how people view stressful events; so if people think bad things will occur, they will view everything in a more negative light, creating a more stressful environment, and leading to ineffective coping. Coping includes planned and conscious activities such as relaxation and problem solving, as applied to social support which is a coping strategy that enables people to be more positive. Enacted support enhances coping and appraisal, while perceived support indicates a history of receiving enacted support.

Stress and coping theory appears in Cohen and Wills' (1985) study and describes the stress buffering action of social support. However, one limitation in this study is that enacted support is not related to better outcomes (Barrera, 1986, Uchino, 2009).

Life span theory (Uchino, 2009) deals with the way that trait-like features of social integration and perceived support can clarify relationships with physical health. This theory suggests that social support is generated throughout the life span, but is particularly important in early childhood being developed through the attachment of children with their parents. Social support in later life is generated in correspondence with some personality aspects such as low neuroticism, low hostility, and high optimism, in addition to coping and social skills. Support and other features of personality largely impact on health by enhancing healthy activities such as weight control and exercise, and by reducing stressors that impact on health (Uchino, 2009; Lakely, 2010).

Relational regulation theory (Lakely and Orehek, 2011) developed to illustrate the major effects between perceived support and mental health that come from relational effects. Lakey (2010) suggest that perceived support is mainly relational, while previous studies (Barrera, 1986) have indicated a weaker correlation between enacted support and perceived support. This weaker correlation has been interpreted by Lakely and Orehek (2011) as correlations of perceived support with mental health and is built on other processes such as regulating emotions through shared activities and normal conversations rather than conversations about stress and coping. Thus, relational regulation theory infers that individuals control their emotion across normal communications and shared activities. However, this regulation is relational, since the conversation areas, support provider and the activities that assist in emotion control are basically a matter of personal taste.

3.2.5 Mechanisms of social support

Social support has direct and indirect effects in defending against stressful situations (Cohen and Syme, 1985; Cohen and Wills, 1985; Stelman, 1998). The direct mechanism reveals that individuals with higher levels of social support are in better health than those with lower levels despite the stress, while the indirect mechanism suggests that social support protects individuals against unpleasant impacts of stressful life events.

3.2.5.1 The direct effect of social support

This direct effect is the main effect of social support and can be felt from its role as an obstacle to the consequences of the stressor (Cohen and Syme, 1985). This defensive action may appear as a result of encouragement that patients may receive when they experience stressful conditions. Encouragement can appear in various forms such as kind words from a friend or supplying suitable feedback or knowledge to overcome the stressor (Cohen and Wills, 1985). The defensive effects may also develop from tangible assistances such as money or other resources comprising of group membership to provide assistance and self-confidence (Cobb, 1976; Stelman, 1998). It appears that social support can enhance the ability of individuals to deal with inevitable problems or changes.

Cohn and Syme (1985) suggest a different explanation to the direct influence of social support in that lack of social support leads to ill health rather than that presence of social support leads to better health. Social support may therefore be said to directly affect the health in more than one pathway, for example this effect may be established through health-related behaviours such as encouraging people to take exercise, reduce fat consumption or stop smoking (Cohen *et al.*, 2000). However, this only appears to partially describe the direct effect of social support on health and the support from other individuals may be worthwhile if they themselves (the others) follow healthy behaviours and, then, this behaviour is applied by the patients (Marmot and Wilkinson, 2006).

Another pathway for the direct effect of support can be viewed from the potential ability of support to increase the perception of control over the environment and provide the premise of self-worth, which subsequently may improve health (Bisconti and Bergeman, 1999). In general, this mechanism suggests that both the lack of support due to social isolation and the positive effects of support have a direct impact on health.

3.2.5.2 The buffering effect of social support

Buffering is sometimes called the moderating effect and it suggests that the impacts of stressors are relieved by the existence of social support. In addition, the consequences of stressful situations are associated with the lack of social support (Cobb, 1976; Kaplan *et al.*, 1977; LaRocco *et al.*, 1980). Therefore, it seems that this model of social support indicates that social support acts as a buffer between the unpleasant stimulus and its reaction in order to reduce its consequences.

Evidence for this mechanism appears when the relationship between unpleasant situations and poor physical and mental health is weaker for individuals with high levels of social support than for those with low levels. The weak association between health and stress for individuals with high levels of social support can be interpreted as social support and has a protective effect against stress (Cohen and Wills, 1985). Buffering can improve the coping abilities of persons or alter their ideas toward the

stressor so as to lessen its consequences. In addition, social support may contribute in soothing the neuro-endocrine system of the subject leading to a decrease in his/ her reaction to stimuli (Stellman, 1998). However, according to the type of the stressor, social support buffers some stressors more successfully than others (Mitchell *et al.*, 1982).

The mechanism through which social support affects the stressor was also explained by Marmot and Wilkinson (2006) who documented that the buffering effects of social support may work in a number of ways. For example, discussion of a prospective hazard with a supportive individual may assist in reappraising the hazard hidden in the stressor, therefore making it more avoidable or manageable. Another way is that emotional support or tangible aid may help to control the effects of stressor and assist in the individual dealing with the harmful outcomes of the stressor. The stress buffering mechanism is more likely to be viewed in cases of perceived support rather than for social integration or enacted support (Cohen and Wills, 1985; Barrera, 1986).

3.2.6 Dimensions of social support

Numerous possible dimensions of social support have been identified by researchers (Hirsh, 1980; House, 1981; Sherbourne and Stewart, 1991; Cutrona and Suhr, 1992). Table 14 illustrates the components of each dimension and gives a brief description of how each dimension of social support has been coded in the different frameworks.

Support Dimension	Author	Description of coding
Informational	Cutrona and Suhr, 1992	Advice/ suggestions- Referral- Situation appraisal- Teaching
	Sherbourne and Stewart, 1991	Offering (advice , information, guidance and feedback)
	House, 1981	Advice - Suggestion – Directive
Emotional	Cutrona and Suhr, 1992	Relationships - Physical affection - Confidentiality -Sympathy - Listening - Empathy - Encouragement - Prayer
	Sherbourne and Stewart, 1991	The extent of positive effect - Empathetic understanding - Encouragement of expressions of feelings.
	House, 1981	Empathy - Concern - Caring - Love - Trust
	Hirsh, 1980	Care - Comfort - affection - Love - Sympathy
Esteem	Cutrona and Suhr, 1992	Compliant - Validation - Relief of blame
Network	Cutrona and Suhr, 1992	Access - Presence - Companions
Tangible	Cutrona and Suhr, 1992	Loan - Direct task - Indirect task - Active participation - Express willingness
	Sherbourne and Stewart, 1991	Provision of (material aid and behavioural assistance)
	Hirsh, 1980	Money - Aid with tasks (<i>the extent to which a person feels relieved of burdens</i>)
Instrumental	House, 1981	Money - Time - In-kind assistance - Performing task
Appraisal	House, 1981	Affirmation - Feedback - Social comparison
Positive social interaction	Sherbourne and Stewart, 1991	The availability of other persons to do fun things with you
Affectionate	Sherbourne and Stewart, 1991	Expression of love and affection
Encouragement	Hirsh, 1980	Praise - Compliment (<i>the extent to which a person feels inspired by supporter to feel courage</i>)
Advice	Hirsh, 1980	Useful information to solve problem (<i>the extent to which person feels informed</i>)
Companionship	Hirsh, 1980	Time spent with supporter (<i>the extent to which a person does not feel alone</i>)

Table 14: Social support dimensions by different authors

As it can be seen from Table 14, within each of the author's coding systems, types or dimensions of social support overlap. For example, while Hirsh (1980) has indicated five possible dimensions of social support (emotional, encouragement, advice, companionship and tangible aid), House (1981) and Sherbourne and Stewart (1991) used frames that can be seen as a modification of Hirsh's frame (Hirsh, 1980). For instance, the "encouragement" element in Hirsh's frame has been substituted by "appraisal" support that comprises information which is usually evaluative, whilst Sherbourne and Stewart (1991) separate tangible support into a separate category in its own right.

One of the most commonly used frameworks is the social support behaviour code (SSBC) (Cutrona and Suhr, 1992). This framework has been used to assess the frequency of 23 communication behaviours related to support. These behaviours have been categorised under five main classes (emotional, informational, esteem, network and tangible assistance). The social support behaviour code (SSBC) of Cutrona and Suhr, (1992) has been used effectively by many researchers (Braithwaite *et al.*, 1999; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu 2009) in investigating social support online. Details of studies used the Social Support Behaviour Code in investigating social support in OSGs are available in Table 15.

Author /date	Aim	Study design	Sample	Country	Method	Result
Braithwaite <i>et al.</i> (1999)	To investigate the extent and types of messages of social support exchanged by individuals with disabilities who participated in a computer-based support group	Cross-sectional	1472 messages	Nebraska-Lincoln/ USA	A modified version of Social Support Behavior Code (<i>Cutrona and Suhr's, 1992</i>)	<ul style="list-style-type: none"> - The highest percentage of the support messages provided emotional and informational support - Messages directly rectified challenges and limitations associated with disability-related mobility, self-care and socialization
Coulson (2005)	To explore the nature of social support communication that exchanged within a computer-mediated support network for persons with Irritable Bowel Syndrome	Cross-sectional	572 messages	Nottingham / UK	<ul style="list-style-type: none"> - Deductive thematic analysis was carried out using the guidelines set out by Boyatzis (<i>Boyatzis, 1998</i>) - The data was examined using <i>Cutrona and Suhr's (1992)</i> coding system 	The principal function of this group was the exchange of informational support, particularly within the areas of illness management, symptom interpretation, and communication with health care professionals
Coulson <i>et al.</i> (2007)	To investigate the offered social support in messages posted to individuals with Huntington's disease in an OSG bulletin board.	Cross-sectional	1313 messages	Nottingham / UK	A modified version of the Social Support Behavior Code (<i>Cutrona and Suhr 1992</i>)	Informational and emotional support were the main function of Huntington's disease OSG followed by the remaining dimensions of support with less frequency.

Mo and Coulson (2008)	To explore the dimensions of social support offered within messages posted to HIV/AIDS related-OSGs	Cross-sectional	1138 messages	Nottingham / UK	A modified version of the Social Support Behavior Code (<i>Cutrona and Suhr 1992</i>)	The most frequently offered types of support are informational and emotional support, followed by esteem, network support then tangible assistance.
Coursaris and Liu (2009)	To investigate, in depth social support exchanged in HIV/AIDS related-OSGs.	Cross-sectional	5000 messages	Michigan/ USA	A modified version of the Social Support Behavior Code (<i>Cutrona and Suhr 1992</i>)	<ul style="list-style-type: none"> - The most frequently exchanged support were Information and emotional followed by network and esteem support whereas tangible assistance was rare. - Three other types of interactions in the group (offering congratulations, expression of gratitude and sharing experience) can facilitate exchanges of social support
Coulson and Greenwood (2012)	To investigate the role of OSGs in supporting families affected by childhood cancer	Cross-sectional	487 messages	Nottingham / UK	A modified version of the Social Support Behavior Code (<i>Cutrona and Suhr 1992</i>)	<ul style="list-style-type: none"> - All the five dimensions of social support indicated in SSBC (i.e. information, emotional, esteem, network and tangible assistance) were existing. - The two most frequent dimensions were emotional and informational support

Table 15: Studies using a modified version of the Social Support Behaviour Code of Cutrona and Suhr, (1992)

Given the usefulness of this coding system to online social support, and given it is the coding system used in the present thesis, the five categories of the system are discussed in more detail below.

3.2.6.1 Informational support

Informational support refers to the support that others may offer through supplying information, since it supplies data and advice concerned with different types of stress, and also provides ways of coping. According to Cutrona and Suhr (1992) this kind of support can be coded as *suggestions* and *advice* to suggest guidance or actions and offer ideas, *referral* to supply assistance in guiding the subjects to other sources of assistances such as experts, *teaching* provides information, news or facts concerned with the skills or condition needed to cope with it. It can also be coded as *situation appraisal* by reassessing or redefining the condition in a manner that helps in making the recipients more positive or disclose new helpful knowledge.

This dimension of social support has also been listed under two other frameworks, one is House's framework House (1981), in which informational support has been subcategorised into advice, suggestions or directives that help the individual to respond to situational or personal dimensions. The other framework was established by Sherbourne and Stewart (1991) in which the informational support was subcategorised into advice, information, guidance and feedback.

An example of this dimension of social support can be seen from the patient-physician interaction in which physician supplying information has been related to many outcomes of physical and psychological care, including improved functional conditions (Greenfield *et al.*, 1985; Greenfield *et al.*, 1988; Maly *et al.*, 1999), reduced hospital stay and post-operative pain (Egbert *et al.*, 1964; Langer *et al.*, 1975; Fortin and Kirouac, 1976) and improved psychological outcomes (Orth *et al.*, 1987).

Informational support was found to be helpful before and after treating compromising illness such as cardiac disease (Cupples, 1991; Kattainen *et al.*, 2004). In addition, effective informational support is thought to improve health self-care skills, decision making and compliance to treatment and recommendations, and also is active in

reducing anxiety, fear and cancer morbidity and increasing employment and hope (Broeders *et al.*, 2002; Gornick *et al.*, 2004; Lambert and Loiselle, 2007). This kind of support might also have an effect on access to and utilisation of health care services (Berg *et al.*, 2004).

3.2.6.2 Tangible assistance

Tangible assistance is sometimes called instrumental support, and offers goods or services that are necessary in dealing with stressful situations (Langford *et al.*, 1997). According to Cutrona and Suhr (1992) tangible support can be coded as ‘*loan*’ by providing money or similar things to recipients, ‘*direct task*’ to perform tasks related directly to the recipient’s need or ‘*indirect task*’ to perform some of the recipient’s tasks during their stress period. In addition, it can also be coded as ‘*willingness*’ by expressions of willingness to provide help or as ‘*active participation*’ by leading the recipient to participate in activities valuable in coping with stress.

Tangible support has been defined in similar ways in other models, for example Hirsh (1980) has presented tangible support as the extent to which an individual feels relieved of burdens by provision of money and/ or assistance with tasks, while Sherbourne and Stewart (1991) have identified tangible support as provision of material aids and behavioural assistance. In a similar manner, House (1981) has defined tangible assistance as instrumental support and coded it as money, time, in-kind assistance, and performing tasks. Previous studies have indicated that tangible support from family is one factor that is closely related to compliance with medical treatment (DiMatteo, 2004).

3.2.6.3 Emotional support

Emotional support refers to a person’s efforts to prevent or alleviate a negative impact on another (Heller and Rook, 1997). It provides love, care, and concern when in contact with recipients. According to Cutrona and Suhr (1992) emotional support can be coded as a ‘*relationship*’ that emphasises the role of love and proximity in relationships with subjects, ‘*physical affection*’ provides physical contact such as hugs, hand holding, kissing and shoulder patting. Moreover, it can also coded as

'*confidentiality*' certifying that the problems of recipients are kept in confidence, '*empathy*' expresses similarity of the recipient's problem and understanding the situation, '*sympathy*' includes expression of distress, grief or unhappiness at the condition of the recipient, '*listening*' comprises of sympathetic comments on the recipient's words. Emotional support can also be coded as '*prayer*' including praying with the recipient or as '*encouragement*' providing hope and confidence to the recipient.

Emotional support has also been listed as a dimension of social support within other models (Hirsh, 1980; House, 1981; Sherbourne and Stewart, 1991). Hirsh (1980) divided emotional support into five subcategories; affection, care, comfort, love and empathy. House (1981) suggests that emotional support is the commonest identified dimension of social support and it is usually provided by family and close friends. He shares two subcategories with Hirsh (love and caring) and added three other subcategories, which are empathy, concern and trust. In addition, Sherbourne and Stewart (1991) have expressed emotional support as the extent of positive effect, empathetic understanding and encouragement of the expression of feelings.

Emotional support has an effect on health, for example previous studies have found a relationship between emotional support and high positive impact and lower negative impact in people living with HIV/AIDS (Gonzalez *et al.*, 2004). There also appears to be an association between emotional support from a partner and patient adjustment to disease (DeLongis *et al.*, 2004; Revenson *et al.*, 2005), and numerous studies have found that emotional support from a spouse is related to coping and recovery from cancer (Helgeson, 1993; Revenson, 1994).

3.2.6.4 Social network support

Social network support includes interactions with individuals who share similar interests and concerns. It is usually coded as '*access*' by ascertaining accessibility of subjects to new members, and '*presence*' which includes reminding the recipient that someone is listening to them and ready to provide support. This kind of support can also be coded as '*companion's*, which includes reminding the recipients about the

availability of companions of individuals who have the same concern and experience (Cutrona and Suhr, 1992).

3.2.6.5 Esteem support

This kind of support comprises of confidence, ability and communication respect. It is usually coded as '*validation*' by expressing similar concern and agreement with the recipient, '*compliment*' by highlighting and positively assessing the ability of the recipients, or it can be coded as '*relief of blame*' by reducing the blame and feeling of guilt that might be expressed by the recipient about the situation (Cutrona and Suhr, 1992).

In summary, the classification of social support depends on the way it is expressed, since it can either refer to particular supportive actions such as “enacted support” or refer to the presence of particular people who have the ability to offer the required help, termed “perceived support”.

3.2.7 Social support and health

A great deal of research has investigated the influence of social support on health (Lin *et al.*, 1985; Cohen, 1988; Heitzmann and Kaplan, 1988; Bloom, 1990) and a range of observational and intervention studies have evaluated the relation between social support and consequent outcomes (Helgeson and Cohen, 1996).

These studies appear to suggest that social support has been constantly linked to physical and mental health. For example, more sub-clinical symptoms of anxiety and depression have been reported amongst individuals with low levels of social support than amongst those with high levels of support (Cohen and Wills, 1985; Barrera, 1986;) with higher degrees of major mental disorders were reported in those with lower levels of support. These higher degrees of mental disorders comprise; social phobia (Torgrud *et al.*, 2004), post-traumatic stress disorder (Brewin *et al.*, 2000), severe depressive disorders (Lakey and Cronin, 2008), panic disorders (Huang *et al.*, 2010), eating disorders (Grisset and Novell, 1992; Stice *et al.*, 2002) and dysthymic disorders (Klein *et al.*, 1988).

People with lower levels of social support may also experience more suicidal thoughts (Casey *et al.*, 2006) and more drug and alcohol problems (Wills and Cleary, 1996, Stice *et al.*, 1998) and comparable results have also been recorded in children (Chu *et al.*, 2010). In addition, people with lower levels of social support who have Schizophrenia may exhibit more symptoms (Norman *et al.*, 2005).

In relation to physical health more cardiovascular diseases were recorded in people with low levels of social support (Uchino, 2009, Hoit-Lunstad *et al.*, 2010), with reported lower rates of immunity and higher levels of infection (Kiecolt-Glaser *et al.*, 2002; Uchino, 2006).

Cobb (1976) reports that socially supported people experience the feeling of being cared for/ or being a part of reciprocal interpersonal promise system, so this appears to implicate the quality of interactions with others. This is supported by Craighead *et al.*, (2002) who propose that there is a relationship between emotional support and social contacts, since emotional support increases with developing social contact, and individuals who are socially supported address stressful or unpleasant conditions more effectively than those who lack social support. Their final caveat suggests that those who lack social support may be more vulnerable to poorer mental and physical health.

Social support has been studied widely from the perspective of psychosocial reactions to many medical conditions including cancer, and since this thesis is related to people with H&N cancer, more details on the relationships of social support with cancer in general and H&N cancer in particular are discussed below.

3.2.7.1 Social support and cancer

The social environment may be an essential area in cancer research, since its features have been shown to encourage well-being and reduce the impact of stressful life events (Cohen and Will, 1985). Although the experience of cancer depends on several factors such as patient's demographics, cancer site and stage and type of treatment, it is suggested that cancer patients face a group of common psychosocial problems and

similar requirements that can be organised by individuals in their social environment (Helgeson and Cohen, 1996).

The varying definitions of the concept of social support as well as the inconsistent classification of its types and dimensions has led to inconsistent and mixed findings regarding the role of social support in cancer progress (Nausheen *et al.*, 2009). A relatively large number of studies have been conducted on the relationship of social support and cancers from many aspects throughout the last few decades. This body of work has recently been reviewed by several researchers (De Boer *et al.*, 1999b; Hoodin and Weber, 2003; Thaxton *et al.*, 2005; Falagas *et al.*, 2007; Nausheen *et al.*, 2009).

De Boer *et al.* (1999b) reviewed the literature on the psychosocial relationship of cancer relapse and survival in the period from 1979 to 1995. The reviewed studies have illustrated that the factors most commonly assessed were anxiety, depression, helplessness, marital status, hostility and social involvement, but results were inconsistent. However, the strongest verification for an association between psychosocial variables and prognosis was observed for social support (social involvement) in seven of the 15 studies reviewed. A positive association (that social support related to better prognosis) was established whereas no negative relationships were observed. As regards the inconsistent results, a number of methodological limitations related to sample size, study design, and statistical analysis were listed. For example, small sample sizes were apparent in many studies and sometimes patients in different stages of cancer and with different types of cancer were studied together. In numerous studies, the outcome variables differed and unsuitable statistical methods were used in several studies for analysis. Moreover, although several studies were longitudinal /prospective in design, follow-up times were often short and varied considerably across studies. Furthermore, most studies lacked any substantive theoretical framework to guide the choice of variables, hypotheses or subsequent data analysis.

Hoodin and Weber (2003) reviewed the databases for studies of psychosocial variables that influence survival in patients who undergo bone marrow transplants. The authors suggest that although some studies found an association between psychosocial factors

and survival, the most methodologically sound studies indicate that survival in patients with bone marrow transplantation is essentially influenced by psychopathological factors or social support.

Another review of cancer support groups conducted by Thaxton *et al.* (2005) focus on prostate cancer. Before this study, there were several studies dealing with support groups for females with breast cancer suggesting that support groups can improve the psychological functioning dramatically and may increase longevity in some cases. What the Thaxton *et al.* study adds to the existing knowledge base is that informational support was especially valued by men with prostate cancer who were members of a support group, especially if it was open-ended large group and efficiently structured in the presence of a healthcare professional.

More recently, a systematic review (Falagas *et al.*, 2007) was conducted to analyse the evidence concerned with the influence of psychosocial factors on the survival of women with breast cancer. In this review, 31 studies of psychosocial relationships through cancer relapse and survival and on the effect of psychological interference on survival were reviewed between 1979 and 2006. More than 80% of the studies showed a significant association between at least one psychosocial variable and cancer outcomes. Social support was one of the factors that related to better prognosis of breast cancer, while depression and constraint of emotions were related to decreased survival of breast cancer. However, not all the studies verified the role of these parameters. The actual psychosocial factors that linked to survival were not consistently measured among the studies, and results for many factors with recurrence/survival were not uniform.

The previous reviews have not addressed many of the concerns related to social support in detail possibly due to the involvement of a series of psychosocial factors and the limited availability of associated studies. A recent systematic review conducted by Nausheen *et al.* (2009) partially addresses the concerns in recognising and summarising the evidence for the properties of social networks represented by the structural aspects of social and functional support. In this review, a thorough search was established through Web of Science, Medline and PsycINFO electronic data bases for the relationship of social support and cancer to include articles from 1970 to 2008.

Due to the high number of articles that deal with breast cancer, the studies were subcategorised into breast cancer, other cancers rather than breast cancer and mixed cancers which include articles with more than one kind of cancers. A number of 31 longitudinal prospective studies were included, and classified social support into functional and structured support.

Results of the above review indicated sufficiently strong evidence for the association between support and cancer progression for females with breast cancer. However, the evidence appeared unconvincing for other cancers or for studies that included more than one kind of cancer. This review found that structural support indices were more commonly related to cancer progression than that of functional support in cases of breast cancer. In addition, the role of psychosocial variables in cancer-related results is dependent on many cancer related factors such as treatment site, severity and metastasis. It has been suggested that the functional features of social support (for example emotional support), the structural features and social network (such as size), all have been linked to cancer mortality (Reynolds and Kaplan, 1990; Glanz and Lerman, 1992).

Social support has also been related to QoL of patients, since single studies and reviews have suggested that emotional support is positively related to HRQoL outcomes in a number of patients with cancer (Courten *et al.*, 1996; Helgeson and Cohen, 1996), with a number of researchers reporting positive correlations between the level of support and the degree of emotional and psychological well-being (Cohen and Wills, 1985; Ell *et al.*, 1992; Krishnasamy, 1996; de leeuw *et al.*, 2000b), since social support can buffer or diminish the negative effects of diagnosis and treatment of cancer (Cohen and Wills, 1985; Komproe and Rijken 1995; Ruiters, 1995). However, some studies reported that social support might also have negative effects (Wortman, 1984; Komproe *et al.*, 1997). This may include unfavourable forms of support such as overprotection or reinforcement of health-damaging actions.

Although the results are general and not specific, the literature has indicated that greater levels of social support were related to improved adjustment in cancer patients generally (Weisman *et al.*, 1980; Bloom, 1982; Bloom and Spiegel, 1984; Dunkel-Schetter 1984; Neuling and Winefield, 1988; Zemore and Shepel, 1989; Robers *et al.*,

1994). Improved psychological adjustment together with social support itself have been indicated in many studies to have an impact on QoL of patients with various cancers (Watson *et al.*, 1984; Di Clement and Temoshock, 1985; Greer, 1985; Watson *et al.*, 1991; Stanter and Snider, 1993; Roberts *et al.*, 1994; Hann *et al.*, 1995; Thomas and Mark, 1995, Wagner *et al.*, 1995), and some researchers have suggested that they can also influence survival in patients with some types of cancer such as melanoma (Fawzy *et al.*, 1993) and breast cancer (Greer *et al.*, 1990; Ell *et al.*, 1992; Maunsell *et al.*, 1995).

Many of the studies that have been conducted on the relationship between social support and cancers (other than H&N cancer) have highlighted the role of social support in improving patient outcomes. For example, Goodwin (2005) suggests that support groups can improve the psychological outcomes of patients with metastatic breast cancer. Social support has also been found to be beneficial for cancers in adolescence and childhood. For example, Decker (2007) reviewed 17 studies, although mainly exploratory and descriptive in nature, and concludes that support, from both family and friends, was valued for adolescent cancer survivors, with support from parents being of greater importance and more significance. One suggestion is that social support is an important factor in determining QoL in adolescent cancer survivors, although the relationship seems to be complex (Spangler, 2009).

To sum up, although the varying definitions of the concept of social support, as well as the inconsistent classification of its types and dimensions, has led to contrasting and conflicting findings regarding the role of social support in cancer. Social support appears to be beneficial for cancer patients for many reasons. It has been associated with reducing the impact of stressful life events including the cancer itself, reducing mortality rates, improving psychological functioning and adjustment of patient's with cancer, encouraging well-being and HRQoL as well as improving patient survival and prognosis, and it may well increase longevity.

3.2.7.1.1 Social support and head and neck cancer

In spite of the large body of studies that investigate the relationship of social support to cancer, a relatively few studies have been conducted on the relationship between

social support and H&N cancer. Social support might be of particular importance for this group of patients due to the anatomically sensitive location of these cancers in the H&N region and their functional and physical influences such as their effects on speech, swallowing and facial appearance. Details of the studies that have been conducted to date can be seen in Table 16.

Author /date	Aim	Study design	Sample	Country	Method	Result
Baker (1992)	To evaluate the effect of social support, disfigurement, dysfunction and mode of treatment on rehabilitation outcomes	Cross-sectional	51 participants	OHIO/ USA	<ul style="list-style-type: none"> - The Sickness Impact Profile - 136-Item (<i>Gilson et al., 1975</i>) (Dependant variable rehabilitation outcomes) - Personal Resources Questionnaire (<i>Brandt and Weinert, 1981</i>). (Perceived social support). 	<ul style="list-style-type: none"> - No significant relationship between facial disfigurement and rehabilitation outcomes - Perceived social support was significantly related to rehabilitation. - Different modes of treatment did not show significant differences in rehabilitation outcomes
Ma (1996)	To evaluate the perceived and desired social support from family, friends and health professional in patients with nasopharyngeal carcinoma	Cross-sectional	125 participants	Hong Kong/ china	<ul style="list-style-type: none"> - Self-constructed scale (social support) - Likert Scale (the degree of satisfaction) - Anxiety and depression subscales of symptom check list (<i>Derogatis, and Savitz, 2000</i>) (Psychological distress) 	<ul style="list-style-type: none"> - Patient's desire for social support was moderately strong during treatment and post treatment stages - Patients sought support most frequently from health professional followed by family then friends - Patients' satisfaction for 4 types of support (emotion, information, instrumental and affiliational) was moderately high.
Mathieson <i>et al.</i> (1996)	To investigate whether social support play a role in improvement of psychological state and QoL of H&N cancer patients	Cross-sectional	45 participants	Halifax/ Canada	<p>Structured questionnaire contains</p> <ul style="list-style-type: none"> - Demographics - Medical variables - The Social Support questionnaire (<i>Sarason et al., 1983</i>) (social support) - Functional Living- Index Cancer Scale (<i>Schipper et al. 1984; Schipper and Levitt, 1985</i>) (for QoL) - The Centre for Epidemiological Studies Depression Scale (CES-D) (<i>Radloff, 1977; Devins et al., 1988</i>) (Psychological status) 	<ul style="list-style-type: none"> - Four factors predicted quality of life: (severity of cancer, satisfaction with family physician support, type of cancer and sex of patient). - Three predictors of psychological state: (family physician support, loss of appetite, and sex of patient). - Social support, especially from family physician, have a great role in improvement of psychological state and QoL in H&N cancer patients

De Leeuw <i>et al.</i> (2000 a)	To evaluate the effect of different features of social support in depression symptoms in patients with H&N cancer treated with surgery and /or radiotherapy.	Cross-sectional	208 participants	Utrecht/ The Netherlands	<ul style="list-style-type: none"> - Social Support List Interaction (received support). - Social Provision scale (<i>Cutrona and Russel, 1987</i>) (Available support). - CES- D Scale (<i>Radloff, 1977; Devins et al., 1988</i>) (Depression symptoms) - EORTC and QoL Core questionnaire (<i>Aaronson et al., 1993</i>) (General health complaints) 	<ul style="list-style-type: none"> - Clear relationship between social support and depression symptoms was noticed particularly in patients with few complaints. - The availability of social support is advantageous for all cases. - The effect of perceived support was unclear. - 4. Provision of support should be modified according to patient's need.
De Leeuw <i>et al.</i> (2000b)	To evaluate whether pre-treatment variables are valued in predicting depression 6 and 12 months later	Cross-sectional	155 participants	Utrecht/ The Netherlands	<ul style="list-style-type: none"> - Social Support List Interaction (<i>Van Sonderen, 1991</i>) - The Inventory of Socially Supportive Behaviors (<i>Barrera et al., 1981</i>). - Social Provision Scale (<i>Cutrona and Russel, 1987</i>) (Social support) - Utrecht coping List (<i>Komproe and Rijken, 1995</i>) (Coping) - Cancer Locus of Control Scale. (<i>Pruyn et al., 1988; Watson et al., 1990</i>) (Locus of control) - Center for Epidemiologic Studies—Depression scale (<i>Eaton et al., 2004</i>). (Depression symptoms) - European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC) C30+35 (<i>Aaronson et al., 1993</i>) (General physical symptoms and physical functioning) 	<ul style="list-style-type: none"> - Emotional support and extent of social network before treatment are factors in determining which patients are at risk of suffering from depression symptoms after treatment. - It was possible to predict patients who would have symptoms at 6 (81%) and 12 months (67%) after treatment by using five variables (emotional support, depressive symptoms, physical symptoms, avoidance coping and extent of the social network).

Hassane in (2001)	To investigate the relationship between functional status and depression, anxiety, coping style and the quality and quantity of social support	Cross-sectional	68 participants	Manchester/ UK.	<ul style="list-style-type: none"> - UW- QoL questionnaire (<i>Hassan and Weymuller, 1993</i>) (Patient evaluation) - Hospital Anxiety and Depression scale (<i>Zigmond and Snaith, 1983</i>) (Anxiety and depression) - Mental Adjustment to Cancer Questionnaire (<i>Watson et al., 1988</i>) (Patients' adjustment) - Short Form Questionnaire (<i>Sarason et al., 1987</i>) (Perceived social support) 	<ul style="list-style-type: none"> - While the worse functional domain was associated with depression, anxiety, and ineffective coping, level of social support and satisfaction with that support was associated with better functional score.
List <i>et al.</i> (2002)	To explain the pre-treatment coping approaches of H&N cancer patients who were receiving concentrated radio-chemotherapy and to investigate the relation between coping and demographics and QOL	Cross-sectional	79 participants	Chicago/ USA	<ul style="list-style-type: none"> - Ways of Coping -Cancer Version (<i>Dunkel-Schetter et al., 1992</i>) - Function assessment of cancer therapy-Head and Neck (<i>Cella et al., 1993 and 1994</i>) - Performance status Scale for H&N Cancer Patients (<i>List et al., 1996</i>) - Karnofsky Performance Status Rating Scale (<i>Karnofsky and Burchenal, 1949</i>) - 5. The GAGE (<i>Ewing, 1984</i>) 	<ul style="list-style-type: none"> - Patients with H&N cancer used a variety of coping strategies, the greatest portion of whole coping effort (25%) was represented by social support seeking behaviours. - Using avoidant coping strategies was associated with poorer QOL.
Katz <i>et al.</i> (2003)	To assess the psychosocial impact of gender, disfigurement and social support after surgical	Cross-sectional	82 participants	Toronto/ Canada	<ul style="list-style-type: none"> - Disfigurement Rating Scale (<i>Katz et al., 2000</i>) (Disfigurement) - Standardised Coping Sheet (Abstracting medical variable) - The Medical Outcome Study Social Support Survey (<i>Sherbourne and Stewart, 1991</i>) (Social support) - Three other measures were used to 	<ul style="list-style-type: none"> - Women who experienced facial disfigurement and low levels of social support were at highest risk for psychosocial dysfunction. - It seems that social support buffers the influence of high levels of disfigurement on well-being for women but not for men.

	treatment for H&N tumour				assess subjective QoL.	- Participants with greater disfigurement were more depressed
Karnell <i>et al.</i> (2007)	To investigate the association between social support and H&N cancer specific- QoL outcomes	Cross-sectional	394 participants	Iowa/ USA	<ul style="list-style-type: none"> - Patients filled out surveys addressing HRQoL - Social Provisions Scale (<i>Cutrona and Russel, 1987</i>) (Perceived social support) - Head and Neck Cancer Inventory and Beck Depression Inventory (<i>Beck, 1972</i>) (HRQoL outcome) - The Medical Outcomes Study Short-Form 36 (<i>Ware and Sherbourne 1992</i>) 	<ul style="list-style-type: none"> - Greater levels of social support were significantly linked to greater scores in general mental health, speech, social disruption, aesthetics, and some depression symptoms - Given this association between social support and HRQoL outcomes, adjustment of perceived social support by clinical interventions might improve the survival rate in the H&N cancer patients.
Chueh <i>et al.</i> (2009)	To identify the influence of social support on depression and anxiety in patients with oral cancer	Randomised trial	134 participants	Chang Gung/ Taiwan	<p>Patients take part in 3 arms randomised trial and were evaluated for depression and anxiety status by:</p> <ul style="list-style-type: none"> - Hospital Anxiety and Depression Scale (<i>Zigmond and Snaith, 1983</i>) - Social Support Questionnaire (<i>Sarason et al., 1983</i>) <p>Patients were evaluated 3 times (pre surgery, 2 weeks after surgery and at discharge from hospital)</p>	- Patients with oral cavity experience depression and anxiety from admission to discharge. However, concentrated social support care can significantly improve this condition during admission.
Howren <i>et al.</i> (2011)	To understand the influence of social support at diagnosis (before treatment) on HRQoL outcomes in H&N cancer patients at 2	Longitudinal	366 participants	Iowa / USA	<ul style="list-style-type: none"> - Beck Depression Inventory (depression Symptoms) - SF- 3 (HRQoL) <p>Patients evaluated at diagnosis and then at 3 and 12 months post treatment</p>	- The score of social support available before commencement of treatment can have a significant effect on depression and HRQoL with time in patients with H&N cancer.

	particular post-treatment point of time.					
Deno <i>et al.</i> (2012)	To investigate how self-efficacy and social support mediate the relationship between emotional distress and social distress in patients with H&Ncancer	Cross-sectional	225 participants	Tokyo / Japan.	<ul style="list-style-type: none"> - Social Support Scale (<i>Okabayashi et al., 1997</i>) - The Self-Efficacy for Advanced Cancer measure (<i>Hirai et al., 2001</i>) - Social Distress Scale (<i>Deno et al., N.D</i>) - EORTC QLQ-H&N35 (<i>Bjordal et al., 1994</i>) - Hospital Anxiety and Depression Scale (HADS) (<i>Zigmond and Snaith, 1983</i>) 	<ul style="list-style-type: none"> - The negative impact of social distress on emotional distress was strongly buffered by self-efficacy - Direct or indirect influence on emotional distress caused by social support from family members - Lower social distress and higher emotional distress were related to support from friends
Milbury and Badr (2012)	To study the relationship between actual observed support behaviours and avoidance and cognitive intrusion in patients newly diagnosed with H&N cancer and their partners	Cross-sectional	60 participants	Texas/ USA	<ul style="list-style-type: none"> - An explicit measure of cognitive intrusion and avoidance included in baseline questionnaires - A problem-solving discussion task immediately in the laboratory - The Social Support Interaction Coding System (SSICS) (<i>Floyd et al., 1987</i>) for coding video-recorded discussions. - An implicit measure of cognitive intrusion (Cancer Stroop Task (CST)). - 	<ul style="list-style-type: none"> - Receiving more positive support behaviours related to slower reaction times on the CST which indicate greater cognitive intrusion.
Penedo <i>et al.</i> (2012)	To assess alterations in perceived availability of social support	Cross-sectional	32 participants	Florida, USA	<ul style="list-style-type: none"> - The ENRICH Social Support instrument (ESSI) (perceived social support) - The Functional Assessment of Cancer Therapy-Head & Neck 	<ul style="list-style-type: none"> - Perceived social support reduced significantly from pre-treatment to post-treatment - Change in perceived social support a significant predictor of post-

	from pre-treatment to post-treatment and to identify whether declines in perceived social support predicted worse post-treatment disease-specific QoL among people with H&N cancer				(FACT-H&N) (Cella <i>et al.</i> , 1993, 1994) (Disease-Specific- QOL).	treatment and disease-specific- QOL After adjusting for related covariates and pre-treatment disease-specific QOL,
Howren <i>et al.</i> (2013)	To explore whether pre-treatment social support predicted QOL outcomes up to 12 months later in survivors of H&N cancer	Cross-sectional	364 participants	Iowa / USA	<ul style="list-style-type: none"> - The Short Form Health Survey (SF-36) (Ware and Sherbourne, 1992) - Head and Neck Cancer Inventory (HNCI) (Funk and Karnell, 2003) 	<ul style="list-style-type: none"> - More perceived social support at diagnosis significantly predicted better global and H&N cancer-specific HRQoL at follow-up (3 and 12-month).

Table 16: Studies on the relationship between social support and head and neck cancer

Since H&N cancer may interrupt the normal daily activities of patients as a result of changes to normal eating, speech and facial aesthetics (Pruyn *et al.*, 1986; Penner, 2009), social support may be of particular importance for this group. As can be seen from Table 16, outcomes of the studies that have investigated this area suggest that social support does appear to exert a positive influence for patients with H&N cancer, especially in relation to reducing the impact of anxiety, depression or depressive symptoms. For example, a higher degree of patient-reported available social support was linked to lesser depressive symptoms (de leeuw *et al.*, 2000a). In addition, social support care could significantly improve the levels of depression and anxiety during admission to hospital (Chueh *et al.*, 2009). Regarding the timing of support, level of pre-treatment social support could have a significant effect on level of depression and score of QoL of the H&N cancer patients over time (with progress of time) (List *et al.*, 2002; Howren *et al.*, 2011). In addition, pre-treatment support may also determine which patients are at risk of depression after treatment.

The studies in the table also indicate that social support might play an important role in improving both psychosocial (Mathieson *et al.*, 1996) and functional states (Hassanein *et al.*, 2001) of patients with H&N cancer, and is significantly associated with better HRQoL outcomes (Karnell *et al.*, 2007; Howren *et al.*, 2011, Penedo *et al.*, 2012; Howren *et al.*, 2013). Contrasting studies have investigated the role of social support in adjustment to H&N cancer and suggest that perceived social support relates to positive adjustment (Baker, 1992; de leeuw *et al.*, 2000a), particularly amongst females where better adjustment to disfigurement is reported (Katz *et al.*, 2003).

However, the majority of these studies are retrospective or cross-sectional and the findings of some of them were equivocal with no statistically significant findings. In addition, some of them depend on relatively small samples and none of the studies have examined online support. Online support may be of great benefit to this group of patients, because of the issues around visual impairment and communication. This is explored in more depth in Chapter 3, Section 3.3.

Summary

Although there is an extensive amount of research concerning the nature of social support and its dimensions, there appears to be no consensus concerning its meaning. Some researchers have identified three distinctive subtypes of social support; perceived support, enacted support and social integration, each having a different relationship with health. Numerous theories have also been suggested to explain the link between social support and health. The most common of these are stress and coping theory, life span theory, and relational regulation theory. Moreover, several frameworks have been established to identify the possible dimensions of social support, under which social support has been divided into many subcategories.

Research has investigated the influence of social support on health and suggested that social support has been consistently linked to both physical and mental health outcomes. Social support has been studied widely from the perspective of psychosocial reactions for many medical conditions, including cancer, and a relatively large number of studies have been conducted on the role of social support in cancer. In contrast, only a few studies have been found in relation to H&N cancer, and these suggest that social support does appear to exert a positive influence.

3.2.8 Social support and social networks

The Social network of the individual is differentiated from social support because whilst social support refers to the received emotional support that a person can obtain from social relationships, social network ties represent the amount, pattern and configuration of ties that connect the individual with another or with organisations (Craighead *et al.*, 2002). One of the most important differences is the quality and type of support supplied by network members (Marmot and Wilkinson, 2006).

Social network can be subdivided into the number of primary group contacts (a group of individuals to which the person is most attached) and more distant contacts are not expected to supply significant support (Seemnan and Syme, 1987; Marmot and Wilkinson, 2006).

Density of the network is considered as another important measure, which subsequently provides an overview about the integration of network members (Yogt *et al.*, 1992; Marmot and Wilkinson, 2006). These network measures are characterised by their relative ease of measure, recall by respondents in surveys, and verification by external evaluators. In addition, these measures can give an indicator of social integration, but do not supply any index regarding the quality of the interaction occurring in social contacts (Berkam and Syme, 1979, Kawachi *et al.*, 1996; Marmot and Wilkinson, 2006).

3.2.8.1 Social network and cancer

Several studies have been conducted on the relationship between social networks and cancer (Goodwin *et al.*, 1991; de Ruiter *et al.*, 1993; Guidry *et al.*, 1997; Michael *et al.*, 2002; Sapp *et al.*, 2003; Bauer *et al.*, 2005; Kroenke *et al.*, 2006; Beasley *et al.*, 2010; Pinquart and Duberstein, 2010). However, none of them have dealt specifically with H&N cancer. A brief description of the studies on social networks and cancer can be seen in Table 17.

Author /date	Aim	Study design	Sample	Country	Method	Result
Goodwin <i>et al.</i> (1991)	To evaluate the social networks and functional status of old people newly diagnosed with cancer	Cross-sectional	799 participants	Milwaukee/ USA	Patients were assessed for functional limitations and social support network	<ul style="list-style-type: none"> - Having a poor social network was predicted by being non-Hispanic white ethnicity, advanced age, low income, and being a recent migrant to the area. - More likely to see poor social support networks in individuals with functional limitations than individuals without such limitations. - The destructive combination of restricted social support network and impaired functional status can clarify the cause of increased risk in older cancer patients for not receiving proper treatment
Welin <i>et al.</i> (1992)	To investigate the association between social network and activities and some causes of mortality including cancer	Prospective	989 participants	Gothenburg / Sweden.	The sample attended a health examination and completed two questionnaires. The procedure was repeated after 10 years for the existing patients, who had been followed 12 years later.	<ul style="list-style-type: none"> - Cancer mortality was associated with few number in a household, reduced levels of social activities and poor perceived health, - A good social network (measured as a high level of activities socially, at home, and outside home) for middle aged men can protect them against non-cancer mortality
de Ruiter <i>et al.</i> (1993)	To investigate the influence of social network and social interaction on QoL of patients with cancer	Cross-sectional	409 participants Surgery (N=109) Chemotherapy	Groningen/ Netherlands.	<ul style="list-style-type: none"> - Scale constructed with a four point Likert Index <i>to measure social network support</i> - Tempelaar Scale (Tempelaar <i>et al.</i>, 1987) <i>for +ve and -ve experience in social interaction</i> 	Social network and social relations was related to better quality of life. However, variations in QoL related to these components were very small.

			apy (N=108) Ex- patients (N=192)		- Social constructed questionnaire <i>for components of QoL</i>	
Guidry <i>et al.</i> (1997)	To investigate the role of formal and informal social network among different racial groups of cancer patients	Retrospective	593	Texas/ USA	Patients were intended to complete self-constructed survey regarding their participation in social network groups.	The patients of all ethnic/ racial groups indicated that formal support groups supplies emotional help. In addition, Hispanics and Blacks reported that informal social network were more helpful
Michael <i>et al.</i> (2002)	To evaluate the effect of social network on HRQoL in breast cancer survivors	Cross-sectional	708	Portland/ USA	Women completed questionnaire in average 4 years post diagnosis include: - Cancer Rehabilitation Evaluated System Short Form (<i>Schag et al., 1991 and 1993</i>) (HRQoL) - Modified Berkman- Syme Social Network Index (<i>Berkman and Syme, 1979</i>) (social network ties)	- The most socially integrated women were less adversely affected by breast cancer compared to socially isolated women - Social interaction at pre-diagnosis level is a significant factor in the future HRQoL among breast cancer patients and it seems to explain more of the variations in HRQoL than tumour features or treatment.
Sapp <i>et al.</i> (2003)	To investigate the HRQoL among females with long-term colorectal cancer survivors in relation to social	Cross-sectional	307	Madison/ USA.	- Short Form health survey (SF-36) (<i>Ware and Sherbourne, 1992</i>) (HRQoL) - A modified version of Berkman- Syme Social Network Index (<i>Berkman and</i>	Mental health was positively associated with: - Individual measures of social network (number of friends and relatives) - Composite measures of network (number of ties viewed at least once monthly, network size and overall social

	network				<i>Syme, 1979</i>) (social network)	connectedness)
Bauer <i>et al.</i> (2005)	To explore the topology of social network and perceived social support in American Indian cancer survivors	Case-control		Rochester, NY/ USA	Exploring the social network topology and perceived social support in both cases (American Indian cancer survivors and control)	<ul style="list-style-type: none"> - Expressive social supports (eg, friendship, moral support, companionship, advice and encouragement) were highly ranked through each component of the network. However, there were no significant variations between case and control groups. - The family appeared to be the main source of social support compared with community /church or the best/ closest friend.
Kroenke <i>et al.</i> 2006	To evaluate social support, networks and survival in women after being diagnosed with breast cancer	Prospective Longitudinal	2,835	Oakland, CA/ USA.	<p>Data on social network and social support was collected from women diagnosed with breast cancer from 1992 to 2002.</p> <ul style="list-style-type: none"> - Social networks were assessed 3 times with 4 years period apart using Berkman-Syme Social Network Index (<i>Berkman and Syme, 1979</i>) - Social support was assessed two times with 8 years period - Cox Proportional Hazards Models (<i>Cox, 1972</i>) was used to analysis of social support and network 	<ul style="list-style-type: none"> - Socially isolated women (before diagnosis) had a two-fold increased risk of mortality due to breast cancer and a 66% increased risk of mortality due to all causes compared with women who were socially integrated. - Women without children, close relatives or friends had high risks of all-cause mortality and breast cancer mortality compared with the most socially integrated women. - Neither participation in community or religious activities nor having a confidant was related to the results. - Women who were socially isolated had a high risk of mortality after being diagnosed with breast cancer

Leimeister <i>et al.</i> (2008)	To study whether OSGs meet their theoretical potential to offer an atmosphere in which social relationships can take place and help people with cancer to cope with their conditions.	Cross-sectional	301 participants	Kassel/Germany.	Influencing factors on the formation of virtual relationships and their effect in the form of social assistance are researched using an explorative approach. <ul style="list-style-type: none"> - An explorative research approach (Bortz and Doering, 2002). - Online questionnaire (Leimeister <i>et al.</i>, 2008) 	<ul style="list-style-type: none"> - Online relationships for patients took place in OSGs and play an essential role in accessing the social needs of the patients - The perceived disadvantages of OSGs and the intensity of general internet usage (active posting vs. lurking) are important factors for the formation of online relationships for patients - More than 61% of the changes of perceived social assistance of cancer patients were explained by cancer-related online relationships.
Gagliardi <i>et al.</i> (2009)	To assess the areas of anxiety, depression and social support in patients with breast cancer and healthy control respondents	Case - control		Ancona/Italy.	A sample of patient with breast cancer was compared with healthy control respondents using structural model of social network	<ul style="list-style-type: none"> - Women with breast cancer exhibited denser and smaller networks and higher degrees of depression and anxiety compared with healthy women, - Social support and social network measures correlated in a difference ways with anxiety and depression in the two cohorts.
Pinquart and Duberstein (2010)	To analyse the association of social network with cancer mortality	Meta-analysis	87 studies	Marburg/Germany.	Samples of studies identified from electronic database (Cochrane, PSYINDEX, MEDLINE and Psyclit) <ul style="list-style-type: none"> - The variable has been coded - Random-effects Models was used for meta-analysis 	<ul style="list-style-type: none"> - Divorced, widowed and /separated patients had lower mortality rates than never married patients - Younger patients exhibits stronger relationships of mortality with social network whereas associations of mortality with marital status were stronger in early-stage cancer in studies with shorter time intervals - Relationships differed by cancer site, since stronger relationships of social support were noticed in studies of patients with lymphomas and leukemia

						and stronger relationships with the size of network were noticed in studies of breast cancer
Beasley <i>et al.</i> (2010)	To investigate the association between elements of social interaction and survival in a large group of women survived from breast cancer	Cross-sectional	4,589	Seattle, WA/ USA	<ul style="list-style-type: none"> - Berkman- Syme social Network Index (<i>Berkman and Syme, 1979</i>) (measure social support) - Date for mortality was based on a national death index 	<ul style="list-style-type: none"> - Elevated degrees on a measure of social connectedness as measured by the rate of attendance of religious services, contacts with friend and family, and contribution in the activities of community was related to a 15-28% less risk of mortality from any cause - Reverse trends were seen between all-cause mortality and number of hours per week occupied in community activities as well as rate of attendance at religion services - No relationship between breast cancer-specific mortality and social networks were identified - Participation in different activity outside the home was related to lower general mortality rates.
Sjoland <i>er et al.</i> (2012)	To identify the meaning of social support networks for close family of adult people with gastrointestinal or lung cancer in their early stage of treatment	Cross-sectional	17 participants	Lund/ Sweden.	An interview. (The data has undergone qualitative latent content analysis and validated through identifying critical attributes and antecedents)	<ul style="list-style-type: none"> - The key attribute of the social support network was shown by the theme “Confirmation through togetherness” derived principally from encouragement, spiritual community, information, understanding and involvement - As antecedents to social support, three subthemes were emerged: Network to turn to, Desire for a deeper relationship with relatives and Need of support. - Social support contains reciprocal exchange of information, verbally and

						non-verbally offered generally by lay persons.
Menezes Rodrigues <i>et al.</i> (2012)	To describe the social support network of adult people with cancer	Cross-sectional	69 participants	Sao Carlos/ Brazil.	Convoy of Social Support (<i>Kahn and Antonucci, 1980</i>)	<ul style="list-style-type: none"> - Patients supposed that they offered more support than they received, except "Caring in a situation of disease." - The most common form of support offered and received was "Respect" and the least common was "Caring in a situation of disease." - The study showed the relevancy of affective bonds for patients and presented the limitation of families as the only supportive bonds.
Kroenke <i>et al.</i> (2012)	To clarify how both social support and social burden influence the relationship between size of social networks and level of breast cancer mortality	Prospective Longitudinal	4,530 participants	Oakland, CA/ USA.	Data collected from women diagnosed with breast cancer from 1993 to 2009 on: <ul style="list-style-type: none"> - Social networks (spouse or intimate partner, religious ties, club ties, and number of first-degree relatives) before diagnosis. 	<ul style="list-style-type: none"> - Being married was associated with reduced all-cause mortality among women with high but not low social support - By contrast, more of first-degree relatives, comprising children, parents and siblings, had greater breast cancer and all-cause mortality among women with high but not low social burden - Similar relationship by social strain was achieved although it was not influenced by level of social support. - Other members of social network were not related to mortality
Purinthrapibul <i>et al.</i> (2012)	To explore the characteristics of personal social networks among women with breast cancer in southern	Case study	5 participants	Hat Yai/ Thailand and Palmerston North/ New Zealand,	Qualitative interview (interviews, conversations, observations, social network mapping and document analysis)	<ul style="list-style-type: none"> - Women's personal social networks were mainly family work place-based and family-based only with some overlap. - The majority of the relationships between network members formed before diagnosis with cancer and continued through the cancer course

	Thailand					<ul style="list-style-type: none"> - Some women identified temporary relationships with health professionals in their social networks. - Relationships with other breast cancer patients were mainly established during treatment phases and some continued after treatment. - Characteristics of the network were influenced by illness experiences of the patients, the prior personal health and the network members.
Kroenke <i>et al.</i> (2013a)	To evaluate how levels of social support and burden influence the relationship between size of social networks and breast cancer mortality	Cohort /study	2264 participants	Oakland, CA/ USA.	<p>Data was taken from the Life After Cancer Epidemiology cohort study (Caan <i>et al.</i>, 2005) about women diagnosed with breast cancer from 1997 to 2000 and provided data on</p> <ul style="list-style-type: none"> - Social support, - Social networks (religious/social ties, spouse or intimate partner, number of first-degree female relatives volunteering and time socializing with friends) - Caregiving 	<ul style="list-style-type: none"> - Women with both levels of support and small networks low had a considerably higher risk of death than women with high levels of support and larger networks - No higher risk of death observed in women with high levels of support and small networks - Depending on the burden and quality of family relationships, larger social networks can predict better prognosis after breast cancer.
Kroenke <i>et al.</i> (2013b)	To examine mechanisms through which social relationships influence QoL in	Prospective Longitudinal	3,139 participants	Oakland/ USA.	<p>Data collected from women diagnosed with breast cancer between 2006 and 2011 on:</p> <ul style="list-style-type: none"> - Social support (informational support, emotional/ affection, 	<ul style="list-style-type: none"> - Women who were characterized as socially isolated had significantly lower QoL, physical well-being, functional, social, and emotional scores and higher breast cancer symptoms compared with socially integrated women.

	survivors of breast cancer				<p>tangible support, positive social interaction)</p> <ul style="list-style-type: none"> - Social networks (religious/social ties, the presence of a spouse or intimate partner, numbers of close friends and relatives as well as volunteering) - QoL, measured by the FACT- (Cella et al., 199 and, 1994) (2 months post diagnosis) 	<ul style="list-style-type: none"> - Every member of social network predicted higher QOL independently. - Adjustment for social support and social networks simultaneously, decreased relationships between social networks and QoL partially - QoL outcomes were predicted mostly by “Positive social interaction” - Higher levels of social networks and higher scores of social support were related to better QoL after a diagnosis of breast cancer
Ju et al. (2014)	To investigate the dynamics and scope of the support network of African American cancer patients and to recognize variables that may influence social support for African American cancer patients, specifically those who have depression	Cross-sectional	57 participants (34 depressed , 24 non-depressed)	Cleveland/ USA	Qualitative interview	<ul style="list-style-type: none"> - People with cancer who are African American indicated that their social network involves friends, family members, colleague, professional encounters with therapists or support group peers and church members. - More depressed patients (compared to non-depressed patients), significantly reported that they did not receive family support and they did not have a support system - People with cancer who are African American exhibited a significant relationship between a lack of social support and depression, mainly the family support.

Table 17: Studies related to the relationship between social networks and cancer

De Ruiter *et al.* (1993) claim that only a small proportion of QoL can be explained by social networks. However, the evidence for social networks establishes that social isolation increases the risk of mortality after being diagnosed with breast cancer, with the buffering effect for reduction being provided by relatives or friends and participation in activities outside the home (Kroenke *et al.*, 2006, Beasley *et al.*, 2010). This is supported by studies with younger people with lymphoma and leukaemia, and older males with cancer (Welin *et al.*, 1992; Pinquart and Duberstein 2010). Further support comes from the literature around older patients with cancer who experience greater levels of impairment which can be directly related to restricted social networks (Goodwin *et al.*, 1991). In addition, Sapp *et al.* (2003) have found an association between social networks and HRQoL, especially mental health in female colorectal cancer survivors. Moreover, Michael *et al.* (2002) has also concluded that social interaction at pre-diagnosis level is a significant factor in future HRQoL among females who experienced breast cancer and it appears to describe more of the differences in QoL than tumour features or treatment.

Although women with breast cancer appear to exhibit denser and smaller networks and higher degrees of depression and anxiety compared with healthy women, social support and social network measures correlate in different ways with anxiety and depression in the two cohorts (case and control) of breast cancer (Gagliardi *et al.*, 2009). Social networks also appear to have a mediating effect on anxiety and depression amongst cancer patients with family appearing to be the main source of social support compared to the community/ church or closest / best friend (Bauer *et al.*, 2005). The positive effect of social networks also applies cross-culturally with Hispanic and black ethnic groups who report that informal social networks such as civic clubs or extended family can supply more emotional help than formal support groups which enable them to continue treatment (Guidry *et al.*, 1997). In general, it appears that social networks can be more helpful in supporting recovery after diseases have arisen than in preventing the occurrence of new illness (Vogt *et al.*, 1992).

Sjolander (2012) suggests that social networks are one of three main antecedents to social support together with the need of support and the desire for a deeper relationship with relatives. He also suggested that the meaning of the social network for close family of cancer patients was expressed by a theme “Confirmation through

togetherness” derived mainly from encouragement, understanding, information, spiritual community and involvement. The importance of family support for patients with cancer patients was identified by Ju *et al.* (2014) who found a lack of family support to be significantly related to higher levels of depression, whereas Menezes Rodrigues *et al.* (2012) demonstrated the suitability of affective bonds for patients and argued about the limitations of families as unique supportive bonds.

The size of the social network in terms of improved prognosis and QoL of patients with breast cancer appears to be of importance (Kroenke *et al.* 2012; 2013a and 2013b). The same studies also suggest that social relationships may have both beneficial and adverse influences on breast cancer survival. However clarifying these findings may require understanding the context of the relationships between women. In addition, the network characteristics might be influenced by other factors such as the illness experiences and the network members of the women as well as their prior personal health (Purinthrapibal *et al.*, 2012). Online support groups appear to play a significant role in meeting patients' social needs, especially patients with cancer (Leimeister *et al.* 2008).

Summary

Head and neck cancer is commonly considered as the most emotionally traumatic of all tumours and has a multidimensional impact on patients' lives due to a series of functional and psychosocial impacts or consequences, with approximately half of patients reporting depression.

Recently, increased attention has been paid to the factors that may be linked to the risk for poorer psychological outcomes. Coping is one variable that might have a critical influence on health outcomes and it has been investigated widely among patients with different cancers especially breast cancer. However, only a few studies have been conducted on coping with H&N cancers.

The high rate of people experiencing depression might also be linked to pre-morbid factors such as lack of social support, which represents the highest percentage of the total coping effort. A considerable number of researchers have investigated the

influence of social support on health and found that social support has been consistently linked to physical and mental health. Social support has been studied widely from the perspective of psychosocial reactions to many medical conditions including cancer in general. However, only a few studies have been conducted on the relationship between social support and H&N cancer. These suggest that social support does appear to exert a positive influence for patients with H&N cancer, especially in relation to reducing the impact of anxiety, depression or depressive symptoms.

There have been relatively few studies conducted in relation to social networks and cancer and none of them deal specifically with H&N cancer. Social networks have been related to HRQoL and also appear to have a mediating effect on anxiety and depression amongst cancer patients. In relation to social support and H&N cancer, no studies so far have dealt with online social support for this group of patients although several H&N-OSGs and groups are available online.

3.3 Online support groups (OSGs)

3.3.1 Background

In the beginning of 20th century, support groups and group therapy appeared as a method of managing psychological issues. Group therapy for psychological problems was introduced in the 1930s to facilitate solving interpersonal disagreement. During the 1940s and 1950s, the use of this kind of group therapy increased as a means of supporting soldiers who experienced psychological problems after the Second World War (Fobair, 1997).

The health benefits of participation in face-to-face support groups have been reported in several studies (DiMatteo and Hays, 1981; Cohen and Syme, 1995; Sarason *et al.*, 1997). Examples of the reported benefits include favourable symptoms changes and adaptation to diagnosed illness (Spiegel *et al.*, 1981; Berger, 1985; Taylor *et al.*, 1988; Spiegel *et al.*, 1989).

Cancer support groups have been developing for more than 40 years and were originally delivered in the form of traditional face-to-face groups and led by a medical practitioner (Klemm *et al.*, 2003). Studies on face-to-face cancer support groups, in particular, reveal that these groups can diminish unpleasant emotional responses to cancer, promote coping, and assist members in resuming their everyday activities (Yossef, 1984, Taylor *et al.*, 1988).

Alongside traditional face-to-face groups, there are also the rise of online support groups (OSGs) which is related to the recent development in the Internet and technology and its use for health purposes. Since approximately half of Internet users report searching for support and health information and with the rise in technology, the percentage of users appears to have increased dramatically over the past thirty years (Rice, 2001). Indeed, searching for health information has become one of the most prominent reasons for Internet use (Christensen and Griffiths, 2003), and an increasing number of people with cancer are reportedly using the Internet as a method of support. The rise in internet use has been accompanied by a corresponding increase in the

number of online cancer support groups (Madara and White, 1997; Klemm *et al.*, 1999). Whilst other studies suggest that the Internet has modified the manner in which people work, learn, and find health-related information; it has become a part of their life (Madden and Fox, 2006).

The accessibility of the World Wide Web has led to ways of providing new opportunities for people with particular illnesses to communicate with each other and with health care professionals (Sullivan, 2003). In 2003, approximately 39% of people with cancer in the developed countries were using the Internet and approximately 2.3 million individuals with cancer worldwide are online (Eysenbach, 2003) and by 2005, hundreds of online cancer groups were existed with thousands of members in each (Im *et al.*, 2005). The internet has also been proposed as a facilitator in coping, offering support, and for making significant decisions after discussion with others online (Horrigan and Rainie, 2006). In general, OSGs for people with cancer appear to be effective sources of social support (Fogel *et al.*, 2002 and 2003).

3.3.2 Internet communication tools

There are numerous electronic communication tools available to people who live with cancer, these are discussed in more detail below:

3.3.2.1 Internet Discussion Groups

Considered as wide spread form of communication through the Internet usually called a Listserv. This is a subscription service to an existing discussion on a particular topic such as treatment or type of cancer. The subscription takes place either by filling an online subscription form or by posting an email to a central computer. The member will then be given an email address to communicate with all other subscribers. This service allows users to send or receive messages 24 hours a day (Sharp, 2000).

3.3.2.2 Web forums

Web forums work by posting messages through a website on a specific topic to be read by others. These messages appear immediately on the website after being posted and are usually classified under a specific topic and sometimes termed as "threads".

Members of web forums have the opportunity to post their individual stories. This may have a potential benefit in the form of therapeutic value to the survivors who write their stories and provide a means of validation from other readers who have similar experiences (Sharp, 2000).

3.3.2.3 Chat rooms

These rooms are also a popular form of online communications, but unlike the previous tools, depend on live communications through the web, so there is an opportunity for numerous individuals to explain specific issues at the same time. Sometimes they are administered by an expert or health professional to provide answers for member's questions at a scheduled time (Sharp, 2000).

The tool that will be used in the current study is Web forums, and since online support is exchanged within these forums, they are sometimes called online support forums (or online support groups "OSGs"). This kind of online communication tool has been chosen because it offers an opportunity for the members to post their stories. Although some OSGs require subscription or registration to view, post and receive messages, many OSGs are available to the public and even people who are not registered can benefit from messages in the form of stories that illustrate diversity and a range of experiences.

The administrators of online cancer support groups usually aim to provide a range of functions; comprising of psychological understanding and support, offering hope and encouragement for people with cancer and their families, discussing different treatments for cancer and distributing information on the latest updates of treatment and their side effects (Finfgeld, 2000; Han and Belcher, 2001; Henderson and Fogel, 2003; Klemm *et al.*, 2003).

A review of the literature indicates that cancer support groups do not use special moderators, but they are usually owned or facilitated by a person who has expertise in using computers and may sometimes be a cancer survivor (Klemm *et al.*, 2003). The responsibility of the moderator is to subscribe and unsubscribe members, solve technical problems and reply to enquiries related to the forum (Klemm *et al.*, 2003).

3.3.3 Demographics of online support group users

Fisher *et al.* (2009) suggests that the demographics of web tool users indicate that users were within a wide range of ages from 30 - 70, which illustrates the use of Internet by both younger and older people, and this was also the case for OSGs (Seçkin, 2011).

In terms of gender, it is not clear whether there are differences by gender in OSGs use. Reviewing the literature showed that the majority of OSGs users were female in some studies (Sullivan, 2003; Kraan *et al.*, 2006; Lieberman, 2008; Fisher *et al.*, 2009), while others found the opposite.

One researcher claims that the under representation of men might be explained by suggesting that men experience greater fear and anxiety (Lieberman, 2008), while others argue that men have the tendency to hide personal details and stories that may exhibit them as vulnerable or weak (Tannen, 1990). In addition, Wood and Inman (1993) suggest that, in general, males do not value conversations about problems and feelings as much as real activities or assistance that may divert them from their issues. Women do seem to have more concern for a wider network of people and a greater tendency to be engaged in assistance providing activities than men (Kessler and Mcleod 1985).

It appears that using OSGs can differ by race, for example, Im *et al.*, (2005) revealed that ethnic minorities were rarely users of OSGs. In addition, African Americans were found to be under-represented in OSGs compared to their white counterparts (Fogel *et al.*, 2008). This difference was also noticed in more recent studies investigating the use of OSGs by Asian and White persons (Im *et al.*, 2010; Im *et al.*, 2011). This under representation might be related to three possible reasons; preference to culture-specific

online groups or face-to-face groups, digital inequality/ digital divide (that a health inequality exists with regard to the use of information that can be achieved from OSGs) and trust concerns (that African Americans appeared to have an issue in trusting information and users of OSGs) (Fogel *et al.*, 2008).

With regard to other socio-demographic factors, different studies exhibited varying characteristics for the users of cancer OSGs. Im and Chee, (2004) suggest that people with cancer who use OSGs tend to be white, of high income and highly educated, but also seriously unwell (the majority of them in advanced stages of cancer). However, another study advocated that users of cancer OSGs appeared to be white males who were of high income and highly educated and were healthier compared with their counterparts in the face-to-face groups (Fawcett and Buhle, 1995). Others suggested that participants on OSGs can be influenced by many factors such as type of disease culture, need, background and Internet use factors (Im, 2011). Therefore, it is difficult to draw conclusions from studies to date, as the characteristics of OGGs users are not clear in the literature, and further research is required.

3.3.4 Advantages and disadvantages of online support groups

A review of the literature suggests that OSGs have a set of advantages and disadvantages some of which are included below:

3.3.4.1 Advantages

1. OSGs for people with cancer offer personal and professional support, information, patient advocacy and shared experiences (Bastian, 2008).
2. Reducing barriers associated with face-to-face support groups:
 - a. Geographic distance; people who live in remote places can receive and give support from the comfort of their homes (Scott, 1999).
 - b. Members do not have to be physically present in a particular place and at a certain time with others, and there is no need to wait for a weekly group meeting

as they can post their messages at any time, even out of the normal working business hours. Online groups were found to be more active between 7:00pm and 1:00am (Ferguson, 1996). Members, therefore, can still receive support even when they are alone at night which is usually the time when doubts and fears surface (Hoybye, 2002; Weis, 2003; Winzelberg *et al.*, 2003).

- c. Visual distractions such as gender, age, dress and socioeconomic status which are common drawbacks in conventional face-to-face support groups are not found in OSGs (Madara and White, 1997; Martin and Youngren, 2002).
 - d. Size of the group no longer represents a barrier to the members (Scott, 1999). In addition, other barriers such as children and baby sitters, health condition of the participants, parking, accommodation and any related social anxiety are also eliminated (Braithwaite *et al.*, 1999; Sullivan, 2003; Winzelberg *et al.*, 2003).
3. Online support groups provide an accessible and convenient environment for participants (Fernsler and Manchester, 1997; Sharf, 1997) for example:
- a. Beside the 24 hours accessibility and availability of communication with people enrolled in OSGs, another benefit is the opportunity to participate selectively without any pressure (Klemm *et al.*, 1999; Han and Belcher, 2001).
 - b. The anonymity provided by OSGs appears to enable participants to discuss their anxieties and difficult feelings in a less stressful way (Sharp, 2000), since they can raise “taboo topics” or express negative emotions without embarrassment or fear of rejection (Scott, 1999). In addition, some researchers suggest that anonymity can provide safer surroundings to the participants to undertake creative and non-conforming examples of support such as poetry writing (Braithwaite *et al.*, 1999).
4. OSGs are connected with reduced costs compared to face-to-face groups, since fewer resources are needed for managing online groups (Finfgeld, 2000; Winzelberg *et al.*, 2003). Online groups may reduce the economic expense of phone calls for people with cancer looking for cancer-related information. They may also develop

feelings of connectedness between people with cancer and their support environment (Fisher *et al.*, 2009).

5. The ability to share ideas and feelings in virtual or real time can act as a way of sharing information and help people with cancer to become more conscious of the disease and its treatments (Smith, 1998). The informational support that members receive from others with the same disease may supply members with a sense of control over their experiences (Martin and Youngren, 2002).

6. The flexibility provided by OSGs can allow users to read others' postings without making an immediate response, deciding on what is of relevance to them, and the amount of time and support they feel they require (Finfgeld, 2000; Sullivan, 2003).

7. Participation in OSGs allows people with cancer to avoid being looked at particularly if there is a lot of surgery that alters their face or speech, and people who may hesitate to join face-to-face groups may feel more comfortable using OSGs (Finfgeld, 2000).

8. People with uncommon or rare cancers who use OSGs may have the opportunity to feel the sense of "they are not alone". Such an opportunity is hard to achieve in face-to-face support groups because the group is restricted to a small number of people locally compared to an online group which people can access and participate from anywhere in the world (Sharp, 2000).

9. OSGs provide cancer survivors who have finished their treatments with the opportunity to help others (Sharp, 2000). They can write messages on specific topics to hundreds of people (Sullivan, 2003).

10. Many cancer OSGs consist of members who are medical professionals specialising in cancer (Sharp, 2000).

11. It has been noticed that OSGs are unique since they create and enforce their own rules (Sharp, 2000).

3.3.4.2 Disadvantages

1. There is doubt about the quality of the information and support offered by some online OSGs (Martin and Youngren, 2002; Coulson, and Knibb, 2007; Malik and Coulson, 2010; Mo, and Coulson, 2014a), this might be because of the difficulties in controlling interactions (Kraan *et al.*, 2006) or the lack of professional moderators for cancer OSGs (Klemm, *et al.*, 1998). Information might be based only on personal experience or unproven methodologies and not on scientific evidence or medical advice, it may, therefore provide wrong or misleading information (Sharp, 2000). In addition, users should be told that clinical information from the physician should not be replaced by other information from a person on the Internet (Martin and Youngren, 2002).
2. The credentials of the message posters are hard to be verified and it is possible that anyone can post messages posing as a cancer survivor. This may reduce the credibility of OSGs (Martin and Youngren, 2002).
3. Individuals from different backgrounds can participate from anywhere in the world and not all OSGs are monitored, security and use of offensive language may be possible issues, therefore, users should be warned to not provide personal details, such as name, address and bank account. They also should be informed about the possibility of finding offensive language in the OSGs (Mizsur, 1997). Presence of such inappropriate behaviour in OSGs can be considered as a potentially disempowering process (Mo, and Coulson, 2014a).
4. Communication through OSGs means that there is a lack of verbal intonation which aids communication and facial expressions making it difficult to perceive and decipher meaning and is considered a disempowering process (Finfgeld, 2000; Mo, and Coulson, 2014a).
5. Delay in response to enquiries and the normal lag time between posing an enquiry or seeking support and receiving responses may be distressing to the senders (Martin and Youngren, 2002).

6. Sometimes, people may require a long time to gain confidence and display a level of trust great enough to interact with OSGs (Finfgeld, 2000).

7. As in conventional support groups, unsupportive communications or conflicts may happen in online groups (Sharp, 2000). For example, expressing and reinforcing negative emotions and remarks or posting negative experiences with OSGs can be seen widely (Kraan *et al.*, 2006; Malik and Coulson, 2010; Holbrey, and Coulson, 2013).

8. Lack of professional moderators from many OSGs may put those who feel emotionally vulnerable at risk of being victimised (Sharp, 2000).

9. As in face-to-face support groups, the issue of death is one of the problems that affect OSGs, persons in the OSGs may be affected emotionally when they hear a member of the group has died. This issue is dealt with online as in real life with empathy, whilst at the same time being remote from the situation. However, the fear of a similar fate for other members in the future is still an issue (Sharp, 2000).

3.3.5 Face-to-face versus online support groups

Some studies have investigated OSGs comparing them to traditional face-to-face groups (Klemm *et al.*, 2003; Golant *et al.*, 2004; Broom, 2005; Im *et al.*, 2005). Whilst some studies (Golant *et al.*, 2004) suggested that generally the two groups were very similar, others (Klemm *et al.* (2003) suggested that people with depression and cancer were more likely to use OSGs than face to face groups. What is unclear is whether people had depression before diagnosis or the diagnosis of cancer exerted a negative effect on their coping strategies.

Benefits of OSGs for people with cancer over the traditional face-to-face groups are that they enable people to share experiences, obtain information, vent feelings, receive support and have accessibility to other people with similar experiences and diagnoses (Finfgeld, 2000; Han and Belcher, 2001; Henderson and Fogel, 2003). In addition, some researchers argue that the characteristic nature of online communications allow OSGs to offer a type of support that cannot be attained with face-to-face counterparts

(Lamberg, 1997; Sharf, 1997; Turner *et al.*, 2001). This may be related to the lack of non-verbal communication, facial cues, the degree of anonymity that OSGs provide, and the ability to disclose and reveal sensitive information (Walther 1996, Hardey 1999, Turner *et al.*, 2001).

Some drawbacks of OSGs are suggested in a few articles in that receiving large numbers of emails may be a form of communication overload and stressful for members, unsupportive messages being posted create negative emotions, and the lack of interpersonal contact which is sometimes necessary for effective communication (Finfgeld, 2000; Han and Belcher, 2001; Henderson and Fogel, 2003). In contrast, the majority of the published research appears to suggest that there are more positive factors than negative for members of OSGs (Klemm and Hardie, 2002; Martin and Youngren, 2002; Klemm *et al.*, 2003; Lieberman *et al.*, 2003; Winzelberg *et al.*, 2003).

3.3.6 Mechanism by which OSGs may be beneficial

Online cancer support groups have been found to be associated with a reduction in the levels of both physiological and psychological stress in their members (Golant *et al.*, 2004). There are a number of possible explanations for this. Firstly, one possible explanation is that OSGs provide members with a safe environment to vent the intense emotions usually associated with cancer (Golant *et al.*, 2004), enabling them to discuss the challenges of their disease with others who have similar experiences (National Cancer Institute, 2002). Another explanation is that using OSGs for people with cancer increases social support because they increase patients' self-esteem, personal empowerment and functional status and decrease reported depression, reduce feelings of helplessness, distress, and social isolation (Fogel *et al.*, 2002; Houston *et al.*, 2002, Lieberman *et al.*, 2003; Winzelberg *et al.*, 2003; Shaw *et al.*, 2006). OSGs may also improve survival rates of members because they provide a sense of belonging and address anxiety about treatment, leading to better coping and resilience (Han and Belcher 2001, Martin and Youngren 2002).

A variety of studies have explored OSGs for other health conditions such as (food allergy, dental anxiety, infertility, HIV/AIDS, families affected by childhood cancer, Parkinson's disease, Polycystic Ovary Syndrome, Inflammatory Bowel Disease, permanent involuntary childlessness and prostate cancer). These have suggest that OSGs can provide social support; particularly informational and emotional, improve and provide a guide on coping strategies, reduce the sense of isolation, loneliness and levels of depression and anxiety, improve planning and increase levels of optimism towards life (Coulson, and Knibb, 2007; Coulson, and Buchanan; 2008; Malik, and Coulson, 2008; Mo, and Coulson, 2010b; Elwell *et al.*, 2011; Mo, and Coulson, 2011; Attard and Coulson, 2012; Coulson and Greenwood, 2012; Campbell, *et al.*, 2013; Mo, and Coulson, 2014a; Mo, and Coulson, 2014b) (See Table 18 for details).

Several studies have indicated that OSGs can benefit users through enhancing the process of empowerment (van Uden-Kraan *et al.*, 2008; Malik and Coulson, 2008; Mo and Coulson, 2010a; Bartlett and Coulson, 2011; Mo and Coulson, 2011; Holbrey and Coulson, 2013; Campbell *et al.*, 2013; Mo and Coulson, 2014a; Mo and Coulson, 2014b). Details of all of these studies are available from Table 18.

A range of empowerment processes have been reported including; access to and exchanging information, finding recognition, encountering social support and understanding, connecting with others who understand, discussion of sensitive topics, comparison with other members, helping others, sharing experiences, cognitive guidance, amusement, connecting a group of members, supporting the self-esteem of members, interaction with healthcare professionals; improved adjustment and management and treatment-related decision making (Bartlett and Coulson, 2011; Mo and Coulson, 2011; Holbrey and Coulson, 2013; Campbell *et al.*, 2013; Mo and Coulson, 2014a).

There has also been a range of empowerment outcomes predicted adequately by empowerment processes including; feeling better informed, increased confidence in relationships with physicians, increased acceptance, increased confidence in treatment, improved disease management, enhanced self-esteem, enhanced social and emotional well-being and increased optimism and hope for the future (Bartlett and Coulson, 2011; Mo and Coulson, 2014a).

In addition to these studies, the mechanisms by which OSGs can be beneficial to its users have been examined more clearly by Mo and Coulson (2012) in relation to HIV/AIDS. This cross sectional study investigated the mechanisms by which participation in OSGs may enhance empowerment among 340 individuals with HIV/AIDS through measuring OSGs use, empowering processes, self-care self-efficacy, coping and QoL. Findings indicate that higher frequency of OSGs use (Lengths of time since participants started using HIV/AIDS-related OSGs, number of days they accessed these groups per week and number of hours spent accessing in the average week) was related to greater rates of empowering processes facilitated by receiving social support, receiving useful information, helping others and finding positive meaning. Mo and Coulson (2012) in this study also suggest that receiving useful information and experiencing positive meaning were linked to reduced levels of maladaptive coping and greater levels of adaptive coping. Helping others and receiving social support were linked to greater levels of self-efficacy, self-care, and linked to lower levels of maladaptive coping and greater levels of adaptive coping. Greater levels of adaptive coping were linked to better QoL, while greater levels of maladaptive coping were linked to poorer QoL. (More details about this study can be found from Table 18).

This evidence suggests that there is an important place for OSGs in supporting people diagnosed with cancer, and that future research in relation to OSGs and their role in improving QoL and other psychosocial outcomes is worthwhile. However, there have been no studies to date investigating the mechanisms by which OSGs can influence the QoL and well-being of people with H&N cancer.

Author /date	Aim	Study design	Sample	Country	Method	Result
Coulson and Knibb (2007)	To investigate the reasons for participation in an OSG for people affected by food allergy, its perceived disadvantages and advantages as well as influence on the relationship with providers of healthcare	Cross-sectional	32 participants	UK	Online structured interview	<ul style="list-style-type: none"> - Several benefits have been identified by group members including receipt of social support, accessibility together with guidance on coping strategies. - The only drawbacks identified were about the trust and accuracy in the exchanged information within the group - participation in the group appeared to have a role on relationships with providers of healthcare - Members reported greater empowerment through decision-making.
Malik and Coulson (2008)	To investigate the experiences of people accessing infertility related OSGs.	Cross-sectional	95 participants	UK	<ul style="list-style-type: none"> - Background information including age, gender, country and diagnosis of infertility - Open-ended questions exploring reasons for accessing OSGs. 	<p>Five recurrent themes were identified</p> <ul style="list-style-type: none"> - Improved relationship with partner, - Unique features of online social support - Information and empowerment - Reduced sense of isolation - Negative aspects of online communities.
Coulson and Buchan (2008)	To investigate the self-reported effectiveness of existing dental anxiety related-OSGs in the view of perceived level of anxiety since start using OSGs.	Cross-sectional	91 participants	UK	<ul style="list-style-type: none"> - The Modified Dental Anxiety Scale (MDAS) (<i>Humphris et al. 1995</i>). - Respond to the statement rated the changes in level of dental anxiety with using OSG on five Likert scales ('greatly lessened', 'somewhat lessened', 'stayed much the same', 'somewhat 	<ul style="list-style-type: none"> - Sixty percent of the participants considered OSGs had greatly or 'somewhat' lessened their anxiety. - Overall MDAS scores were significantly less in the 'greatly lessened' group

					increased,’ and ‘greatly increased’).	
Mo and Coulson (2010b)	To investigate the relationship between using OSG and health status, social support and coping in HIV/AIDS patients	Cross-sectional	640 individuals	UK	<ul style="list-style-type: none"> - Questions about medical history - Questions about OSGs use - The Medical Outcomes Study Short form 36 (SF-36v2) - The Brief COPE (Carver, 1997) - The Medical Outcomes Study Social Support Survey (MOS-SSS). 	<ul style="list-style-type: none"> - Frequent users seemed to be single, younger, female, and in a more advanced stage of disease - poorer health was reported by frequent users than non-users - higher scores in active coping planning, tangible and emotional support coping were reported from both infrequent and frequent users scored - No significant difference was noticed for social support.
Mo and Coulson (2010a)	To investigate how different levels of contribution in OSGs are related to empowering processes and outcomes for people with HIV/ AIDS.	Cross-sectional	340 individuals	UK	<ul style="list-style-type: none"> - An online questionnaire consisting of: - Empowering processes scales of (van Uden-Kraan, et al., 2008). - The Strategies Used by Patients to Promote Health (SUPPH) Scale (Lev and Owen, 1996). - The UCLA Loneliness Scale (Russell, 1996). - The Life Orientation Test revised (LOT-R) scale (Scheier, Carver, and Bridges, 1994). - Brief Cope (Carver, 1997). - The Center for Epidemiologic Studies Depression Scale-revised (CESD-R) (Eaton et al., 2004) - The Medical Outcome 	<ul style="list-style-type: none"> - Lurkers scored lower “compared to posters” in receiving useful information and receiving social support in empowering processes, and lower in satisfaction with their relationship with members of the group - Lurkers also scored lower in planning and social function and higher in distraction and in energy. - There were no significant differences in loneliness, optimism, self-care self-efficacy or depression, between lurkers and posters. - lurking in the OSGs may be as empowering as reading and posting messages to the groups.

					Study HIV Health Survey (MOS-HIV) (Wu, et al., 1997).	
Malik and Coulson (2011)	To compare the experience and use of infertility-related OSGs between posters and lurkers	Cross-sectional	295 participants	UK	<ul style="list-style-type: none"> - Online questionnaire containing questions about the use and experience of OSGs and measures of social support, loneliness, perceived infertility-related stress and marital satisfaction. 	<ul style="list-style-type: none"> - Compared with posters, lurkers visited OSGs less frequently and scored significantly lower in overall satisfaction with OSGs. - There were no significant differences in social support, loneliness, marital satisfaction and infertility-related stress between posters and lurkers.
Bartlett and Coulson (2011)	To examine the potential of OSGs to enhance empowerment and how membership might influence the relationship between patients and health professional	Cross-sectional	246 participants across 33 OSGs	UK	<ul style="list-style-type: none"> - Demographics and OSGs related questions - Questions from van Uden-Kraan et al., (2008) - Questions about Participants' - professional relationship. 	<p>All empowerment processes and outcomes identified by van Uden-Kraan et al. (2008) were found</p> <ul style="list-style-type: none"> - the most commonly found empowerment process was comparison with other members - The most commonly found empowerment outcome was feeling better informed.
Mo, and Coulson (2011)	To analysis messages posted to OSGs and investigate the presence empowering processes and how may empower people living with HIV/AIDS	Cross-sectional	1162 messages	UK	A hybrid inductive-deductive thematic analysis	Empowering processes of HIV/AIDS related -OSGs participation was best captured in following themes: encountering emotional support, exchanging information, helping others understanding, sharing experiences, finding recognition, supporting the self-esteem of members, amusement, cognitive guidance, and connecting a group of members
Elwell et al. (2011)	To investigate the dimensions of social support offered to adolescents with cancer	Cross-sectional	393 messages	UK	A deductive (Theory-driven) thematic analysis (Hayes, 1997)	Frequent instances of both emotional and informational support provision and sub-themes including: <i>losing friends, treatment concerns and struggling with</i>

	who use a computer-mediated support group					<i>school.</i>
Mo and Coulson (2012)	To explore the mechanism through which participation in OSGs may enhance patient empowerment among people with HIV/AIDS.	Cross-sectional	340 participants	UK	Questionnaire contain: <ul style="list-style-type: none"> - Demographic and medical information. - Questions on OSGs use - Empowering Processes Scale (<i>Mo and Coulson, 2010a</i>) - The Strategies Used by Patients to Promote Health Scale (<i>Lev and Owen, 1996</i>). - The Brief Cope (<i>Carver, 1997</i>) - The Medical Outcome Study HIV Health Survey (<i>Wu, et al., 1997</i>) 	<ul style="list-style-type: none"> - Greater use of OSGs was related to frequent occurrence of the empowering processes as measured by: (receiving social support, receiving useful information, helping others and finding positive meaning) - Finding positive meaning and receiving useful information were associated with lower levels of maladaptive coping and higher levels of adaptive coping. - Helping others and receiving social support were associated with higher levels of self-care self-efficacy, which subsequently was associated with lower levels of maladaptive coping and higher levels of adaptive coping. - Higher levels of adaptive coping were associated with better quality of life while higher levels of maladaptive coping were associated with poorer quality of life.
Coulson and Greenwood (2012)	To investigate the role of OSGs in supporting families affected by childhood cancer	Cross-sectional	487 messages	UK	Deductive thematic analysis using SSBS (<i>Cutrona and Suhr's, 1992</i>)	<ul style="list-style-type: none"> - All five types of social support (i.e. information, emotional, esteem, network and tangible assistance) were available. - Both informational and emotional support were the most frequent
Attard and Coulson (2012)	To gain an awareness about the negative and positive aspects of virtual	Cross-sectional	1013 messages	UK	Data-driven thematic analysis using Braun and Clarke (2006) framework	Participation in OSGs allowed patients to share knowledge and experiences form friendships, and help them to cope with the challenges of living with Parkinson's

	communication through analysing messages posted within Parkinson's disease discussion forums					disease.
Holbrey and Coulson (2013)	To explore the experiences of women living with Polycystic Ovary Syndrome who use an OSG related to issues surrounding this illness.	Cross-sectional	64 participants	UK	<ul style="list-style-type: none"> - An online questionnaire, consisted of closed and open-ended items - Closed items included the following: demographic information, medical status and the use of OSGs - Seven open-ended items explored participants' motives for accessing the OSGs as well as their experiences. 	<ul style="list-style-type: none"> - Several empowering processes were reported including (Access to information and advice, Connecting with others who understand; Treatment-related decision making; Interaction with healthcare professionals; Improved management and adjustment) - The disempowering processes, included: (Reading about the negative experiences of others and Feeling like an outsider).
Coulson and Shaw (2013)	To assess the views of moderators across a varied and geographically broad range of OSGs about their experiences and to explore both the challenges and the personal benefits involved	Cross-sectional	33 patient moderators	UK	An online questionnaire including a series of open-ended questions specifically concerned with moderator role.	<ul style="list-style-type: none"> - Three themes; <i>empowerment</i>, <i>emergence</i> and <i>nurturing</i>. - Several moderators indicated their own diagnosis and being able to share personal experiences motivated them to establish the group. - They felt empowered by learning more about other's conditions and helping others through accessing the "communal brain".
Coulson (2013)	To assess how participation in OSGs may affect the experience of people with Inflammatory Bowel Disease (IBD).	Cross-sectional	249 participants	UK	<ul style="list-style-type: none"> - An online questionnaire included background questions about the participant and use of IBD OSGs. - Questions about the reasons for accessing OSGs 	<ul style="list-style-type: none"> - Patients reported being members for about two years, with the majority accessing the group everyday (46.9%) or every week (40%) - Members spend on average four hours per week online, - Almost two-thirds of members posted

					- A series of open-ended questions about online experiences.	between 1 -5 messages per week.
Malik and Coulson (2013)	To recognise the role of OSGs in the lives of women encountered with permanent involuntary childlessness.	Cross-sectional	224 messages	UK	A thematic analysis (A phenomenological analysis (<i>Beck, 1994</i>).	OSGs appeared to empower women to move on with their lives and learn a new sense of identity and self-worth after that of motherhood.
Campbell, <i>et al.</i> (2013)	To assess empowering processes within prostate cancer - related OSGs	Analytical Cross-sectional	682 messages	UK	Coding for the presence of potentially empowering processes (<i>van Uden-Kraan et al., 2008</i>).	All the six potentially empowering processes were exist; providing emotional support, providing information, providing esteem support, discussion of sensitive topics, chit-chat and noting similarity of experiences.
Mo, and Coulson (2014a)	To examine how OSGs might enhance empowerment and the potential disadvantages associated with using OSGs among people with HIV/AIDS	Cross-sectional	115 participants	UK	An online questionnaire contain 1. Background information, 2. Series of open-ended questions exploring: - Reasons for participating in OSGs, - Differences between support obtained online and face to face - Perceived advantages and disadvantages of using OSGs - Impact of OSGs use on disease treatment (<i>Buchanan and Coulson, 2007; Coulson and Knibb, 2007</i>)	- Thematic analysis showed six empowering processes; (sharing experiences, exchanging information encountering emotional, support, connecting to others, helping others and finding understanding and recognition). - Six empowering outcomes were identified; (emotional well-being, increased optimism, improved disease management, social well-being, feeling confident and being better informed, in the relationship with physicians). - Potentially disempowering processes included: (inappropriate behaviour online, being unable to connect physically, information overload, misinformation, and declining real life

						relationships)
Mo and Coulson (2014b)	To investigate the psychological impact of using OSGs for people with HIV/AIDS.	Cross-sectional	340 participants	UK	<p>An Online questionnaire contain</p> <ul style="list-style-type: none"> - Demographic and medical information - Question about using OSGs (<i>Nonnecke, 2006</i>) - Empowering processes Scale (<i>Mo and Coulson, 2011</i>). - The UCLA Loneliness Scale (<i>Russell, 1996</i>) - The Life Orientation Test-revised (LOT-R) Scale (<i>Scheier et al., 1994</i>) - The Center for Epidemiologic Studies Depression Scale-revised (CESD-R) (<i>Eaton et al., 2004</i>) 	<ul style="list-style-type: none"> - People who participate more in OSGs had higher levels of empowering processes, and subsequently, had higher degrees of optimism toward life. - Optimism was associated with lower levels of loneliness and depression while loneliness was also associated with higher degrees of depression.

Table 18: Beneficial aspects of OSGs

3.3.7 Ethical considerations in internet research

3.3.7.1 Introduction

Online support groups appear to play an important role in promoting mutual patient-to-patient support, customer health information and practitioner-patient communication (Skinner, 2002). This has led to a growth in the number of researchers using data from the internet to investigate the interplay of health behaviour and health services. The main aim of ethics is that no harm should come to people as a result of research and several articles have been issued on the significance of ethical issues in research that use Internet groups (Jones, 1994; Roenoer *et al.*, 1995; Allen, 1996; Reid 1996; Frankel and Siang, 1999; Rodriguez, 1999; Sharf, 1999; Hsiung, 2000; Eysenbach and Till 2001; Sixsmith and Murraray, 2001).

The internet provides access to an unprecedented archive of human life and activities (Lindif and Shatzer, 1998; Jones, 1999). It differs from other communication tools and media in many aspects that may influence study design. It reaches past national borders, cultural boundaries and legal jurisdictions (Mitra and Cohen, 1999; Geist, 2001; Commercenet, 2002). It incorporates various patterns of content and ways of communication (DiMaggio *et al.*, 2001) and offers technical advantages for efficient data collection and processing (Lindlif and Shatzer, 1998; Turkle, 1999).

These disparities between face-to-face and online environments oblige researchers to adapt existing methods used for face-to-face research. Adapting some methods and using them for online environments may become difficult due to the ethical conventions of some disciplines (Frankel and Siang, 1999; Bruckman, 2002).

Every unique research methodology is bound by and has different ethical considerations during the course of designing, conducting and reporting of the research (Emerton and Bowles, 2003). For example, in some internet mediated research the extent of risk to participants might not be easy to manage due to the lack of direct control over the behaviour and identities of the participants. Accessibility to the internet may be an issue and might exhibit implications for consent, debriefing, withdrawal and participants' protection (Hewson and Buchanan, 2013).

As is the case in the offline life, the internet has a community and while the offline community is commonly defined as a cohort of people with different characteristics share common views, linked by social ties, and involves in combined action in geographical locations (MacQueen *et al.*, 2001). Internet communities appear to be built on sharing interests rather than sharing demographical features (Wellman and Gulia, 1999). The idea of conceptualising internet research sites as communities comes from the view that participants with their textual traces are dealt with as human subjects.

Historically, community has usually been identified with place (Frenback, 1999; Jones, 1999) and this led researchers to view the Internet environments as cyber-communities or virtual communities (Cavanagh, 1999; Fernback, 1999; Bassett and ORiordan, 2002). However, common methods of categorizing spaces can be difficult in Internet research as they do not have a tangible base, may disappear without notice, and borders may not be easily defined due to hyperlinks and other complexities in designing software (Mita and Cohen, 1999).

3.3.7.2 Implications and guidance for researching ethically on the internet

The welfare and rights of any participants who may be influenced directly or indirectly during studies that include human beings are protected by the terms and conditions of the human subject protocol (NHMRC, 1999). Participants' rights have also been protected by international guiding principles of ethical research which come from The Belmont report (NCPHSBBR, 1979; Harrington *et al.*, 2010) and suggest:

“ 1- Respect for persons

2- Beneficence (the importance to maximise possible benefits and minimise possible harms)

3- Justice”

Introducing guideline ethics for online research starts with the hypothesis that online research containing human subjects should obey existing models (White, 2002). However, some problems have been identified in experimental research including the wide variation in the sites on which online research can be conducted (Kendall, 1999;

DiMaggio *et al.*, 2001). In addition, establishment of valid, ethical research requires that the methodology matches the characteristics of the site to the aim of the study (Emerton and Bowles, 2003).

The implications and guidance for researching ethically on the internet are discussed briefly from four perspectives; confidentiality, informed consent, harm and linking public and private data, which are explored in more detail in the next section.

3.3.7.2.1 Confidentiality in online research

Research suggests that online content in the public domain are based on the inherited insecurity of information posted online (Jones, 1994; King, 1996; Waskul and Douglass, 1996). Therefore, it is assumed that Internet users should understand that their online information can be susceptible to manipulation, interception and republication. However, it is hoped to apply private status to all sites to protect users, using the principal that their privacy is altered by the medium (Boehlefeld, 1996; King, 1996).

Numerous criteria have been proposed to determine the extent of privacy proposed by online sites users. For example, technical constructions of a site such as *use of encryption software, passwords or members only* can give views of users' expectation about "private" and public sites (Allen, 1996, Boehlefeld, 1996). This is particularly beneficial in mixed sites that have different privacy settings such as bulletin boards or chat rooms (Emerton and Bowles, 2003).

3.3.7.2.2 Informed consent

The World Medical Association Declaration of Helsinki (2000) has confirmed the ethical principle of autonomy to health research, that participants deserve respect and their rights to privacy, dignity and health should be protected at all times (WHO, 2001). This concept is usually established via the process of informed consent, in which participants are informed about the ethical aspects of a study and they have the chance to freely discuss and decide whether they wish to participate (Frankle and Siang, 1999; Tri-council of Canada, 2000). However, lack of personal contact in

online research can lead to a range of ethical and research concerns such as difficulty in enrolment and seeking informed consent (Flicker *et al.*, 2004), since the methodology used in traditional face-to-face contact- when consent is obtained as a signed authority document- is not practical and seems to be unworkable in internet research (Bassett and O'Riordan, 2002; Walther, 2002). Therefore researchers suggested that the whole procedure of online research should be established online (Nosek and Banaji, 2002).

Obtaining informed consent online requires all the components that would routinely be part of the consent procedure to be available online. These can be placed individually or collectively in a hyperlink through the internet (Flicker *et al.*, 2004). However, researchers sometimes face the logistical difficulty of contacting participants as they need to decide who the participants are and the type of consent needed. In addition, it is not guaranteed that online research participants may share demographic variables with the online identity used in the research site (Frankel and Siang, 1999; Walther, 2002). This can be an issue especially if the mental capacity or age of the participant provides a legal barrier to them being legally unable to provide informed consent (Junes, 1994; Bruckman, 2002; Walther, 2002). Some researchers believe that negotiations should start with the group owner prior to data collection (Waskul and Douglass, 1996). Ess and The Association of Internet Researchers recommended that obtaining permission from facilitators, moderators or list owners might be enough in the online sites with indefinite group membership (Ess and AoIR, 2002).

3.3.7.2.3 Harm

Researchers are responsible for the protection of research participants from inadvertent harm during the research process (NHMRC, 1999). Protecting confidentiality and privacy of the participants on the internet is a new challenge for the research environment (Frankel and Siang, 1999; Eysenbath and Till, 2001). These challenges can include limiting online data for service delivery and research purposes, protecting online support users from other users or from themselves and ensuring that results do not trigger embarrassment, breach privacy or cause inadvertent harm to participants (Flicker *et al.*, 2004).

Researchers can directly harm their participants, harm the setting of the research or ease harm by third parties (Emerton and Bowles, 2003). However, with online contact, low chance for physical harm can be seen as a risk, but inadvertent direct harm by researcher focus on two concerns; failure to observe the results of the research and breaching of the trust and expectations (Emerton and Bowles, 2003). Other insults, threats, blackmail and harassment, which also takes place in the office environment, may appear in unique forms in the online environment. However, it has been thought that opportunities for defence against non- physical (online) harassment can be better than that in an offline environment (Spertus, 1996).

3.3.7.2.4 Linking public and private data

There are ethical concerns about whether analysing data in the public domain needs consent. However, previous commentators argue that personal conversation on internet sites such as message boards or chat rooms, by their nature, are public discourse and not subject to the usual research constraints with participants. Therefore, a consent procedure or ethical approval from participants is not necessary (inn and Lavitt, 1994; Sudweeks and Rafaeli, 1996; Salem *et al.*, 1997; Sharf, 1997). On the other hand, some researchers suggest that online message boards are both “privately public” and “publically private” as users may not know that their postings might be used for research purposes (Waskul and Douglas, 1996). Others have indicated that the requirement for consent seeking to be necessary are conditional and might be dependent on group norms, size and accessibility of the site (Eysenbach and Till, 2001).

In spite of the different levels of thought and opinions about researching ethically on the internet Flicker *et al.* (2004) have established some points that can be used as ethical guidelines for researching online communities. This guideline includes 12 points and can be seen from Table 19.

“

Ethical Guidelines for Researching Internet Communities

1. *Supply a readily available link to the individuals and institutions responsible for the research project.*
2. *Describe study aims, potential benefits, and harms.*
3. *Provide information about what data will be collected and how it will be used.*
4. *State clearly what kinds of services you are (and are not) able to provide.*
5. *Identify any commercial or competing interests.*
6. *Offer direct contact information for the principal investigator and/or study coordinator, so that participants can get their questions answered.*
7. *Seek informed consent.*
8. *Grant users that do not consent to be part of research comparable service.*
9. *Be explicit about steps taken to preserve confidentiality and anonymity.*
10. *Create policies and procedures to ensure the well-being of the community (e.g., protocols for maintaining community values, moderating site, and managing crisis); make policies public and transparent.*
11. *Limit the ability of search engines to access message boards directly to safeguard privacy.*
12. *Gain approval from a credible human subjects ethics review committee.*

Table 19: Ethical guidelines for researching internet communities (established by Flicker *et al.*, 2004. P:132)”

Recent updates regarding the ethical guidelines for internet research

The British Psychological Society (BPS) (2013) published a recent report on ethical concerns related to Internet-mediated research, outlining ethics guidelines for such research. The BPS guidelines suggest that the normal principles of ethical research with human participants apply to internet-mediated research, and the basics of ethical practice are not changed. However, the guidelines state that the implications of these ethical principles for practice may differ in Internet-mediated research contexts, and aspects of online environments may make particular issues salient in ways they have not been in traditional (face-to-face) research. Table 20 outlines the BPS’s summary

of the main ethics issues for researchers to consider when designing, implementing or assessing an Internet-mediated Research study.

“

<i>Principle</i>	<i>Considerations</i>
<i>Respect for the autonomy and dignity of persons</i>	<p>Public/private distinction – The extent to which potential data derived from online sources should be considered in the public or private domain;</p> <p>Confidentiality – Levels of risk to the confidentiality of participants' data, and how to minimise and/or inform participants of these risks, particularly where they may potentially lead to harm;</p> <p>Copyright – Copyright issues and data ownership, and when permission should be sought to use potential data sources;</p> <p>Valid consent – How to implement robust, traceable valid consent procedures;</p> <p>Withdrawal – How to implement robust procedures which allow participants to act on their rights to withdraw data;</p> <p>Debriefing – How to implement robust procedures which maximise the likelihood of participants receiving appropriate debrief information.</p>
<i>Scientific value</i>	Levels of control – How reduced levels of control may impact on the scientific value of a study, and how best to maximise levels of control where appropriate.
<i>Social responsibility</i>	Disruption of social structures – The extent to which proposed research study procedures and dissemination practices might disrupt/harm social groups.
<i>Maximising benefits and minimising harm</i>	<p>Maximising benefits – How each of the issues mentioned above might act to reduce the benefits of a piece of research, and the best procedures for maximising benefits;</p> <p>Minimising harm – How each of the issues mentioned above might lead to potential harm, and the best procedures for minimising harm.</p>

Table 20: Ethical guidelines for researching internet communities (British Psychological Society, 2013. P: 5).”

3.4 Summary of the literature review

Despite the variations in the prevalence of each specific type of head and neck cancer, some researchers consider this cancer amongst the six most prevalent cancers in the world (Shah and Lydiatt, 1995; Fan, 2004; Dobrossy, 2005; Altumbabic *et al.*, 2008; Marur *et al.*, 2010;) with more than half a million new cases of H&N cancer are diagnosed each year (Fan, 2004; Dobrossy, 2005; Vermorken, 2005; Adeyemi *et al.*, 2008; Altumbabic *et al.*, 2008; Boyle *et al.*, 2008; Haddad and Shin, 2008; Marur and Forastiere, 2008; Pai and Westra, 2009; Michl *et al.*, 2010; Rad *et al.*, 2010) and there is a high mortality rate from this type of cancer (Price, 2010; Rad *et al.*, 2010). It is commonly cited as the most emotionally traumatic of all tumours (Dropkin, 2001) and often results in the development of a series of functional and psychosocial problems (McDonough *et al.*, 1996).

Reviewing the literature indicates that H&N cancers can have a negative influence on QoL (Morton and Izzard, 2003; Rogers *et al.*, 2007; Penner, 2009; Rogers *et al.*, 2007; Penner, 2009; So *et al.*, 2012). However, some factors may mitigate or aggravate the impact of cancer on patient's psychological wellbeing (McDonough *et al.*, 1996). For example, there are many strategies that people diagnosed with H&N cancer can employ that may influence health outcomes. Coping is one such strategy (Sherman *et al.*, 2000). Higher levels of adaptive *coping* have been found to be related to better *quality of life* (Mo and Coulson, 2012).

Psychological factors such as anxiety and depression have been recognised as important factors in a number of studies of patients with H&N cancer (de Leeuw *et al.*, 2001; Massie, 2004; Archer *et al.*, 2008; Haman, 2008; Haisfield-Wolfe *et al.*, 2009). These factors have widely been linked to reduced *quality of life* in many studies (Rapaport *et al.*, 2005; Brenes, 2007; Quelhas and Costa, 2009).

Self-efficacy is a personal resource that signifies a self-belief in individual's capability to apply control over adverse events (Bandura, 1997) and has been shown to be related to better coping, and relatively low levels of psychological distress (Benight *et al.*, 1997). In addition, it has been suggested that people who receive social support are

expected to have stronger self-efficacy beliefs, which subsequently may affect health-related outcomes (Benight and Bandura, 2004). The few studies conducted on the relationship between social support and H&N cancer suggest that social support does appear to exert a positive influence for patients with H&N cancer, especially in relation to reducing the impact of anxiety, depression or depressive symptoms (Mathieson *et al.*, 1996; De Leeuw *et al.*, 2000 a and b; Hassanein, 2001; Karnell *et al.*, 2007; Chueh *et al.*, 2009; Howren *et al.*, 2011; Deno *et al.*, 2012).

Studies on social networks and cancer (Goodwin *et al.*, 1991; de Ruiter *et al.*, 1993; Guidry *et al.*, 1997; Michael *et al.*, 2002; Sapp *et al.*, 2003; Bauer *et al.*, 2005; Kroenke *et al.*, 2006; Pinguart and Duberstein, 2010; Beasley *et al.*, 2010) suggest that social networks are related to better Health Related QoL (HRQoL) and also appear to have a mediating effect on anxiety and depression amongst cancer patients. Social networks appear to play an important role in enhancing the coping ability of the patient (Relic *et al.*, 2001).

An increasing number of people have explored the internet for support, information and advice related to many aspects of health (Coulson, 2005) and there are an expanding number of OSGs available for different health conditions including cancer (Eysenbach *et al.*, 2004). Online support groups may have many advantages over conventional face-to-face groups, and some of them can be very suitable for people with H&N cancer since they can mitigate embarrassment and facilitate interaction if people have a facial disfigurement, speech impairments, or have a feeding tube, all of which are common in people with H&N cancer.

Reviewing the literature has showed that online cancer support groups have been found to be associated with reduction in levels of both physiological and psychological stress in their members (Golant *et al.*, 2004). These groups can increase social support by increasing self-esteem, personal empowerment and functional status and decreasing depression, feelings of helplessness, distress, and social isolation (Fogel *et al.*, 2002; Houston *et al.*, 2002, Winzelberg *et al.*, 2003; Lieberman *et al.*, 2003; Winzelberg *et al.*, 2003; Shaw *et al.*, 2006).

Other studies investigating OSGs for other non-cancer health conditions have suggested that OSGs can provide social support, particularly informational and emotional, improve and provide a guide on coping strategies, reduce sense of isolation, loneliness and levels of depression and anxiety, improve planning and increase levels of optimism toward life (Coulson, and Knibb, 2007; Coulson, and Buchanan; 2008; Malik, and Coulson, 2008; Mo, and Coulson, 2010b; Elwell *et al.*, 2011; Mo, and Coulson, 2011; Attard and Coulson, 2012; Coulson and Greenwood, 2012; Campbell *et al.*,2013; Mo, and Coulson, 2014a; Mo, and Coulson, 2014b).

3.5 Rationale for the research

Several studies have indicated that OSGs can benefit users through enhancing the empowerment process (van Uden-Kraan *et al.*, 2008; Malik, and Coulson, 2008; Mo, and Coulson, 2010a; Bartlett, and Coulson, 2011; Mo, and Coulson, 2011; Holbrey, and Coulson, 2013; Campbell, *et al.*, 2013; Mo, and Coulson, 2014a; Mo, and Coulson, 2014b). Yet, interestingly, there have been no studies to date investigating OSGs for people with H&N cancer. This is despite the high incidence of H&N cancer and evidence pointing to the influence on the QoL of patients and the beneficial role of OSGs, especially in providing social support and empowerment and improving users' QoL, and the availability of many OSGs for H&N cancer.

This gap led the researcher to begin to explore this area as a potential topic for his PhD. As outlined in the literature review (Section 3.3), previous studies with other health conditions have suggested that OSGs can be a good source of a range of types of social support (Braithwaite *et al.*, 1999; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu, 2009; Coulson and Greenwood, 2012). Given that no previous studies had examined OSGs for H&N cancer, the first step was to examine what type of support messages were being sought and posted to H&N OSGs. By firstly understanding what social support was offered and received within such OSGs, it was felt that this would then guide the next step of the research, which was to explore how the support available within OSGs, alongside other key factors identified in the wider literature, was related to the QoL of people with H&N cancer.

To examine types of social support, the PhD utilised an existing methodology which has been widely used in the OSG literature for other patient groups (Braithwaite *et al.*, 1999; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu 2009; Coulson and Greenwood, 2012). These studies have used the Social Support Behaviour Code (SSBC) (Cutrona and Suhr, 1992) to code messages in terms of the type of social support offered within OSGs. The framework has been shown to be a valid and reliable method of examining what social support is available in OSGs in these previous studies. In addition, to examine what social support was sought within OSGs a second framework developed by Coursaris and Liu (2009), and previously

used in relation to HIV/AIDS, was employed. Again, whilst this framework has been used far less than the SSBC, it has been shown to be a reliable and valid method of examining what social support is sought in OSGs in this study.

This first study aimed at increasing our understanding of what types of social support are available within OSGs for H&N cancer. The results of this study showed that H&N cancer OSGs were used frequently by some people, from many different countries; sometimes both patients and carers used the OSGs. Importantly, many types of social support were being sought and offered within these OSGs – for example, informational, emotional, esteem, social network and tangible support. This led to the development of the next stage of the research which was to examine the relationship between the use of these OSGs and other key factors which have been shown, in the literature, to mitigate or aggravate the impact of cancer on psychological wellbeing and QoL (McDonough *et al.*, 1996; Penner, 2009). Those factors include social support in addition to, coping strategies, social networks, self-efficacy, anxiety and depression. In order to examine the relationships between the use of OSGs and this wide range of factors, a cross-sectional study was designed utilising a range of pre-validated questionnaires available within the existing QoL, psychology and on-line literatures.

At this stage, a quantitative method was chosen because it allowed the research problem to be stated in very specific and set terms, and precisely and clearly specified both the dependent and the independent variables under examination (Frankfort-Nachmias and Nachmias, 1992). Quantitative studies offer data that can be expressed in numbers which allow applying statistical tests in making statements about the data and can also provide data that is descriptive (Madrigal, McClain, 2012). Therefore, it allows the researcher to measure and analyse data as well as to test hypotheses and models (Matveev, 2002). This research approach has other advantages such as achieving high levels of reliability of collected data (Balsley, 1970) and diminishing subjectivity of judgment (Kealey & Protheroe, 1996).

Conducting a longitudinal study would be problematic on-line for several reasons; for example, it is hard to follow up users of OSGs due to the general low response rates or nonresponses associated with the online questionnaire (Couper, 2000; Nosek *et al.*,

2002; Kraut *et al.*, 2004; Matsuo *et al.*, 2004). Since, it seems that, within virtual environment, it is not guaranteed that people who participate at the baseline of the study will participate in the follow up sessions. In addition, for pragmatic reasons, a longitudinal study was not possible during the time available for the PhD. To minimise such difficulties, and for pragmatic reasons, a cross sectional study was chosen to address the research question. This approach, in spite of its cross sectional nature, and the limitations in making causal inferences, is relatively inexpensive and takes up little time to conduct; can estimate occurrence of outcome of interest, useful for planning and generation of hypotheses and does not have the problem of loss of follow-up (Levin, 2006).

Whilst this part of the PhD enabled a greater understanding of the relationship between using OSGs and key factors, nevertheless, it was felt that there were a number of limitations of using pre-existing questionnaires. For example this method is thought to be insufficient to understand some forms of information such as changes of behaviour, emotions or feelings, in the time that it only asks a limited amount of information without deep explanation (Popper, 2005). In addition, participants may misunderstand the questions within pre-existing questionnaires and reply based on their own interpretation of the question (Popper, 2005).

Thus, alongside this quantitative study, a companion qualitative study was carried out utilising unstructured interviews with participants who had responded to the questionnaires. These interviews aimed to explore, in more depth, aspects of using OSGs which were not covered within the questionnaires. These interviews therefore allowed OSGs users to discuss why they had joined the OSGs, their feelings toward the OSGs, what they perceived they benefited from the OSGs and how the OSGs empowered them to cope with their H&N cancer. Thus, the interview gave the potential for greater detail that could not be achieved from the numerical data from the questionnaire. Thus, the interviews provided a comprehensive view of the phenomena under exploration (Patton, 1980), the ability to interact with the participants on their own terms and in their own language (Kirk and Miller, 1986), and provided detail and depth on the behaviours, feelings and attitudes of the participants and encouraged them to expand on their response in order to open up new themes or areas not initially considered (O'Neill, 2008).

Online interviews were chosen (rather than face-to-face) because participants were already using the medium (given the nature of the study concerned their use of online groups). In addition, limitations of face-to-face interviews such as geographic distance (users came from many different countries), cost, time and convenience were minimised.

Using three different methods to address the aim of the PhD enabled an exploration of the potential role of OSGs for H&N cancer; an area thus far unexplored. Firstly, by examining what social support is ‘already out there’ and available to H&N cancer patients and their carers. Secondly, by examining the relationships between OSG use, QoL and a range of possible mediating factors using existing and pre-validated questionnaires. Thirdly, by exploring the role of OSGs for H&N cancer by allowing participants the opportunity to discuss their experiences of OSGs in a detailed and unrestricted manner through interviews.

3.6 Aim of the research

The aim of the present research is to explore online social support groups for people with head and neck cancer.

3.7 Objectives of the research

The overall objectives of the research are to:

1. Explore the types of social support, sought and offered, within online support groups for H&N cancer.
2. Examine the relationship between using OSGs and QoL and examine the psychosocial factors that may influence this relationship.
3. Explore, in depth, the OSG experiences of people with H&N cancer

To meet the objectives of this body of research, two studies were conducted. The first study (Study 1) was a quantitative content analysis of messages in H&N cancer OSGs both offering and seeking social support. This study addressed Objective 1.

The specific objectives for Study 1 were to:

- review existing OSGs for people with H&N cancer
- choose suitable OSGs according to inclusion and exclusion criteria
- code and analyse the types of social support available in OSGs for H&N cancer using a pre-validated coding framework
- code and analyse the types of social support sought in OSGs for H&N cancer using a pre-validated coding framework

The second study (Study 2) consisted of two parts. The first part (Part 1) was a cross-sectional study examining the use of OSGs, its relationship to QoL and possible factors influencing this relationship (social network, self-efficacy, anxiety, depression, adjustment and empowerment). This part addressed Objective 2 of the research.

The specific objectives for Study 2 (Part 1) were to:

- select suitable measures to assess the use of H&N cancer -OSGs.
- using existing, pre-validated questionnaires to examine QoL, social network, self-efficacy, anxiety, depression, adjustment and empowerment in a sample of people using online support groups for H&N cancer.
- using regression analyses to examine the relationship between using OSGs and QoL, and the possible mediation role of the other psychosocial variables in this relationship.

The second part (Part 2) of Study 2 consisted of unstructured online interviews which aimed to explore in more detail the experience of using of OSGs. This part addressed Objective 3 of the research.

The specific objectives for Study 2 (Part 2) were to:

- explore, in depth, people's experiences of using OSGs for H&N cancer
- analyse the data using a narrative thematic experience analysis to identify emergent themes

Chapter IV: Study 1: Exploring Online Social Support in Head and Neck Cancer Groups

4 Study 1: Exploring online social support in head and neck cancer groups

4.1 Introduction

Whilst head and neck cancer is commonly cited as the most emotionally traumatic of all tumours (Dropkin, 2001) and often results in the development of a series of functional and psychosocial problems (McDonough *et al.*, 1996), there are many strategies people diagnosed with H&N cancer can employ to influence health outcomes. Coping is one such strategy (Sherman *et al.*, 2000).

Coping has been investigated widely among people with different cancers especially breast cancer (Stanton *et al.*, 2000; Petticrew *et al.*, 2002). However, relatively few studies have been conducted on coping specifically with H&N cancers. Yet, approximately half of the people with H&N cancer are reported to suffer from depression (Duffy *et al.*, 2007). One hypothesis is that this high rate of depression might be linked to pre-morbid factors such as lack of social support (Baile *et al.*, 1992), which has been found to be of increasing importance in other cancer studies, as social support is considered to be the most significant factor implicated in coping. A considerable number of researchers have suggested that social support has been constantly linked to physical and mental health (Lin *et al.*, 1985; Cohen, 1988; Heitzmann and Kaplan, 1988; Bloom, 1990).

To date, there have been a relatively large number of studies conducted on the relationship between social support and cancers (De Boer *et al.*, 1999b; Hoodin and Weber, 2003; Thaxton *et al.*, 2005; Falagas *et al.*, 2007; Nausheen *et al.*, 2009). Of the studies that have been conducted with H&N cancer, the findings suggest that social support does appear to exert a positive influence, especially in relation to reducing the impact of anxiety, depression or depressive symptoms (Baker, 1992; Ma, 1996; Mathieson *et al.*, 1996; De Leeuw *et al.*, 2000 a; De Leeuw *et al.*, 2000b; Hassanein, 2001; List *et al.*, 2002; Katz *et al.*, 2003; Karnell *et al.*, 2007; Chueh *et al.*, 2009; Howren *et al.*, 2011).

An increasing number of people have explored the internet for support, information and advice related to many aspects of health (Coulson, 2005) and there are a growing number of OSGs available for different health conditions including cancer (Eysenbach *et al.*, 2004). Many studies dealing with different health conditions suggest that these support groups can be useful for patients to obtain the required support (Winzelberg, 1997; Braithwaite *et al.*, 1999; Finn, 1999; White and Dorman, 2000; Coulson, 2005; Mo and Coulson, 2008). However, to date, there have been no studies examining online social support for people with H&N cancer.

Within the literature, several possible dimensions of social support have been identified (Hirsh, 1980; House, 1981, Cutrona and Suhr, 1992, Sherbourne and Stewart, 1991) and the aim of this study was to assess the types of social support, sought and offered, within OSGs for people with H&N cancer.

4.2 Aim

The aim of this study was to explore the types and frequency of social support, sought and offered, within online support groups for H&N cancer.

4.3 Objectives

- Review existing OSGs for people with H&N cancer
- choose suitable OSGs according to inclusion and exclusion criteria
- code and analyse the types of social support available in OSGs for H&N cancer using a pre-validated coding framework
- code and analyse the types of social support sought in OSGs for H&N cancer using a pre-validated coding framework

4.4 Strategic choices for method

Content analysis is a method for systematically describing spoken, written or visual communication in a quantitative way (Krippendorff, 2012). The technique can be applied to existing material (any material that can be documented and reviewed such as newspapers and internet) or to new data collected by the researchers, or to categorise open-ended responses to survey questions or interview (Berelson, 1971; Sommer, 2006; Krippendorff, 2012).

Quantification allows researchers to describe the material in a way that is potentially valid and reliable. The information is broken down into categories and then summarised. Both format (the form or structure of the information) and content (the meaning of the information) of the communication can be quantified (Sommer, 2006; Krippendorff, 2012). The unit of measurement needs to be specified after the materials to be coded have been selected. There must be a clear specification of the coding categories and the procedure. Categories must be comprehensive, mutually-exclusive, and non-instances may need to be recorded (for completeness). For reliability, two people independently coding the information should show a high degree of agreement in their classifications (Budd, *et al.*, 1967; Sommer, 2006).

Reviewing the literature (Budd, *et al.*, 1967; Weber, 1990; Krippendorff, 2004; Sommer, 2006; Krippendorff, 2012) suggested that content analysis has the advantages of being readily-understood and an inexpensive research method. It is unobtrusive (i.e. does not intrude; inconspicuous, out of the way) and very useful for analysing historical material, documenting change over time and comparing media from different sources and locations (Krippendorff, 2004). In addition, establishing reliability is easy and straightforward with content analysis, since it scores highest with regard to ease of replication compared with the other research methods as the materials tend to be easy to obtain and available for others to use (Krippendorff, 2004; Sommer, 2006; Krippendorff, 2012).

Content analysis has been used in a range of health contexts in online methodologies (for example, disabilities, Irritable Bowel Syndrome, Huntington's disease,

HIV/AIDS, families affected by childhood cancer) to assess the types of social support available online (Braithwaite *et al.*, 1999; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu, 2009; Coulson and Greenwood, 2012). These studies have provided useful information about the nature (type) and frequency of social support available in OSGs by utilising existing social support coding frameworks which is the Social Support Behaviour Code “SSBC” that was developed by Cutrona and Suhr (1992). This framework has been used in the current study as well (See Data analysis “Section 4.5.5” for details and rationals for using this framework).

Since the aim of this study was to explore the types and frequency of social support, sought and offered, within online support groups for H&N cancer, knowing the frequency of each type of social support sought and offered can give a general idea of whether users of the OSGs get corresponding support to what they seek?. It allows comparison between the types and frequency of social support sought and offered. Therefore, content analysis (not thematic analysis) has been chosen for the aim of this study because it allows quantification and can express the result in numbers and percentages for each type of social support (sought and offered).

4.5 Method

4.5.1 Study design

Content analysis

4.5.2 Sampling

4.5.2.1 OSGs selection

A thorough search was performed using Google as the search engine with a set of key words (Head, neck, cancer, tumour, forum, online, message boards, support group, chat, blog, oral, pharyngeal, laryngeal, lip, tongue, tonsil, throat, gingival, gum, mouth, dental, cheek, epiglottis). Several publicly accessible H&N cancer-OSGs were identified for the purposes of the study as follows. Nineteen main sites were identified with some containing more than one OSG. A total of 56 OSGs were identified (see Appendix 3).

Groups were selected according to the following inclusion criteria:

1. Online support groups that deal with H&N cancer

The following exclusion criteria were applied to whole groups during selection:

1. Groups that also deal with health conditions other than H&N cancer.
2. Groups that require registration to access the messages in the group.
3. A group where the support is only provided by professional or nurse. (This was determined by reading the terms and conditions of each online group and by screening the messages in the groups).
4. A group being no longer active or generally inactive with very few postings per year (less than 12 posting per year at least one in every month).

Rationale for choosing groups with at least 12 postings per year (at least one posting in every month):

During the process of searching for H&N cancer OSGs to be included in the study (Objective 1), it became apparent that, in spite of the availability of many OSGs for H&N cancer, only a few of them were active with daily messaging. The activity of the remaining groups was very varied, but with some groups not having any messages posted for a full month. In order to ensure that as many OSGs were included as possible but still include those that were active, a cut-off criteria was applied of at least one posting per month (i.e. at least 12 postings per year).

Following application of the exclusion criteria, as can be seen from Figure 5, eighteen OSGs belonging to six websites were included in the study as can be seen in Table 21.

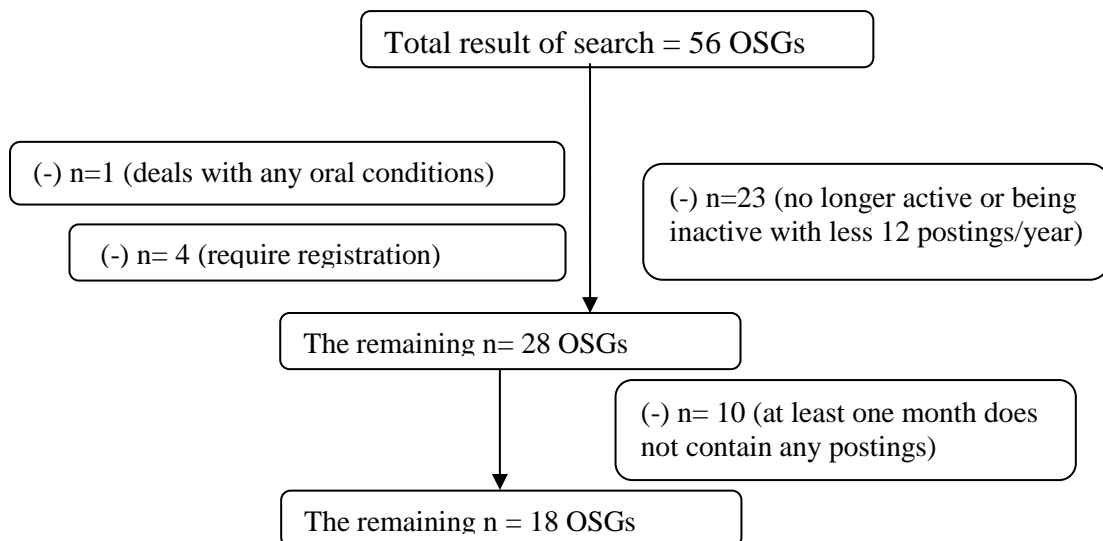


Figure 5: Applying exclusion criteria for OSGs

OSGs based in the UK	<ol style="list-style-type: none"> 1. The cancer forums 2. Macmillan 3. Introduce yourself (MCF)* 4. General chat (MCF) 5. Questions and Answers (MCF)
OSGs based in the USA	<ol style="list-style-type: none"> 6. Head & neck cancer (CancerCompass) 7. Cancer Survivors Network 8. Introduce yourself (OCF)** 9. General Board (OCF) 10. Symptoms and Diagnosis (OCF) 11. Coping / Anger and Fear (OCF) 12. Medications, Treatment, Procedures (OCF) 13. Currently in Treatment (OCF) 14. After Treatment Issues (OCF) 15. Eating, Speech, Swallowing, and Alternative Feeding (OCF) 16. Caregiver / Co-Survivor Forum (OCF) 17. Oral Cancer Recurrence (OCF) 18. Activism (OCF)

Table 21: List of OSGs generating the sample for Study 1

*MCF (Mouth Cancer Foundation), ** OCF (Oral Cancer Foundation)

4.5.2.2 Messages selection

The messages were selected according to the following inclusion criteria:

Inclusion criteria for the support-seeking messages:

- 1- Identified the username of the sender, date of posting, then the actual message itself
- 2- Sought at least one dimension of social support (as defined by the SSBC framework and its modifications, see Data analysis Section 4.5.5)
- 3- Available to be read by the public
- 4- Written in English

Inclusion criteria for the support-offering messages:

- 1- Messages that were replies to the above selected support-seeking messages
- 2- Identified the username of the sender, date of posting, then the actual message itself
- 3- Offer at least one dimension of social support (as defined by the SSBC framework and its modifications, see Data analysis Section 4.5.5)
- 4- Available to be read by the public
- 5- Written in English

The data were selected from the even months in each of these 18 OSGs in the year 2011 by selecting one random posting and its associated reply messages from each month using an electronic True Random Number Generator from the RANDOM.ORG website (<http://www.random.org/>). The total sample consisted of 108 postings (support-seeking messages) yielding 527 reply messages (support-offering messages). The following exclusion criteria were applied to whole messages:

Exclusion criteria for the support-seeking messages:

- 1- Messages with no replies
- 2- Messages not about H&N cancer
- 3- Old messages that were posted before the study time limit (1st January - 31 December 2011)

- 4- Messages outside of the definition of H&N cancer in this study (see Chapter 2, Section 2.1)
- 5- Messages written in a language other than English

Exclusion criteria for the support-offering messages:

- 1- Replies for support-seeking messages not about H&N cancer
- 2- Replies for old support-seeking messages that were posted before the study began
- 3- Replies to support-seeking messages outside of the definition of H&N cancer in this study (see Chapter 2, Section 2.1)
- 4- Messages sent as a reply by the original senders of the support-seeking message
- 5- Multiple replies from the same sender

Rationale for choosing one random message for the even months only:

Reviewing the literature and investigating the studies that used similar methods (i.e. content analysis for messages posted within OSGs) in relation to other health conditions (Irritable Bowel Syndrome, Huntington's disease, HIV/AIDS, and families affected by childhood cancer) indicated that there was no fixed sampling strategy for this particular methodology. That is, authors in these studies had used different time periods, different number of OSGs and different strategies to select their data. For example, Coulson (2005) included all messages posted to one OSG during an 8-month study period, resulting in 572 messages to be analysed; Coulson *et al.* (2007) included all messages to one OSG during a 21-month study period resulting in 1313 messages; Mo and Coulson (2008) selected 1,138 messages randomly from messages posted to one OSG for a period of one month. More recently, Coulson and Greenwood (2012) select 487 messages randomly from messages posted to three OSGs for the period from 2006 up until July 2010.

Given this variability in the literature to date, in the present study, for purpose of generalisability and to investigate the widest possible range of views about OSGs, we decided to ensure that data were collected from as many OSGs as possible (not from only one OSG) and that data came from OSGs that were still active with at least one posting per month (i.e. at least 12 postings per year). These criteria resulted in data being collected from 18 OSGs, some of them very active in terms of the number of

messages posted per month (e.g. up to 200 messages per month) and some of them were not (i.e. the minimum criteria of 1 message per month).

When reviewing the OSGs and messages for the study, it became apparent that members of the OSGs (the support providers) were relatively active in terms of replying to messages of the support seekers. Indeed, there were approximately 6 replies (support-providing messages) for each one support-seeking message. Given the large volume of messages from some OSGs, it was necessary to limit the number selected for practical purposes. Thus, to still maintain the range (18) of OSGs it was decided to include messages from all but to collect messages from a 6 month period distributed throughout the year. If one support-seeking message was included from each of the 18 OSGs in a 6 month period (distributed evenly across the 12 month study period), this would result in 108 support-seeking messages and approximately 600 reply messages (support-offering messages). The latter number was consistent with previous studies utilising the same method: 572 messages (Coulson, 2005) and 487 messages (Coulson and Greenwood, 2012). In addition, during the pilot study and during scanning, reading and reviewing of the messages, it became apparent that members of the OSGs often wrote long messages that contained more than one dimension or sub-dimension of social support. Given that no formal sample size calculation could be conducted, on the basis of the above, it was decided that the number of messages (108 + 600) from 18 different OSGs would provide a representative selection of data that could be analysed. An electronic True Random Number Generator from the RANDOM.ORG website (<http://www.random.org/>) was used to select these messages.

The most recent year was chosen at the time of data collection (2011). To ensure distribution of the 6 months throughout the year, we could either select the odd or the even months. Given that some of the even months include special events (e.g. Easter in April; Christmas in December) celebrated by a large number of people around the world (Ferrell, 2003), we opted to choose the even months when people might be taking holidays, spending time with families, or when social support (or absence of) may be at the fore in people's lives.

In summary, using such sampling strategy allowed collecting data from several OSGs (18 OSGs). In addition, it allowed data to be collected from the most recent year at

time of data collection (2011) and allowed including months with special religious and cultural characteristics.

4.5.2.3 Sample

4.5.2.3.1 Sample: support-offering messages

Figure 6 shows that after application of the exclusion criteria to the 527 support-offering messages from the 18 OSGs the remaining number was 312 messages. These messages were content analysed to investigate the dimensions of social support within the group and, where available, demographics of the message posters as well as their clinical information.

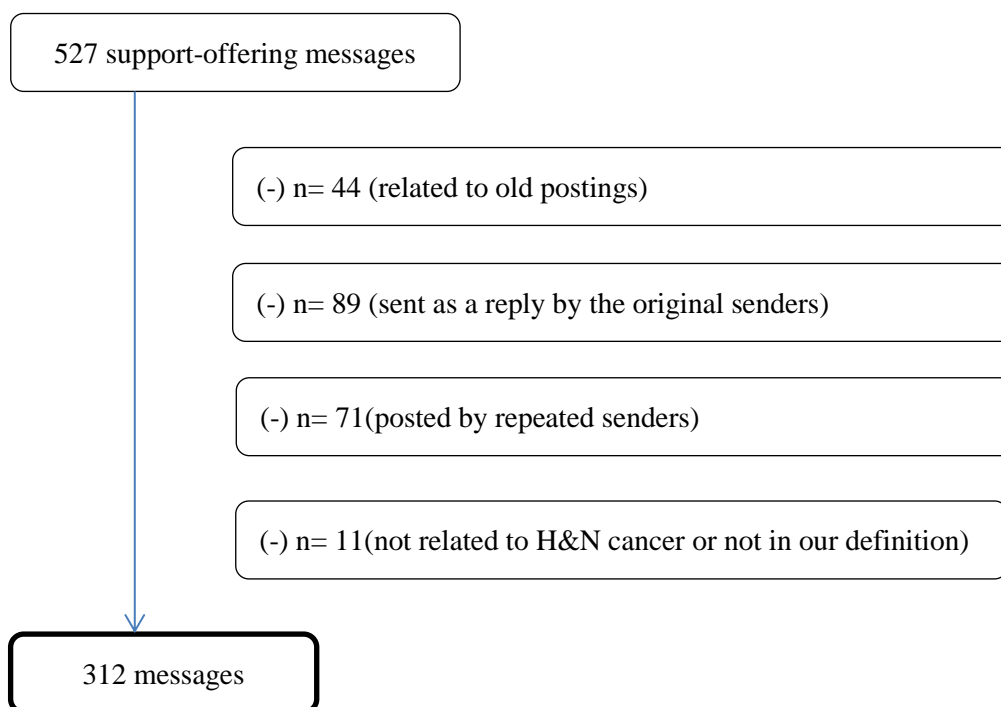


Figure 6: Applying exclusion criteria for support-offering messages

4.5.2.3.2 Sample: support-seeking messages

Figure 7 shows that after application of the exclusion criteria to the 108 support-seeking messages, those remaining totalled 87 messages. These messages were content analysed for support seeking. Again, where available, the demographics of the support seekers together with some clinical information have been collected.

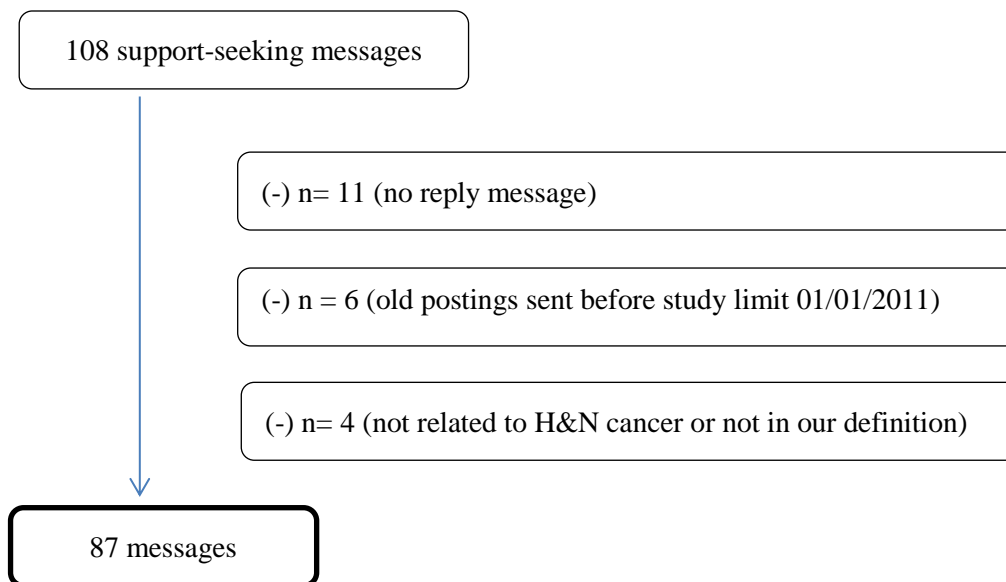
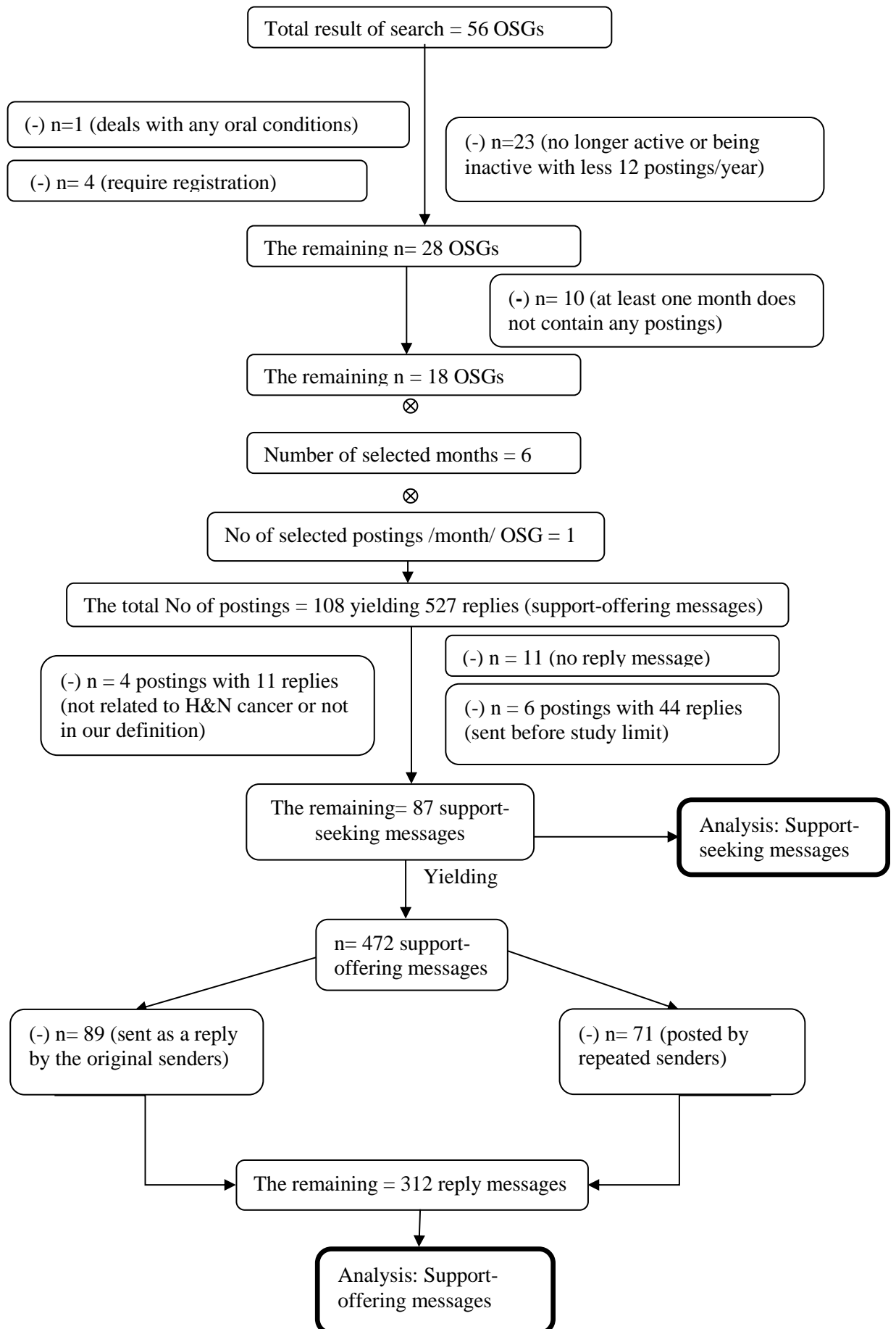


Figure 7: Applying exclusion criteria for support-seeking messages

Seventy-eight unique names were identified as posting 87 support-seeking messages, and 125 unique names were identified for the 312 reply messages to those support-seeking messages. However, 12 names were found to be common between both support-seeking and support-offering messages. Figure 8 shows a flow diagram summarising the details of OSGs and message selection.

Figure 8: Study 1 sample profile



4.5.3 Ethics

All the OSGs that are used in this study did not require any registration or subscription to view the postings and the reply messages. Therefore, these groups were considered to be in the public domain, and the need for informed consent from the participants was not considered necessary (Eysenbach and Till, 2001; Flicker *et al.*, 2004; Coulson, 2005; British Psychological Society, 2013).

Although the study was conducted in 2011, the ethical considerations were compatible with the ethical guidelines of the British Psychological Society (2013) (See Table 20, Section 3.3), including privacy and confidentiality:

- To protect anonymity of individuals, the name or address of the OSGs from which data was collected has not been included. In addition, all the name and usernames of the members of the OSGs, as well as any name mentioned in the messages, have been removed and substituted by pseudonyms. In addition, any name of places or other information that might reveal the identity of the OSG member has been removed.
- To protect confidentiality of OSG members, the original data that contained original name, usernames or any identity information related to the members were kept by the researcher in a password protected electronic document and could only be accessed by the researcher.

4.5.4 Data collection

The researcher (E.A) -himself has performed the data collection, recording, transfer, coding and analysis. The supervisors (S.B and J.O) have read and independently coded the 10 support-seeking and the 10 support-offering messages in the pilot study before and after introducing the modifications to the coding frames. The supervisors have also independently coded a further 10 messages for the main study and compared with researcher's coding. Each of the coders has read and understood the coding frames with some of their applications as examples in previous studies.

4.5.5 Data analysis

The sought and offered social support within the messages posted to the selected H&N cancer OSG were analysed using content analysis. This method allowed the messages to be classified according to a social support framework:

Messages: support offering

The Social Support Behaviour Code (SSBC) developed by Cutrona and Suhr (1992) (see Appendix 4) was adapted for use in this study to investigate and classify the social support in the support-offering messages. The SSBC has previously been used as a coding frame for the analysis of OSG bulletin board messages (Braithwaite *et al.*, 1999; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008). However, since the original social support framework of Cutrona and Suhr (1992) was not originally designed for analysing support in online groups, a modified version adapted and used by Mo and Coulson (2008) for analysing support in online groups was used in this study (see Appendix 5). The modifications in the Mo and Coulson version from the original SSBC were as follows:

- 1- The “listening” subcategory was eliminated.
- 2- A new subcategory, “sharing own experience,” was created under informational support.
- 3- The “presence” and “companionship” subcategories under network support were collapsed into one “presence”.

The Mo and Coulson (2008) coding framework was originally intended to assess the frequency of support-intended dialogue behaviours that existed under five main categories:

- 1) Informational support (provides advices and knowledge relevant to character of the stress or the way of coping with such stress) and included five subcategories, they are; teaching, referrals to expert, advice, sharing own experiences and situation appraisal.
- 2) Esteem Support (contains confidence in communicating respect and ability) and includes three subcategories; validation, compliment and relief of blame.
- 3) Network support (involves communication with individuals who have similar interest and concerns) and contained two subcategories; presence and access.

4) Emotional support (offers love, cares and concern in disclosure with the recipients) and involves seven subcategories; relationship, empathy, expression of care, confidentiality, sympathy, prayer physical affection, and encouragement.

5) Tangible assistance (provides goods or services needed to deal with the stressful circumstance) and involves four subcategories; perform direct task, perform indirect task, express willingness and loan.

Therefore, 22 codes were utilised in the content analysis of the support-offering messages. A brief description of the meaning of each code (subcategories) has been provided in Chapter 3, Section 3.2.6.

Rationale for choosing SSBC as a coding framework for the support-offering messages:

The SSBC coding framework was chosen as it has been used in many previous studies within the on- and off-line social support literature. It has been used to investigate social support messages in the study of OSGs for other health conditions and chronic diseases like disability, HIV/AIDS, Irritable Bowel Syndrome, Huntington Disease and families affected by childhood cancer (Braithwaite *et al.*, 1999; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson 2008; Coulson and Greenwood, 2012). These studies have reported it as a reliable and valid approach to coding and categorising online support messages. Given the wide range of previous contexts in which the framework has been used, it suggests that the typology might be generalisable to H&N cancer OSGs. In addition, given that it is a comprehensive coding system (5 dimensions of support with 22 sub-dimensions) predicated on of an overall theoretical framework (Coulson *et al.*, 2007), it should aid in facilitating understanding of online social support in this new application – H&N cancer OSGs.

Finally, a pilot study conducted prior to the study to examine the utility of the coding system to H&N cancer OSGs, demonstrated that the coding framework was reliable (see Section 4.5.6) with high levels of agreement between coders (86.5%). Furthermore, within the pilot, no messages remained uncategorised after application of the SSBC framework indicating its potential validity in the H&N context.

Messages: Support seeking

The Coursaris and Liu (2009) coding framework was adapted to categorise the postings that were sent by the support seekers (see Appendix 7) (support-seeking messages). This framework was originally based on the Social Support Behaviour Code (SBSS) of Cutrona and Suhr (1992). In Coursaris and Liu's development of the framework, messages seeking social support were firstly classified into the five general dimensions of the SBSS (informational, emotional, esteem, network and tangible support). Then, the postings that did not fit into any of the five general dimensions of the SBSS underwent a thematic analysis to identify other areas of social support exchanges within the group. The following three categories were derived as a result: sharing personal experiences, expressing gratitude and offering congratulations. The final framework therefore consisted of 8 dimensions as follows:

1. Seeking informational support: Included specific questions concerning the situation to obtain factual information, evaluate certain situation or to seek suggestions or advice.
2. Seeking emotional support: Showed emotional or psychological weakness and need for comfort.
3. Seeking esteem support: Validation for perspective/relief of blame.
4. Seeking network support: Asking for prolonged or contact with others in similar situation.
5. Seeking tangible support: Asking for financial, material, equipment, asking to be shown an aspect of care on a one-to-one basis.
6. Sharing personal experiences: Shared personal conditions, thoughts, and feelings related to the issue with others initially and spontaneously.
7. Expression of gratitude: Expressed straightforward thankfulness for the recipient's previous support.
8. Congratulations: Expressed joy or acknowledgment of the recipient's achievement or good fortune.

In the current study, a pilot was carried out (see Section 4.5.6) to examine the utility of this framework for H&N cancer OSGs. As a result of the pilot study, some minor

modifications were introduced. The modifications from the original Coursaris and Liu (2009) framework were the addition of three new categories:

1. Seeking wellbeing information which included specific questions about how to offer support to others.
2. Expressions of care which included messages that contained expression of concern for others.
3. Encouragement which included sending messages of hope and confidence.

After introducing these modifications, the coding framework included 11 dimensions (see Appendix 8).

Rationale for choosing the Coursaris and Liu framework for the support-seeking messages:

Given that the Coursaris and Liu framework was originally based on the five categories of the SSBC, the framework being used to code the support-offering messages, it was felt that choosing this would allow for some comparability in the analysis of the support-offering and supporting-providing messages. In addition, searching the literature showed that the Coursaris and Liu framework was the only scheme available for assessing the sought support for OSGs and it was found to be valid and reliable method for assessing sought support in the OSGs in that study (Coursaris and Liu, 2009).

4.5.6 Pilot study

To assess the applicability of the coding frame for the support-offering messages, 10 support-offering messages were chosen randomly from the postings in the odd months (1, 3, 5, 7, 9, and 11) to one of the groups that used for the main study in 2011. The framework of Mo and Coulson (2008) was applied to content analyse the 10 support-offering messages. The 10 messages were analysed separately by both the researcher (EG) and the two supervisors (SB, JO). The degree of agreement between the three coders was evaluated using Cohen Kappa.

An agreement of 86.5% was achieved between the three coders. In addition, another item (prayer) which had been used originally in the Cutrona and Suhr coding system was added under the emotional support category and a small modification made to the item. The difference being that in the current study, messages within this code contain prayers *with and/or for* the recipients rather than the prayer was *with* the recipients only in the original Cutrona and Suhr. The final coding system used in Study 1 can be seen in Appendix 6.

To assess the applicability of the coding frame for the support-seeking messages, as in the case of support-offering messages, 10 randomly chosen support-seeking messages were content analysed using the Coursaris and Liu (2009) 8-item framework (Appendix 7) by the researcher (EG) and two supervisors (SB, JO) independently. During the initial agreement check, it became clear that a number of statements remained uncategorised using the original framework. As a result, three new codes were identified. These were; seeking wellbeing information (which included specific questions about how to offer support to others), expressions of care (which included messages that contain expression of concern for others) and encouragement (which included sending messages of hope and confidence). This modified 11 item coding system was then used to content analyse a further 10 randomly selected messages, and agreement between the three coders was calculated. Agreement between the three coders was 80%. The modified coding framework can be seen in Appendix 8.

4.6 Results

The result section is divided into two main parts; social support offered and social support sought. In this study, people who posted messages to seek support were called as “Support seekers” and those who replied to them were called as “Support providers”.

4.6.1 Social support offered: Analysis of support-offering messages

4.6.1.1 Demographics of support providers

1. Age

A few support providers supplied their ages in their profiles and some of the care givers (CG) (these people identified themselves as not the person with H&N cancer but rather as carers/family members) supplied the ages of their family members (i.e. the person with H&N cancer), rather than their own. Age was provided by 49 (out of total 125) members, and while 36 of them (32 people with cancer and 4) have provided their own ages, 2 caregivers provided their ages together with their family member’s age. However, 11 caregivers provided the ages of their family member only. Table 22 shows more details of the age distribution of the support providers.

Age group	Number	%
0 – 19	0	0
20 – 29	1 (Pwc*)	2.63
30 – 39	11 (Pwc)	28.94
40 – 49	10 (6 Pwc, 4 CG**)	26.31
50 – 59	9 (8 Pwc, 1 CG)	23.68
60 or above	7 (6 Pwc, 1 CG)	18.42
Total	38	100%

Table 22: Age distribution of the support providers who provided their own ages

* Pwc = person with cancer, ** CG = Caregiver

The ages of the 13 people with cancer supplied by their caregivers were (33, 43, 47, 48, 52, 53, 55, 56, 57, 60, 66, 68, and 76). Almost all members who supplied their ages

were over 30 years, with the highest percentage in the age groups (30 – 39 years). However, by distributing the ages of the 13 people with cancer who were supplied by their caregivers into the table, the highest percentage will be in the age group (50 – 59 years). This is consistent with what previous studies have suggested in the literature that H&N cancer is more common in older people than young (Ridge *et al.*, 2004; Chidzonga and Mahomva, 2006; Warnakulasuriya, 2009a).

2. Gender

Although some members indicated their gender clearly in their profile, gender was unknown for many people, and was, therefore, if possible, deducted from their user names or from their names if they supplied them. In addition, several messages gave clues about the gender such as when the sender was writing about their husband or wife. In total, out of the total 125 members, gender was identified for 113 members, and it appears that more than two-thirds (69%) of them were females.

3. Location

Information about members' location was supplied from all OSGs without subscription or registration except three (Cancer Survivors Network, Macmillan and Cancer Compass). Therefore, data were available for 92 members. Table 23 illustrates the distribution of members among the different countries.

Country	Number	%
USA	69	75.00
UK	9	9.78
Australia	7	7.60
Canada	3	3.26
India	1	1.08
New Zealand	1	1.08
UAE	1	1.08
Hong Kong	1	1.08
Total	92	100%

Table 23: The distribution of participants among countries

From the previous table it appears that 75% of the members (n = 69) were from the United States and the remaining were from different countries in which English is the

predominant language (UK, Canada, Australia, New Zealand). Only three members were from countries whose main language is not English (India, United Arab of Emirates and Hong Kong).

4. Identity of support providers

The identity of support providers could be deduced for 119 members out of the 125. Of those, about 70% (84 members) of the support message senders were people with cancer and around 28% were caregivers (24% were identified relatives and about 4% were undefined caregivers). Only one member was a healthcare professional (see Table 24).

Support provider	Number	%
Person with cancer	84	70.58
CG (Wife)	18	15.12
CG (Daughter)	5	4.20
CG (Son)	1	0.84
CG (Brother)	1	0.84
CG (Sister)	1	0.84
CG (Mother)	1	0.84
CG (Girlfriend)	1	0.84
CG (X-spouse)	1	0.84
CG (Unspecified)	5	4.20
HCP	1	0.84
Total	119	100%

Table 24: Identities of support providers

*CG = caregivers, **HCP = Health Care Professional

Out of the 84 persons with cancer, 77 were recorded as people with cancer only, three were caregivers, two were healthcare professionals and two appeared to have both roles.

5. Number of postings

Number of support-offering messages that were sent by individual members was supplied in all OSGs with the exception of one (Cancer compass). Therefore, information about this number was available for 117 members; see Table 25.

Number of postings per person	10	11 - 100	101-500	501-1000	1000-5000	5001-10000
Number of people	15	23	40	18	19	2
%	12.82	19.65	34.18	15.38	16.23	1.70

Table 25: Distribution of number of support- offering messages

About 18% of members were highly active with more than 1000 messages and approximately half of the members sent between 100 and 1000 messages. The remaining third appeared to be less active with less than 100 messages and around 4% of participants sent only one message.

6. Joining time

The joining time of members to the selected OSGs is available from most of the selected OSGs except two (Macmillan and Cancer Compass), information is therefore available for 108 members as can be seen in Table 26.

Year	Number	%
2002	4	3.70
2004	1	0.92
2005	2	1.84
2006	7	6.48
2007	8	7.40
2008	14	12.96
2009	21	19.44
2010	23	21.29
2011	28	25.29
Total	108	100%

Table 26: Joining time of members to the selected OSGs

Approximately a quarter of the participants joined the relevant group in 2011 followed by 2010 (21.29%). In general, it seems that the highest number of members joined the OSGs recently.

7. Cancer type

Information about cancer type for the people with cancer who sent the support messages themselves, or those who received care from the person who sent the message, was available for 103 people with cancer (see Table 27).

Table 27 indicates that more than a third of the persons with cancer (n = 38) had tongue cancer, of them 10 people had cancer of the base of the tongue. The second most frequent type of cancer recorded was tonsil cancer (16.5%) or a mixture of more than one site of cancer (15.5%). Low percentages of other H&N cancer sites were recorded. Some of them were specified such as floor of mouth, palate, and nasopharyngeal carcinoma while others were only mentioned as oral cancer or H&N cancer.

Cancer type	Number	%
Base of tongue	10	9.70
Floor of mouth	4	3.88
Jaw bone	5	4.85
Nasopharyngeal carcinoma	2	1.94
Throat cancer	3	2.91
Tongue cancer	28	27.18
Tonsil cancer	17	16.50
Pharyngeal Cancer	2	1.94
Palate	2	1.94
Nasal cancer	1	0.97
Follicular lymphoma	1	0.97
Gingiva	1	0.97
Mixed	16	15.53
Oral cancer	3	2.91
H & N cancer	1	0.97
Occult origin	3	2.91
Undiagnosed	3	2.91
Misdiagnosed	1	0.97
Total	103	100%

Table 27: Different cancer sites reported by the support providers

8. Stage of cancer

Information about stages of cancer was available for a relatively few cases (49 cases) and approximately two thirds of them were in their advanced stages (stage IV and stage III), see Table 28.

Stage	Number	%
Stage I	8	16.32
Stage II	5	10.20
Stage III	5	10.20
Stage IV	27	55.10
Multiple stages	4	8.16
Total	49	100%

Table 28: Stages of cancer as provided by support providers

9. Treatment stage

Data about treatment stages were available for 108 persons with cancer (see Table 29). The vast majority (about 85 %) of the cases were in post treatment stages. It can be noticed that, although some people with cancer were deceased, their caregivers were still using the H&N cancer-OSGs.

Treatment stage	Number	%
Post treatment	92	85.18
Under treatment	11	10.18
Pre-diagnosis	2	1.85
Deceased	3	2.77
Total	108	100%

Table 29: Treatment stages as provided by support providers

4.6.1.2 Content analysis of the support-offering messages

Of a total of 312 support-offering messages, 307 messages included at least one form of social support. The remaining 5 messages were not relevant, as they did not include any type of support. While some messages have only one support statement many messages have more than one, therefore, from the 307 messages, there were 1240 support statements, of which 1169 (94.27%) could be coded under the chosen coding framework. The remaining (n=71) could not be analysed within the existing framework. In addition, some statements in the same message included the same category of social support, therefore, the repeated categories of social support within the same message was excluded, thus a number of 160 supporting statements were removed. The final number of statements that contained at least one type of social support was 1009. An overview for these statements can be seen from Figure 9.

Figure 9: An overview of the support-offering messages

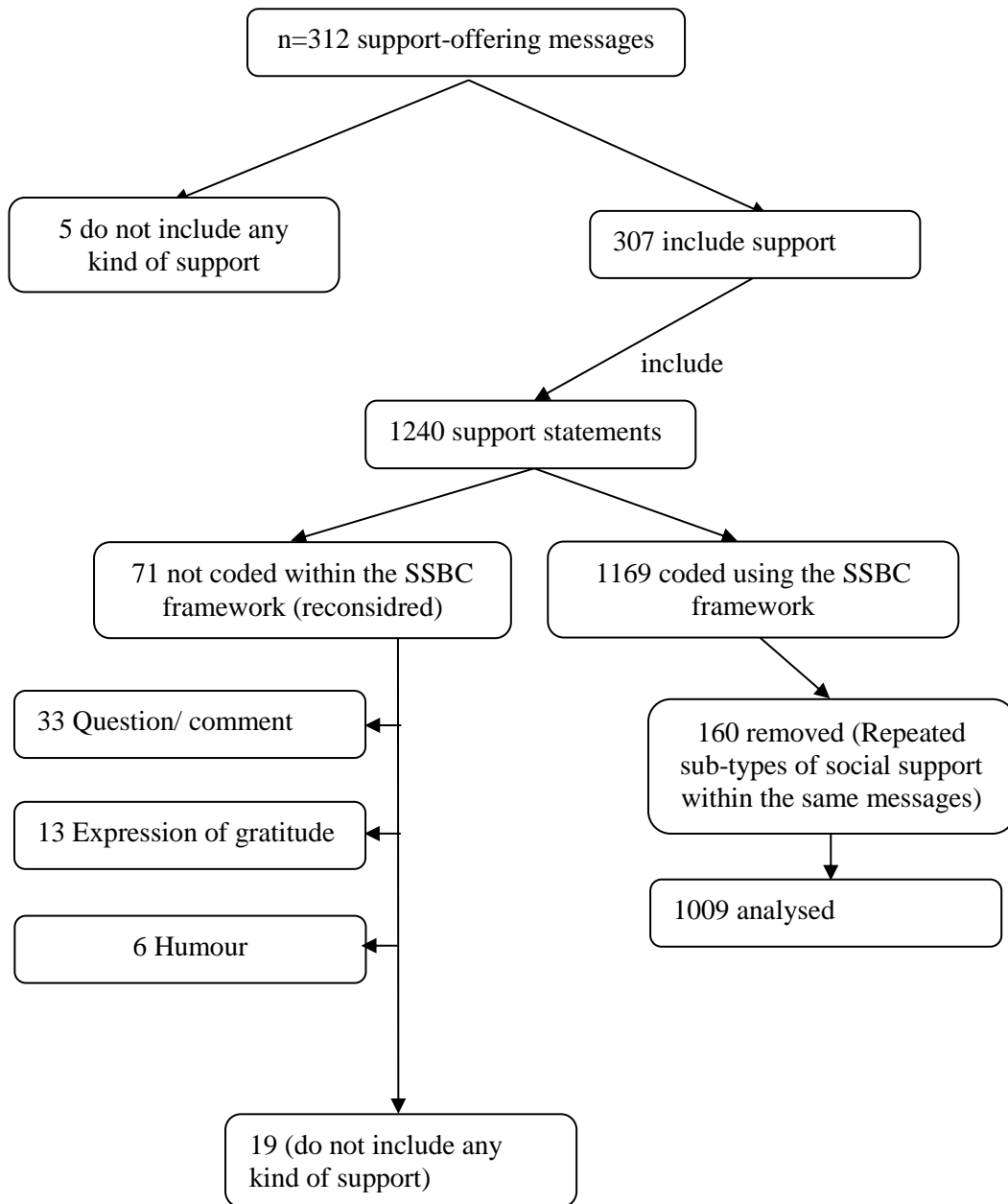


Table 30 shows the number of types of social support within the 307 messages

	Number of messages	%
Messages involved one sub-dimension of social support	53	17.26
Messages involved two sub-dimensions of social support	72	23.45
Messages involved three sub-dimensions of social support	71	23.12
Messages involved four sub-dimensions of social support	48	15.63
Messages involved five sub-dimensions of social support	32	10.42
Messages involved six sub-dimensions of social support	21	6.84
Messages involved seven sub-dimensions of social support	6	1.95
Messages involved eight sub-dimensions of social support	2	0.65
Messages involved nine sub-dimensions of social support	2	0.65
	307	100 %

Table 30: Number of types of social support within the 307 messages

As it can be seen from Table 30, more than 80% of the messages contain more than one category of social support.

Table 31 shows the frequency of each social support dimension and sub-dimension according to the SSBC framework.

Support category	Number of support statements	Percentage of support statements %
Informational support	438	43.4%
Advice	122	12.09
Referrals	32	3.17
Situation appraisal	50	4.95
Teaching	96	9.51
Sharing own experience	138	13.67
Esteem support	158	15.65%
- Compliments	85	8.42
- Validation	69	6.83
- Relief of blame	4	0.39
Network support	61	6.04%
- Access	32	2.99
- Presence	29	2.65
Emotional support	327	32.4%
- Expression of care	42	3.17
- Relationship	2	0.19
- Physical Affection	31	3.07
- Confidentiality	0	0
- Empathy	40	3.96
- Sympathy	47	4.65
- Encouragement	138	13.67
- Prayer	27	2.67
Tangible assistance	25	2.47%
- Loan	3	0.29
- Perform direct Task	5	0.49
- Express willingness	17	1.68
- Perform indirect Task	0	0
Total	1009	100%

Table 31: Frequency of each social support dimension and sub-dimension

All five dimensions and all except two of the sub-dimensions of social support in the utilized coding framework were found in the messages, with considerable variations in the percentage of each dimension and subdimension.

Table 31, shows that the most frequently recorded dimension of social support was the informational support representing 43.4% of the total coding (438 supporting statements), followed by emotional support representing 32.4% of the total coding (327 supporting statements). Esteem support was the third most frequent social support recorded (15.65%) with 158 supporting statements. However, the frequency of both tangible assistance and network support was low (2.47% and 6.04% of the total support respectively).

The most frequently recorded sub-dimension in informational support was “sharing own experience” having the same percentage of the most frequently recorded sub-dimension in emotional support which is “encouragement”. Both of them represented 13.67% of the total support available and were the highest percentage recorded in the result.

1. Informational support

All of the five sub-dimensions that are listed under this dimension of social support were seen in the analysis, and the sub-dimension “*sharing own experience*” was representing the highest percentage (13.67% of the total 1009 support-offering messages). Messages of this subcategory appeared to contain the involvement of experiences that act as references rather than being a tool of education in dealing with H&N cancers. For example, as a response to a member who had finished radiation and chemotherapy for base of tongue cancer and still suffering from severe cramps in H&N region after performing any strenuous action, another member shared his experiences:

“I’m 9 years post treatment and still get the occasional neck/jaw cramp although no where near as often and they don’t last as long - happen about once or twice a month now. I found solpadol works for me although they take a while to work, they

seem to stop the repeat cramps that i get if i dont take anything” (Alex).

In another example, responding to a member who was looking for people experiencing the same type of cancer his mother suffers from, one participant responded:

“I had a nasopharyngeal type in my sphenoid sinus. Went thru 6 weeks radiation and 2 rounds of cisplatin chemo back in October/November 2007” (Addison).

The second most frequent support subcategory under this dimension is “*advice*” messages (12.09% of the total messages) which suggest actions and provided ideas or guidance for coping with H&N cancer. For example, in response to a member who had chemotherapy and radiation treatment for advanced oral cancer and had lost a lot of weight one of the support providers wrote:

“Try to get a good amount of protein and nutrients into you, and try walking outside a bit daily” (Martin).

In another example, a member posted advice for another oral cancer survivor who was annoyed that other people were so concerned about her and made decisions for her because of her cancer:

“How about politely saying cancer isn't contagious and never has been. Then smile knowingly, because apparently they don't” (Janine).

Teaching messages refers to statements that provide technical information or facts about H&N cancer-related conditions or about the needed skills to cope with these conditions. For example a member who was complaining about some symptoms after receiving radiation treatment for nasopharyngeal carcinoma received some explanation about her condition:

“The condition of your neck swollen, red tender skin and warm to the touch is a common condition called Lymphedema. It is very common for people who had radiation treatment to the affected area” (Clare).

Another example posted in response to a caregiver looking for support on how to deal with her father who had a terminal cancer led him struggling in eating and being generally nauseous, one member responded:

“In North America there is a liquid replacement diet product called Ensure, but if it exists in the UK it's by prescription. However, there are canned "shakes" in the markets, if you can manage to get your father's nausea under control and he wants something in his stomach” (Mathew).

Situation appraisal messages appeared to reassess or redefine the condition in a manner that made recipients more positive or disclosed new helpful information to enable coping with cancer. This sub-dimension appears relatively infrequently in the data, with only 4.95% of the total 1009 support statements. An example of this type of support appeared in response to a member who had just finished treatment for tonsil cancer and was still worried about the future, another member wrote:

“The first year was hard wondering but it fades with each passing year. I am now 58” (Ashley).

Another support-offering message was sent to a member who was a throat cancer survivor and had a problem in her face and mouth region and was worried about whether this problem could be a cancer:

“You seem to have some sort of numbness from your previous post. I doubt it to be OC symptoms. However, it may be symptoms of Facial Nerve pain (also called Trigeminal Neuralgia)” (Oliver).

The least frequent support subcategory that appears under this dimension is referral messages (only 3.17% of the total messages). These messages act to direct the recipients to a particular source of resources or expertise such as website, textbook or particular organisation. Most of the referral statements in the data targeted online resources, possibly because these messages were directed to members who can use the internet so that it is easy for them to find support. In addition, most of the participants were not living in the same city or geographic region. For example, in response to a member who was a caregiver and seeking information regarding her father who had cancers of the tongue and floor of the mouth and a perineural invasion (PNI), one member wrote:

“Don't forget this article's statistics should be put into the context that for individual patients like your Dad and I, it's either 100% or zero. PNI is most definitely NOT a death sentence; PNI: chapter 33 H&N Cancer” (Jenny).

Few messages appeared to refer the support seekers to offline expertise, for example, a member was unsure about a problem in his mouth near his throat that he uploaded some photos on one of the H&N-OSGs, this member received a response from another member:

“I don't think anyone here can help you tell what this is, after all we're not doctors. But I do think that you should get an appointment to see an ENT and have it evaluated” (Katy).

2. Esteem support

The most frequent subcategory under this dimension was "complaints" representing 8.42% of the total 1009 messages. This kind of support supplied positive statements about the support seeker's activities and/or personality and noted their ability attributes in resisting their cancer. For example, in response to a member who had finished his treatment for oral cancer, was cancer free but still experiencing side effects from treatment, one of the participants wrote:

“Congrats on finishing your treatments and becoming cancer free! You will bounce back, it just takes time. Next year this time you will be so much better than you are now” (Richard).

In another example, a member was terrified of being permanently unable to speak after surgical removal of laryngeal cancer received support from another member who was a caregiver for her mother and who had undergone a similar operation, in this example Amanda complimented that member by emphasizing his abilities to speak:

“There will be a learning curve, but but you will be able to speak” (Amanda)

Validation messages involved acknowledgment or agreement with the recipient's opinion on the situation related to H&N cancer including the recipient's emotions, action, beliefs or thoughts. For example, some messages expressed validation that a member had felt stressed due to waiting for results of some investigations:

“We all get apprehensive around check up time. I guess that's a fear we can never quite get past” (Tommy).

Other messages expressed validation and agreement with previous respondents other than the original posters. For example, one member posted:

“I agree with everything Joycee has 'said” (William).

Another member validated a previous respondent by writing

“Eric is right about putting on the lean body mass, when you are ready to work on coming back. You can't do it without a good balance of hormones” (Lisa).

This necessitated slight modifications to the definition of this sub-dimension of social support in the utilised coding framework to include such kind of messages. Therefore, the new definition of this item will be messages involving acknowledgment or

agreement with the recipient's opinion or previous respondents on the situation related to H&N cancer including their emotions, actions, beliefs or thoughts.

Only a few statements could be coded under the “relief of blame” category. It could be that people with H&N cancers do not often see themselves to blame. One member, who felt shy and guilty of participation in the H&N cancer-OSGs because she felt that her cancer was superficial and her surgery was nothing compared to other participants, received the following response:

“Yvonne, you are an oral cancer survivor! You are one of the very few lucky people who have battled this disease. Do not for one second feel an ounce of guilt about this. While you may not have had to deal with everything that some others have, you still had cancer” (Mary).

In response to a member who was heartbroken about her husband who had late stage cancer of the base of the tongue with metastasis to brain and pelvis, and she felt guilty that she could not do anything to help him:

“When we are in the depths of crisis, it seems like there is nothing we can do. All our wishes for health and strength for our loved one have come to naught, and we feel helpless: we have done all that is humanly possible. And yet, that is a great deal” (Elizabeth).

3. Network support

The structural connections of social support were listed under this dimension, in which the sender appeared to highlight the social network of the recipients. A relatively low percentage of messages (6.04%) were coded under this dimension of social support and approximately similar percentages of the two subcategories of this dimension (presence and access) were recorded in the data.

Access messages verified the accessibility of people with H&N cancer or caregivers, to new members inviting them to participate in the activities of group. For example, a member with tongue cancer who was new to the OSGs received a response from another member:

“Welcome to OCF HSH. You have come to the right place to get info about oral cancer. This website and forum has the most info all compiled into one place” (Linda).

Access messages seemed to invite recipients to participate in a social support group to expand their social network. Presence messages remind the recipients that the support group acted as a network to provide continuous support, as someone is always available to spend time with them. For example, one member who faced a recurrence of cancer after 6 years received support from another member:

“Please keep posting so we can help support you thru this battle” (Katherine).

In another example, a member with soft palate cancer, who was new to the OSG, received a response from another member who wrote:

“This is a great group of people, please ask any questions you might have” (Jessica).

4. Emotional support

This dimension of social support appeared to be the second most frequent support in the data representing about a third of the total messages. The emotional connections were categorised under this dimension of support which included seven of these subcategories. The “encouragement” sub-dimension represented the highest occurrence of all the supporting messages in the coding frame (13.67% of the total 1009 messages). The same percentage was also represented by messages including sharing personal experience under informational support. However, there were no messages which could be coded as “confidentiality” which include those in which

members promise to ensure that the recipient's issues are kept in confidence. This absence can be attributed to the confidentiality that has been already secured by the anonymity provided by OSGs.

Messages that were coded as "expression of care" included expression of concern toward the recipients. For example one member, after providing other categories of support to a recipient, wrote:

"Take care" (David).

In another situation one member wrote:

"Thinking of you!" (Deborah).

A very low percentage (0.19%) of messages could be coded as "relationship" which emphasise the importance of love, closeness and friendship within and outside of the H&N cancer-OSGs. For example, responding to a member taking care of a person with advanced stages of oral cancer, another member wrote:

"John is leaving the pain and struggle and finding peace...he is leaving knowing that he was loved and that he had a companion that loved him and was willing to be there with him until the end of his journey. As a man who believed my time had come, I can never express the feelings I had (and have) for my wife/caregiver, Aly, knowing she was there with me and for me until I passed on" (Roland).

Physical affection messages should express a verbal physical contact posted by members. Yet, given that there is no real contact which can take place in OSGs, virtual acts posted by support providers were taken as proxies for such physical affection. For example, one member posted:

"Big hugs" (Elizabeth),

and another sent:

"Sending hugs, kisses2" (Dane).

In addition, some respondents sent expressive emotions (emoticons) rather than writing specific words. These emoticons have been included under this category as proxies of physical affection. This has also necessitated slight modifications to the definition of this sub-dimension of social support in the utilised coding framework. So, the new definition for this sub-dimension will include messages that offer physical contact, including hugs, kisses, hand holding, shoulder patting, as well as expressive emotions.

Examples of the different emotions and their meanings that evident in the messages were:

“ (happy),  (welcome),  (laughing),  (sad)”

Empathy messages comprised of an understanding or comprehension of the situation of the support seekers, and often with their own comparison of the experience. For example, one member, in response to another member who was feeling stressed because of waiting for MRI scan result, said:

“I know how hard it can be to wait on your scans” (Elbert).

In another example, one member responded to a caregiver whose wife had been treated from tonsil cancer and was still suffering from terrible mucus:

“I do understand how your wife must be feeling just now”
(Flora).

Sympathy messages expressed distress, unhappiness or grief at the situation of the recipient. For example, one participant supporting a member who was a caregiver to a father with terminal throat cancer, metastasised to his chest, wrote:

“I'm saddened to read this. There's not much that anyone can say really but that we support you and your father for whatever time you two can share” (Eve).

In another example, one member responded to a caregiver whose wife had been treated for oral cancer and still experiencing side effects of treatment:

“I am sorry to hear that your wife is going through this trauma of a cancer journey” (George).

Encouragement messages were the most frequently seen category of support under this dimension of support. Encouragement provides confidence and hope to the recipient. For example, one participant with a prosthetic device (Obturator) to replace the opening resulting from cancer of the hard palate received a response from another member:

“I hope the opening will be closed in the future” (Nicola).

Some messages contained other expressions of encouragement support such as:

“best wishes”, “good luck”, “Hang in there”, “keep the faith”, “good health”.

In addition, one member used a comparison to encourage another member suffering from H&N patient:

“I am almost a year out, and I am also hoping you don't have to have rad or chemo!” (Robert).

Messages included prayers with or for the support seekers due to H&N cancer. Members used different words to express their prayers for the recipients. For instance, the following phrases were seen:

“I will pray for you” (Sandra).

“You are in my prayers” (Paul).

“All of us are here thinking good thoughts and lifting you up in prayer” (Oliver).

“It could be something other than cancer, and I pray it is” (Tammy).

“I’ll say a prayer for you guys in the morning” (Victoria).

“I will keep all of you in my prayers” (Patrick).

5. Tangible support

This dimension of social support appeared to be the least frequent dimension among the five main dimensions in our data representing only 2.47% of the total supporting statements. This dimension of social support included four categories, and while no messages could be coded under the "perform indirect task" category, only a few message were coded under the three remaining categories.

Messages that were coded as "direct task" represented 0.49% of the total supporting statements. In these messages, members offered to execute a direct task related to H&N cancer recipients (persons with cancer or caregivers). For example, one member, who was a caregiver to a person with terminal throat cancer that meant she struggled to eat, received a response from another member:

“I made up a list of easy to eat foods which may help” (Tracy).

In another example, one member replied to another who sought support in how to deal with her husband who had cancer at the base of tongue:

“I am going to PM you some information you might find helpful” (Sarah).

Messages that were coded as "willingness" represented 1.68% of the total messages and included those in which the supporters experienced willingness to assist the support seekers. In this subcategory of support, one member responded to another:

“I am happy to share my experiences with you, so if you would like to know more, please feel free to pm me and I’ll give you my email address” (Peter).

Another wrote:

“If there is anything I can Help with just let me know and if I can Answer it I will” (Julian).

A third wrote

“I’ve been down this road and would like to help if I can”
(Stacy).

Only a few statements were coded as "loan" support that refers to an offer to provide the recipient with money or material object. For example, in response to a member who was seeking financial support to be able to participate in special walk events which require travelling to another country, one member replied:

“Anyone who writes such as great call to action on the walk page deserves my support, I am now officially one of your sponsors on the event page” (Stephen).

Another member responded to the same postings by writing:

“I just donated to your fundraising” (Luke).

6. Uncoded messages

There were 71 support-offering statements that could not be coded using the SSBC framework. These statements were thematically analysed to identify categories of support. Three categories emerged: Question/ comment (n = 33), expression of gratitude (n = 13), and humour (n = 6). The remaining 19 statements did not contain any kind of support and were therefore excluded.

Question/ comment:

These messages involved questions or comments that included hidden support such as expression of interest, advice or care for the person. The advice in this situation was not direct advice as in the case of the existing advice code, but came in the form of a question intended to give indirect advice.

Some participants asked questions illustrating they were interested in the situation and wanted to know more. For example, one posted:

“My question is what stage was it? I am assuming no lymph nodes were involved, and that you probably had scans, but did you have any scans to make sure no lymph nodes were involved? Also was it a partial glossectomy or a hemi-glossectomy?” (Susan).

Another member wrote:

“I am wondering why the hospital did not give you instructions on what you should try to eat” (Oscar).

Some questions were asked in a form of advice. For example one member posted:

“Have you considered having a talk with the source that started this whole thing?” (Becky).

And some questions involved expressions of care for the person:

“will you be having any other treatment such as radiation? It wasnt that long ago, how is your healing coming along?” (Goodwin).

Some replies were interpreted as comments, for example, one member commented in response to another:

“The tagline of this video reminds me of the OCF forum members but with a twist: Instead of the video's "ordinary people with extraordinary dreams", IMO we are "extraordinary people with ordinary dreams". (Or at least I dream of "ordinary" pleasures of eating, drinking, talking,

etc.) And who here would not trade their "new normal" for their old "ordinary"?" (Graham).

Expression of gratitude

These messages included direct thanks for the recipients regarding their participation or posting specific messages. As a kind of behaviour that acknowledges the actions of others, exchanging such kind of messages appeared to have positive outcomes on promoting caring relationships between members in the OSGs. For instance, one wrote in response to another member who had posted his full cancer journey:

"Thank you for joining the site and sharing your story"
(Caroline).

In another example, one member replied to another who was a physician with throat cancer and had shared his manuscript and experience in the OSG:

"Thank you for sharing your manuscript and experience with us Dr.X" (Cathy).

Sometimes, other terms rather than "thanks" were used to express gratitude such as

"much appreciation" (Christine).

Humour

These messages had a tendency to provoke laughter and provide amusement. For example, in response to a member who had finished his treatment for tonsil cancer, but was still worried about his first follow up, one member wrote:

"Dang the appendix was a real thriller of a complication. I'm kind of reminded of the famous Mark Twain saying "when you're up to your ass in alligators, its hard to remember your original intention was to drain the swamp" (Harley).

4.6.2 Social support sought: Analysis of support-seeking messages

4.6.2.1 Demographics of support seekers

1. Age and gender

As seen with support providers, relatively few members supplied their ages in their profiles and some of the caregivers supplied the ages of the family member who is the cancer patient rather than their own age. Age was provided by 31 (out of total 78) members, and while 23 of them (22 persons with cancer and one caregivers) provided their own ages, 8 caregivers provided the ages of the family member who was the person with cancer.

The highest percentage of people with cancer were in the age group (50 – 59) which is again consistent with the age of the typical patient with H&N cancer in the literature (Ridge *et al.*, 2004; Chidzonga and Mahomva, 2006; Warnakulasuriya, 2009). However, unlike the case of support provider, about a quarter of the participants who supplied their ages were under 30 (see Table 32).

Age group	Number	Percentage %
0 - 19	0	0
20 - 29	6	26.08
30 – 39	6	26.08
40 – 49	1 (CG*)	4.34
50 – 59	8	34.78
60 or above	2	8.69
Total	23	100%

Table 32: Age distribution of the support seekers within 6 age groups

* CG = caregiver

The ages of the eight people with cancer supplied by their caregivers were 20, 30, 40, 40, 57, 61, 76 and 82. Using the same method of identifying gender in the case of support providers, the gender for support seekers was identified for 67 members; 67% of them were females.

2. Location

Since not all OSGs provide information about the location of the members without registration, these data were available for 64 members, and about three quarters of them were from the United States. The remainder were from countries in which English is the main/ official language such as United Kingdom, Canada, Australia and Ireland. In addition, only few members were from other countries such as Singapore and Sri Lanka (see Table 33).

Country	Number	%
USA	47	73.43
UK	8	12.50
Australia	3	4.68
Canada	2	3.12
Ireland	2	3.12
Sri Lanka	1	1.56
Singapore	1	1.56
Total	64	100%

Table 33: Location of support seekers

3. Identities of support seekers

Deductions about the identity of the support seekers were established from the messages of all members. About 68% (53 members) of the support seekers were people with cancer and around 30% were caregivers. However, only one member was classified as friend or colleague (see Table 34).

Out of the 53 people with cancer, forty-seven of them were recorded as people with cancer only, two were caregivers at the same time, three were healthcare professionals and one person appeared to have both roles.

Support provider	Number	%
Person with cancer	53	67.94
CG (Wife)	8	10.25
CG (Husband)	1	1.28
CG (daughter)	4	5.12
CG (Son)	2	2.56
Daughter or son	2	2.56
CG (Brother)	1	1.28
CG (Mother)	1	1.28
CG (Girlfriend)	1	1.28
Partner (unspecified)	1	1.28
Family member (unspecified)	1	1.28
Friend /college	1	1.28
CG (unspecified)	2	2.56
Total	78	100%

Table 34: Identities of support seekers

* CG = caregiver

4. Number of postings

Number of support-seeking messages sent by the participants was supplied in all OSGs except one (Cancer compass), therefore, information about this number was available for 75 members as seen in Table 35.

Number of messages	1-10	11 - 100	101- 500	501- 1000	1000- 5000	5001- 10000.
Number of people	33	26	10	-	5	1
%	44	34.66	13.33	-	6.66	1.33

Table 35: The total number of support-seeking messages

Unlike the case of social support providers, where the majority of the members appeared to be actively posting more than 100 messages, more than three-quarters of support seekers showed less activity with no more than 100 messages with about 9.5% sending only one message. In contrast, only 8% of the participants had sent more than 1000 messages.

5. Joining time

The joining time of the members to the OSGs was available except for two (Macmillan and Cancer Compass). Information about the members' joining time was available for the 30 members. More details are available from Table 36.

Year	Number	%
2002	1	1.42
2003	1	1.42
2005	1	1.42
2006	3	4.28
2007	3	4.28
2008	2	2.85
2009	5	7.14
2010	14	20.00
2011	40	57.14
Total	70	100%

Table 36: Joining time of the support seekers

From Table 36, it can be noticed that the majority of members joined the OSGs in 2011. In addition, as in the situation of support providers, it seems that the highest number of members joined the OSGs recently.

6. Cancer type

Information about cancer type for people with cancer seeking online support for themselves, or those who receiving care from the person who sought the support, was available for 75 persons (more details are available from Table 37).

The most frequently recorded cancer was tongue cancer representing more than a third of cancers; more than half of them had cancer of the base of the tongue. The second most frequent type of cancer recorded was tonsil cancer (9.33%). About 17% of support seekers were still undiagnosed at the date of posting their message(s).

Cancer type	Number	%
Base of tongue	10	13.33
Floor of mouth	2	2.66
Jaw bone	1	1.33
Nasopharyngeal carcinoma	1	1.33
Throat cancer	2	2.66
Tongue cancer	17	22.66
Tonsil cancer	7	9.33
Pharyngeal Cancer	2	2.66
Laryngeal cancer	2	2.66
Palate	2	2.66
Leukaemia	1	1.33
Lymphoma	1	1.33
Adenoid Cystic Carcinoma	2	2.66
Mixed	5	6.66
Oral cancer	4	5.33
Mucoepidermoid carcinoma	1	1.33
Occult origin	1	1.33
Undiagnosed	13	17.33
Salivary gland cancer	1	1.33
Total	75	100%

Table 37: Different cancer sites reported by the support seekers

7. Stage of cancer

Information about the stage of cancer was available for a relatively few cases (24 cases), two third of them were in stage IV. Some members referred to their stages using the words “intermediate or terminal” stages. More details are available from Table 38.

Stage	Number	%
Stage I	1	4.16
Stage II	1	4.16
Stage III	1	4.16
Stage IV	16	66.66
Different stages	3	12.50
Intermediate Grade	1	4.16
Terminal cancer	1	4.16
Total	24	100%

Table 38: Stages of cancer as provided by support seekers

8. Treatment stage

Data about treatment stage were available for 76 persons with cancer (see Table 39). More than half (57.89 %) of the cases were in post treatment stages. As in the case of support providers, some persons with cancer were deceased, and their caregivers were still using the H&N cancer-OSGs.

Treatment stage	Number	%
Post treatment	44	57.89
Under treatment	15	19.73
Pre-diagnosis	14	18.42
Pre-treatment	2	2.63
Deceased	1	1.31
Total	76	100%

Table 39: Treatment stages as provided by support seekers

4.6.2.2 Content analysis of the support-seeking messages

Out of all the 87 support-seeking messages, 193 statements were coded using the modified Coursaris and Liu framework. Sometimes, statements coded to have the same category of support are found in the same messages, and since they were counted only once, nine statements were excluded. Subsequently, the final number of statements that seek at least one sub-dimension of social support was 184. The 87 support-seeking messages that contain these 184 statements can be seen in Table 40.

	Number of messages	%
Messages sought one sub-dimension of social support	26	29.88
Messages sought two sub-dimensions of social support	30	34.48
Messages sought three sub-dimensions of social support	26	29.88
Messages sought four sub-dimensions of social support	5	5.74
Total	87	100 %

Table 40: Frequency of sought subcategories of social support within the support-seeking messages

As shown in Table 40, about 70% of support-seeking messages seek more than one subcategory of social support. Table 41 below shows the frequency of sought social support.

Sought support	Number of statements that sought support	% of statements that sought support
Seeking informational support	47	25.54
Seeking wellbeing information	7	3.8
Seeking emotional support	23	12.5
Seeking esteem support	7	3.8
Seeking network support	0	0
Seeking tangible support	2	1.08
Sharing personal experiences	58	31.52
Expression of gratitude	26	14.13
Congratulations	0	0
Expressions of care	2	1.08
Encouragement	12	6.52
Total	184	100

Table 41: Frequency of sought and expressed social support in support-seeking messages

Table 41 illustrates that nine out of the eleven items of social support seeking were found, although with significant variation across categories.

The most frequently sought dimension of support was informational support which was sought by about a quarter of the members, followed by emotional support (12.5%). The third most frequent social support was esteem support representing 3.8%. These frequencies were consistent with those seen in the support-offering messages. Only two support-seeking messages were coded in the seeking tangible assistance dimension and no messages were coded under seeking network support.

1. Seeking informational support

Approximately one quarter of the members had sought informational support to cope with their cancer. Statements that were coded under this section included specific questions regarding the condition of H&N cancer to obtain factual information, seek advice or suggestions, or to help evaluate a certain situation.

For example, one member who had a history of throat cancer and was worried because of the appearance of new symptoms that she was unfamiliar with (rash in the chest area), after sharing her experience asked:

“Has anyone had any experience with recurring throat cancer? I am interested in knowing if the rash has anything to do with it also” (Anna).

Another member was a caregiver for her father who had undergone two operations for tongue cancer and had a swallowing difficulty, she asked:

“I know everyone progresses at a different rate and it takes a long time to get back to anything near to "normal" but how quickly have other people managed to start swallowing and taking some kind of soft foods?” (Clair).

2. Seeking wellbeing information

Messages that sought wellbeing information were sent by caregivers to include specific questions about how to offer support to their family member. As example of seeking this kind of support, a care giver whose father had terminal throat cancer that had metastasised, stated:

“I no there is nothing that can be done treatment wise but was wondering if theres anything i can do or buy to make him more comfortbale and be able to enjoy the remainder of time he has

left. He struggles to eat much at the moment and is nauseous a lot of the time” (Carol).

Another caregiver, after sharing her father’s experience with tongue cancer, stated:

“If anyone has had a similar experience on even learning to swallow after free flap/neck dissection surgery and/or dealing with an NG tube I would be so very grateful to hear from you so I can give my Dad some hope and perhaps give me more of an idea of what questions to ask” (Christina).

3. Seeking emotional support

Messages that were coded under this category included statements in which members, through their messages, exhibited emotional or psychological weakness and needed comfort due to their condition or the condition of their family member. For example, one member who had a throat cancer and was told the treatment may lead him permanently unable to speak, posted:

“How the heck does one FUNCTION at all in society at large without speaking? You guys have been my rock for many years and I know some of you have SOMETHING that I can look upon as "positive" coming out of this. The only thing I can come up with is that "at least I won't have to go around sounding like THIS any more!" :-) (I speak with a very "gravelly" barely understandable voice right now)” (Barry).

In another example, a caregiver was worried about her father who had finished treatment for H&N cancer, was still unable to swallow, and had a new lump:

“It's just been stressful and we are really worried about so many things, like the 'lump', the results next Monday and if he will ever get to swallow again.” (Anne).

4. Seeking esteem support

In these types of postings, members were seeking validation for their perspective or were seeking a relief of blame when they felt guilty regarding a specific situation. In an example for seeking validation support, a caregiver posting a message regarding his colleague who had terminal tongue cancer that metastasised to his lungs and was sent home because nothing more could be done for him. However, he wanted chemotherapy to palliate his suffering:

“We think his wishes should be respected, even if it’s risky. It would appear that the greatest risk is not doing anything, since that seems to lead to certain death. Aren’t doctors obliged to follow the patient’s wishes?” (Jacob).

Another example of seeking esteem support was a member who sought blame support as she felt guilty for participating in the OSGs and in a specific event that had been organised for persons with cancer, because she felt her cancer was insignificant:

“How do I even begin to express what I what to say? I’ll try and do my best. So many of you have been through so much and I am very proud to be part of this forum, yet, I feel so guilty as my cancer was superficial and my surgery was “nothing” compared to what you have endured. I want to do this walk but feel like because my cancer was so minimal, do I belong there? I sometimes feel that way when I am on this site because, like I said - you all have been through so much.” (Linda).

5. Seeking network support

This category was intended to include messages in which people are asking for prolonged contact with others in similar situation; no messages could be coded as seeking this category of support in the OSGs.

6. Seeking tangible support

Only 1.08% of support-seeking messages could be coded under this section and included statements that asked for money, materials or equipment.

In an example of this kind of support seeking, one participant wrote:

“I will be going to the Minneapolis OCF Awareness Walk on October 22nd. I have set up my fundraising page and while I have spared my OCF friends from my e mail requests, I will SHAMELESSLY post my link here - just in case - one or two or twenty of you wanted to support me in this walk. I am after all travelling TO ANOTHER COUNTRY to do this!! Amazing, eh? Here is the link: Minneapolis OCF Awareness Walk - Donna Butcher Fundraising Page” (Leon).

7. Sharing personal experiences

Messages that show sharing of personal experiences appeared to be the most frequent type of messages in the data, as about third of the participants shared their personal experiences with H&N cancer or the experience of their family members. Messages coded under this category included those in which members shared their personal conditions, feelings and thoughts related to H&N cancer with others initially and spontaneously.

Some members posted their experience as an introduction for seeking other kinds of support, whereas others only posted their experience. In an example of this category of support seeking, one member shared his experience with H&N cancer and wrote:

“Stage 4 cancer, Feb 15, 2011. had chemo and radiation which resulted in pneumonia and 2 other fungal diseases of the lung. The latest PET scan was clear and except for the lung infections I am moving forward. I lost 70 lbs. Before this I was extremely athletic, runner, weight lifter, etc. Now a pile of bones with skin. Pain in my joints keeps me down, but I'm alive” (David).

Another member shared the experience of his family member:

“hi im new to group my wife is recovering from major sugery to remove her tumor in her tonsils, which had spread to lymph glands in the neck, causing her to have to have radiotherapy, my wife also suffers with lupus which affected her very badly during radiotherapy, it is seven months since surgery and five since radiotherapy, she still suffers terribly with mucus and still nil by mouth” (Freeman).

8. Expression of gratitude

These kinds of messages were seen in approximately 15% of the total messages in which members expressed straightforward thankfulness for the recipients either initially or because of their previous support. For example, one member, after seeking information support, posted:

“Thank you in advance for any advice” (Angela).

In another, a member posted:

“Ok today I saw the oral surgeron he said I have redness and irraiation but do not need biopsy because I don't have cancer everything appears normal...yayyy...i ve heard from 9 doctors now so I think I will accept this...he said my form of leuopkia isn't cancerous but I'm thankful to everyone here for supporting me through this” (Harrison).

9. Congratulations

This category includes messages that expressed joy or acknowledgment of the recipient's achievement or good fortune; however, no messages could be coded as “congratulations” in the OSGs.

10. Expression of care

Only 1.08% of the messages were coded under this category and included expression of concern for the recipients.

For example, one support seeker, after sharing her experience with oral cancer, wrote:

“Take Care everybody-GOD BLESS” (Sally).

11. Encouragements

Most of the statements that included encouragements in the data were located after sharing personal experience or seeking other dimensions of support. Encouragement messages included sending of hope and confidence to the recipients. For example, in one message; after seeking emotional support, the writer wrote:

“I wish you all the best of luck and I am hoping and praying for all of us” (Amy).

In another example, one member was seeking informational support, and at the end of his posting wrote:

“In the interim, I hope that all of you and your families have a wonderful holiday” (Raphael).

4.7 Discussion

The aim of the present study was to assess the types and frequency of social support, sought and offered, within OSGs for H&N cancer. The application of content analysis in this study was intended to categorise the communication between users of online H&N cancer groups.

4.7.1 What types of social support are available in OSGs for H&N cancer?

The results indicated that of the 87 support-seeking messages and 307 out of the 312 support-offering messages each included at least one type of social support. In addition, about 70% of the support-seeking messages sought (and more than 80% of the support-offering messages offered) more than one type of social support. Moreover, more than two thirds (67.5%) of the support providers expressed high activity in posting messages to the OSGs with more than 100 messages, and 27% of them posted more than 1000 messages. Also, 21.3% of the support seekers sent more than 100 messages, and 37.5% of them posted more than 1000 messages. These figures can roughly give clue about the activity of members of these OSGs in term of exchanging support regarding the issues of H&N cancer.

The content analysis of these messages provided through the 18 selected H&N cancer-OSGs suggested that these groups were used by people to seek and offer a variety of dimensions of support, in particular informational and emotional. The predominance of these two dimensions of support in the findings of this study is consistent with previous research into social support for other health issues (eating disorders; Diabetes; Irritable Bowel Syndrome; Huntington's disease; HIV/AIDS; adolescents with cancer and families affected by childhood cancer) in both face-to-face and OSGs (Winzelberg; 1997; Braithwaite *et al.*, 1999; Preece, 1999; Loader *et al.*, 2002; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu, 2009; Elwell, Grogan, and Coulson, 2011; Coulson and Greenwood, 2012). This might suggest that exchanging informational and emotional support tends to be the primary function of OSGs irrespective of the health issue/topic of the group and that H&N cancer OSGs are no exception to this.

In these previous studies, the predominance of informational support exceeded that of emotional support in some (Winzelberg, 1997; Loader *et al.*, 2002; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu, 2009) whereas in others the opposite was found (Braithwaite *et al.*, 1999; Preece, 1999).

Informational support was the most frequent dimension of social support, and this was consistent with the behaviour of people with cancer in using the internet as it was estimated that 30% of patients with cancer use the Internet to obtain cancer information (Helft *et al.*, 2003). This may be because they value accessing other patients' stories as it offers them with information, emotional support, practical advice and reassurance (Rozmovits and Ziebland, 2004). The Internet is a beneficial resource for accessing stories due to its privacy and unlimited availability and accessibility without the need for travel (Ziebland *et al.*, 2004).

The result of this study showed that 9.51% of the support-offering messages were coded as teaching. This sub-dimension includes messages that provide detailed information, facts, or news about H&N cancer or about skills needed to deal with this disease. This percentage is relatively high and highlights the need to consider the quality of such information, since posting incorrect information on such OSGs will be readily accessible by a high number of people. This issue appeared in previous studies dealing with OSGs for other health condition such as Huntington's disease and HIV/AIDS (Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu, 2009) in which the percentages of teaching messages were 20%, 5.92% and 9.70% respectively. However, no study has been conducted to investigate the validity of such factual information which could be an important question for further research, particularly in relation to groups run by and for lay people.

Members of online H&N cancer support groups have supplied other categories of information support. For example, they supplied advice to members (people with cancer and caregivers) who were struggling to cope with their condition. They also tried to redefine or appraise the negative situations that related to the consequences of H&N cancer and its treatments. The result also suggested that 13.67% of the support providers and 31.52% of the support seekers shared their personal experience or the experiences of their family member with H&N cancer and many of them wrote about

their condition openly with extensive details. The exact reason behind this freedom in providing such details is not clear. However, it may be related to the anonymity provided in online groups, as participation does not require provision of the actual name and other details. As according to Sharp (2000) and Braithwaite *et al.*, (1999), anonymity appears to enable participants to discuss their anxieties and difficult feelings in a less stressful way and can provide safer surroundings to the participants to undertake creative and non-conforming examples of support. This interpretation is supported by other previous studies (Finn, 1999; Reeves, 2000; White and Dorman, 2001; Walther and Boyd, 2002). However, no study has investigated this role of anonymity and would be a question of interest for further research.

The second most frequently offered dimension of social support among members of online H&N cancer groups in this study was emotional support. Providing this dimension of support appeared to be an important function of this group. The most frequent supporting behaviour under this dimension was encouragement which appeared from the provision of hope and confidence for the recipients. In addition, members of these online groups often acknowledged the feeling of the recipients, expressed concern, and prayed with them as well as expressed sorrow for the situations of those recipients who were struggling with H&N cancer. It may be that this, subsequently, has positive influences in the coping process with this disease (Helgeson and Cohen, 1996; Kim *et al.*, 2010).

The other dimensions of support (Esteem, Network and Tangible support) were found in the analysis but with a relatively low frequency compared with informational and emotional support, therefore, statements based on this limited data might not be easily generalised. For example, esteem support, although it was the third frequent offered support by the member of the group, it was representing only (15.65%) of the total messages. This dimension of support included positive assessment of the members by providing compliments such as congratulations and by emphasising their abilities to cope with stressful situations associated with cancer. Another function for this dimension of support appeared to be validating the perceptions and views of the participants by expressing agreement and highlighting similar concerns as them.

Network support was observed in the present data with even lower frequency (6.04%) and appeared to provide a common place for recipients to explain many kinds of problems associated with this disease. The availability of such kind of support appeared to be highlighted by older members particularly to new members. However, after joining the support group, the need for this dimension of support was tackled and a route opened for more important dimensions and sub-dimensions of support (Coulson *et al.*, 2007). This can give an explanation to the low frequency of this dimension of support in the results compared with the previously discussed dimensions.

The least frequent dimension of support in the present data was tangible support (2.47%). This low frequency can be attributed to the nature of communications within OSGs, which reduces the chance of offering this kind of support (Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris and Liu, 2009).

In regard to support seeking, the findings were consistent with that of support provision. The most frequently sought or offered dimension of support was informational support followed by emotional and then esteem support. This consistency may give a hint that support providers offer support according to the need of support seekers. However, this still needs to be investigated in a further study.

4.7.2 Who uses OSG for head and neck cancer?

Although it appeared that the majority of support seekers and providers were people with H&N cancer, other people such as family members, friends and colleagues also posted either to seek support regarding their situation or regarding the situation of the family member with cancer or provide support to other members based on their experience with H&N cancer. It seems that regardless of whether the users were persons with cancer, family members or caregivers, such groups may be beneficial in offering or providing support. These findings are consistent with previous studies investigating online support for family members of children with cancer (Coulson and Greenwood, 2012).

According to the available demographics, the highest percentage of support providers (people with cancer and caregivers) were between 30 - 49 years old and the highest percentages of support seekers were between 50 – 59 years old. This indicated a difference in age group between support seekers and support providers in online H&N cancer groups. However, final judgements cannot be built on these data, since only a few members (less than a third) from the support seekers and the providers supplied their ages. In spite of this, the highest percentage of people with cancer who supply their ages and those whose ages were supplied by their caregivers were in the age group of 50 – 59 years, for both support seekers and providers. This was consistent with the ages of patients with H&N cancer in the literature (Ridge *et al.*, 2004; Chidzonga and Mahomva, 2006; Warnakulasuriya, 2009). This may raise attention about this age group, since it has been thought that older people are less expected to access and use the internet compared with younger people (Berry, 2011) and, therefore, it can be expected that many of those people who live with H&N cancer are deprived of the use of OSGs because of this digital divide.

From the data we can see that 69% of the support providers and 67% of support seekers were females. This may indicate that females tend to use OSGs for H&N cancer more than males, although the literature indicated that the worldwide incidence of oral cancer is more prevalent in males than in females in the majority of countries (Warnakulasuriya, 2009). However, in this study only a few members indicated their gender. Thus, for many members their gender was determined in a deductive way based on information provided through the messages. This may question the accuracy or validity of the gender data in the present study.

The number of messages that were sent by a member to specific OSGs indicates the degree of member activity. The majority of H&N cancer-OSGs used in this study provided this number. Results indicated that the majority of support providers posted more than 100 messages and about 18% were even more highly active with more than 1000 messages and some posted up to 6000 messages. On the contrary, more than three-quarters of the support seekers expressed low activity by messages less than 100 messages and about 9.5% sent only one message. One explanation might be that most of the support providers should have passed the critical stage with H&N cancer. They also might have sought a support before the time limit of our study, as we found that

about three-quarters of the support providers joined the online groups before the study time limit, whereas about 57% of support seekers joined the groups within the study limit. Therefore, the support providers, because of their experiences, seemed to be more willing to enter the online groups and support the new members who may be still be in crisis and not in a position to support others, as only a few members were reported to seek and offer support at the same time.

In line with cancer incidence in the USA and the UK, to which most of the sample belonged (IARC, 2008), the most common type of cancer reported by both support seekers and providers were cancers of the tongue followed by cancers of the tonsil. This may highlight the importance of OSGs for such people since cancers of tongue and its related surgical treatment (Glossectomy) can influence the ability of the patient to speak properly (Maureen, 2009) which might make it more convenient for them to use OSGs.

Although cancer stage was available for relatively few members of both support seekers (24 members) and support providers (49 members), it appeared, of these, the majority of them had reached more advanced stages of cancer. Whilst 86% of support providers were in their post treatment period, more than 40% of support seekers were either under treatment or in pre-treatment stage or even in pre-diagnosis stage. This may indicate that persons with cancer or caregivers seek support when they are concerned about their current situation or the situation of the family member with cancer during the critical time. This is compatible with previous research in which searching for help and sharing fears were one of the most common reasons for using OSGs (Buchanan and Coulson, 2007).

Some caregivers still used the OSGs to offer support to other members even after their family members had died. This may indicate that these online groups, which appeared in a form of forums, work as a suitable social environment through which members can offer social support to each other and feel as if they are connected to and part of one social network. This was consistent with the findings of previous study in which socialising was one of the gratifications of OSGs (Ishii, 2008). It also was consistent with another study conducted for offline support groups related to recipients of implantable cardioverter defibrillators and their carers in which providing information,

connecting with others, helping others was the most common reason for participation in the support group (Williams *et al.*, 2004).

4.7.3 New items and modifications

Although the coding framework for the support-offering messages fitted the majority of the messages, there were a few remaining statements (n= 71) that could not be coded by this coding framework. Accordingly, three new sub-dimensions have been put forward; firstly, it was noticed that some support providers have a tendency to provoke laughter and provide amusement, so their messages were coded as “humour” to add a new sub-dimension to emotional support. Secondly, some members expressed direct thankfulness for the recipients regarding their participation or posting of specific messages, which can have positive outcomes on promoting caring relationships between members in the online groups. Such messages were coded as “expression of gratitude” and can be added as a new sub-dimension to esteem support. Thirdly, some members tended to ask questions or provide comments that included hidden support such as expression of interest, advice or caring for the person. These statements were coded as “question/comment” and can be added as new sub-dimension under informational support. Although messages coded under these three new sub-dimensions were still few, even after reinvestigating the previously coded messages for such kind of the support, these three sub-dimensions of social support need to be considered during the process of content analysis if similar research were to be conducted using the same methodology.

Some modifications were introduced to the definitions of two of the existing sub-dimensions. Firstly, “validation” sub-dimension should be expanded to include those who express a validation and agreement with previous respondents other than the original posters, since results indicate that about 20% of validation messages were not directed to the original poster. Secondly, the definition of “physical affection” should be expanded to include the expressive emoticons that were sent by some respondents, since it represents more than half the physical affection messages. In addition, the role of these emotions appeared to be so proximal to the content of physical affection messages, as most of these emoticons showed facial expression such as laughing, smiling, wondering or sad faces.

Given that these additions and modifications had to be made to the coding framework in the current study, a further study would need to validate the framework before firm conclusions could be drawn on its applicability to OSGs for H&N cancer.

4.7.4 Study limitations

There were a number of limitations of the present study. Firstly, despite the number of advantages in content analysis as the chosen method (see Section 4.4), it is a purely descriptive method. It therefore describes what is there, and does not address why information is in the form shown. The analysis is also prone to user's error and interpretation and is limited by the availability of the material and so may not be an accurate reflection of reality (Weber, 1990; Krippendorff, 2004; Sommer, 2006).

Secondly, although there were a number of advantages supporting the use of the SSBC as a coding system for H&N cancer-related OSGs, there were also some limitations. For example, the framework by its very nature is deductive (i.e. theory-driven). Thus, the analysis of the data is limited to this a priori framework and the results focus on these specific aspects of the data that were determined prior to data analysis (Crabtree, 1999). Such strategy does not allow for inductive approach and no new information (e.g. themes, dimensions) would be expected (Dudovskiy, 2014). In addition, the SSBC framework was originally developed to test controllability of stressful events and satisfaction with spouse support behaviours. This area is somewhat removed from the topic of H&N cancer; the stressful events that might be associated with marriage could be completely different from that associated with H&N cancer. In addition, only a few studies to date have used the SSBC as coding system in the field of online support groups and therefore the applicability of this coding system for online social support needs to be validated further.

In the current study, whilst the coding framework for the support-offering messages fitted with the majority of the messages, there were a few remaining statements (n=71) that could not be coded. Again, this suggests that there are limitations with this deductive approach using a pre-existing framework. Whilst the frameworks did

demonstrate reliability – in that three independent researchers coded with good agreement – by using such a framework, types of support may have been missed or miscategorised. In addition, the coding scheme used to code the support-seeking messages has been used by only one previous study; and that was the study in which the framework was derived. Therefore, the applicability of this coding framework has not been tested in many different health conditions or in different studies. Also, there were low responses across many of the dimensions in both frames, particularly in the support seeking analysis, which might suggest that the coding frame was not as useful as planned.

Thirdly, the selection strategy used in selecting the messages (one random message for the even months) has some disadvantages, for example, for practical reasons (time), although data was collected throughout the full calendar year, only 6 of those months were sampled rather than the full 12 months. In addition, since many messages were removed in line with the exclusion criteria this reduced the sample size. Thus, only 399 messages (87 support-seeking and 312 support-providing) were analysed, which is relatively low compared with previous studies using similar methods (Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coulson and Greenwood, 2012; 572, 1313, 1138 and 487 messages respectively).

Given the variety of social support messages coded within the current study, it appears unlikely that increasing the number of messages (by, for example, widening the data collection period, or increasing the number of months from 6 to 12) would have changed the frequency of social support types found. However, it may be that choosing the messages from the even months (in 2011) rather than the odd months (in 2011) may have biased the results. For example, the data in the present study included December postings – given the importance of this month in terms of public holidays (Christmas, new year) and time spent with family, perhaps different types of support may have been sought or offered during this time.

Another limitation is that, in some cases, members' profiles were not available. This can be attributed to the fact that some OSGs do not oblige members to supply their personal details during the registration process. In addition, some OSGs show such information only to their members. As a result, age and gender of posters was not

always available. Indeed, since only a few members have clearly identified their gender, the gender for the majority of members was estimated depending on their user names or their names when provided and or if they could be understood from their messages. It may be that these were wrongly attributed and thus over- or underestimated. In addition, there was an issue of unrepresentativeness as the result suggested that not all the users of online groups had cancer, since family members and friends of those with H&N cancer were found to use these groups as well. Also, the representativeness of our results to the international offline and online groups has not been tested; therefore, it is difficult to compare the users of these groups with the general incidence of H&N cancer.

Additionally, the majority of members appeared to belong to developed countries such as USA followed by, the UK and Canada in which English language is the main and official language. Not surprisingly, this is probably because the study deals with online groups that were conducted in English. However, the generalisability of results representing H&N cancer-OSGs in other languages or in developing countries has not been tested. This is despite a higher incidence of H&N cancer reported in developing countries. In addition, in the present study, the majority of the members (75% of support providers and 73.43% of the support seekers) were from the USA, which may make the results difficult to generalise to other countries because of cultural differences. For example, potential differences between countries in help-seeking behaviours, emotional reactions, coping strategies, role of social support and relevant support networks as well as differences in H&N cancer treatment pathways.

Finally, data for this study includes information from both current patients and survivors. It may be that people within these two 'groups', might have different experiences impacting on the social support they give or provide within OSGs. In addition, of the patients, most of those in this study were in the advanced stages of cancer (stage III and IV) and in post-treatment stages. Therefore, caution should be exercised in generalising the findings from this study outside of the study sample; particularly to those in the initial stages of cancer and/ or those yet to receive treatment.

4.7.5 Study strengths

In order to ensure reliability, as much as possible, some important measures were conducted. For example, it was decided to gather data from different OSGs dealing with H&N cancer issues and not only from one group. These groups were selected such that they were active with at least one message in each month in a full year to ensure that the possible maximum number of active OSGs was included. In addition, the most recent year was chosen at time of data collection (2011) to ensure that both the most recent OSGs as well as any active old group were included to be more comprehensive and to investigate for any new categories of support used recently in OSGs.

Moreover, for support-providing messages, using a pre-validated coding framework, which has been successfully used for content analysis of online messages in a number of health contexts (Section 3.2.6) has increased reliability of the data analysis and ensured that the analysis in the current study was conducted within the environment of an existing coding framework, since 94.27% of the data could be coded under this framework and only 5.73% of the data have been reinvestigated and categorised under new items of support. With regard to the content categories of the frameworks, it appeared that both of the coding frameworks used in the current study offered clear and well-defined content categories so that a high agreement level was achieved when randomly selected messages from the entire data were coded by three coders.

In spite of the relatively small sample (399 messages “87 support-seeking and 312 support-providing”) compared to previous studies, the selected messages were rich in content and provided examples of all types and categories of social support. For example, more than 80% of the support-providing messages involved more than one sub-dimension of social support and some messages involved up to 9 sub-dimensions of social support. In addition, approximately two-thirds of the support-seeking messages sought more than one sub-dimension of social support and some of them sought up to 4 sub-dimensions of social support. This resulted in a total of 1009 support providing statements and 184 support-seeking statements, which may compensate for the relatively low sample size that occurred due to applying the exclusion criteria.

4.8 Conclusion

Head and neck cancer-OSGs in this study provided a source of H&N cancer-related emotional and informational support for individuals with H&N cancer and/or their carers and family members. This may support calls for more attention to be given to such groups in order to develop the knowledge of people with cancer and caregivers, as well as the public in terms of H&N cancer and the ways of coping with such a condition.

In some cases, highly factual or technical information was supplied by members of H&N cancer OSGs. This undoubtedly raises the question about the role of experts to supervise or assess the quality and accuracy of posted information (Mo and Coulson 2008). However, this study has several drawbacks in terms of the design, methodology and the tools used, as well as the insufficient information about the demography of the users of OSGs. Therefore, further research is needed which validates the current findings, and examines generalisability of the findings in representing face-to-face groups for H&N cancer.

Chapter V: Study 2

5 Study 2

5.1 Study 2 - Part 1: (quantitative component)

5.1.1 Introduction

Reviewing the literature indicates that H&N cancers can have a negative influence on QoL (Morton and Izzard, 2003; Rogers *et al.*, 2007; Penner, 2009; So *et al.*, 2012) (See Section 2.5.3 for definition of QoL). However, some factors may mitigate or aggravate the impact of cancer on patient's psychological wellbeing (McDonough *et al.*, 1996). For example, there are many strategies that people diagnosed with H&N cancer can employ that may influence health outcomes. Coping is one such strategy (Sherman *et al.*, 2000) (See Section 3.1 for definition of coping). Higher levels of adaptive coping have been found to be related to better QoL (Mo and Coulson, 2012). Also, psychological factors may be important such as anxiety, which refers to "*apprehension that may come in the form of feeling tense or keyed up, physical changes in the body, worrying, and having a persistent but somewhat vague feeling of threat or discomfort*" (Hopko and Lejuez, 2008, P; 45) and depression which is "*a human emotion that can be experienced in the form of sadness, disappointment, grief, or being down in the dumps*" (Hopko and Lejuez, 2008, P;31). Indeed, these two factors have been recognised as important in a number of studies of patients with H&N cancer (de Leeuw *et al.*, 2001; Massie, 2004; Archer *et al.*, 2008; Haman, 2008; Haisfield-Wolfe *et al.*, 2009) and widely been linked to reduced levels of QoL in many studies (Rapaport *et al.*, 2005; Brenes, 2007; Quelhas and Costa, 2009).

Self-efficacy, which is a personal resource that signifies a self-belief in individual's capability to apply control over adverse events (Bandura, 1997), has been shown to be related to better coping and relatively low levels of psychological distress (Benight *et al.*, 1997). In line with this, it has been found that people who receive social support are expected to have stronger self-efficacy beliefs, which subsequently may affect their health-related outcomes (Benight and Bandura, 2004). This mediational role of social support on psychological outcomes has been found in relation to a number of health conditions (Cheung and Sun, 2000; Mak, *et al.*, 2009).

Studies on social networks and cancer (Goodwin *et al.*, 1991; de Ruiter *et al.*, 1993; Guidry *et al.*, 1997; Michael *et al.*, 2002; Sapp *et al.*, 2003; Bauer *et al.*, 2005; Kroenke *et al.*, 2006; Pinqart and Duberstein, 2010; Beasley *et al.*, 2010) suggested that social networks have been related to HRQoL and also appear to have a mediating effect on anxiety and depression amongst cancer patients. In addition, social networks play an important role in enhancing the coping ability of the patient (Relic *et al.*, 2001). Reviewing the literature showed that OSGs has been recognised to provide a range of social support and may be associated with a variety of positive psychosocial outcomes including better management of the disease and better use of active coping strategies (Fogel *et al.*, 2002; Kalichman *et al.*, 2005, Mo and Couson, 2008; Coulson and Greenwood, 2012). Studies investigating the mechanism of social support through the internet suggested that the process of seeking and receiving online support has been thought to occur through a potential framework relating to personal empowerment (Barak, *et al.*, 2008, Mo and Coulson 2010a; Mo and Coulson 2012). Personal empowerment has been found to be related to self-efficacy through the process of receiving social support and helping others (Mo and Coulson 2012).

Yet, in spite of the large number of studies investigating OSGs, QoL and the factors that mitigate or aggravate the impact of a health condition on a patient's QoL, there has been no research, to date, on the relationship between OSGs and QoL for people with H&N cancer or on the psychosocial factors that might mediate this relationship.

5.1.2 Aim

The aim of this study was to examine the relationship between using OSGs and QoL and examine the psychosocial factors (social network, self-efficacy, anxiety, depression, adjustment and empowerment) that may influence this relationship.

5.1.3 Objectives

- Select suitable measures to assess the use of H&N cancer -OSGs.
- using existing, pre-validated questionnaires to examine QoL, social network, self-efficacy, anxiety, depression, adjustment and empowerment in a sample of people using online support groups for H&N cancer.
- using regression analyses to examine the relationship between OSGs and QoL, and the possible mediating role of psychosocial variables in this relationship.

5.1.4 Strategic choices for method

In order to examine the relationships between the use of OSGs and QoL, a cross-sectional study was designed utilising a range of pre-validated questionnaires available within the existing QoL, psychology and on-line literatures. At this stage, a quantitative method was chosen because of it have a range of advantages such as precision in specifying the variables, allowing for statistical tests and achieving high levels of reliability (see Section 3.5 for details).

Since conducting a longitudinal study would be problematic online for several reasons (see Section 3.5) and for pragmatic reasons, a cross sectional study was chosen to address the research question. This approach is relatively inexpensive and takes up little time to conduct; can estimate occurrence of outcome of interest, useful for planning and generation of hypotheses and does not have the problem of loss of follow-up (Levin, 2006).

The data for this study are intended to be collected from people with H&N cancer who use OSGs. These groups are available through the Internet and can be accessed and used by people with H&N cancer from anywhere in the world. Using conventional postal mail or telephone surveys can be impractical or expensive way of data collection for this type of study. However, online survey may be more convenient method for data collection in this condition, (Kraut *et al.*, 2004; Reips, 2002). In addition, online surveys provide the ability to conduct large-scale data collection (Couper, 2000) and may achieve sample sizes that exceed mail and

telephone surveys (Kraut *et al.*, 2004). They can provide an inexpensive mechanism for conducting surveys compared to the traditional postal mail survey (Sheehan and Hoy, 1999; Weible and Wallace, 1998). Thus, internet designs are often more cost effective than other techniques (Reips, 2002) and one in which costs per response decrease instead of increase significantly as the sample size increases (Watt, 1999). They can also be time saving since there is no need for printing or postage (Matsuo *et al.*, 2004). In addition, there may be a smaller margin of data transfer error because participants enter their responses directly into the system and no personnel are required to enter data (Naser, 2002).

Online surveys are becoming increasingly common (Lazar and Preece, 1999; Buchanan and Vizdak, 2009), and research comparing online against postal surveys suggested that there may be no difference between online survey content results and postal survey content results, yet the former provide strong advantages because of their quick distribution (Yun and Trumbo, 2000; Swoboda, *et al.*, 1997).

5.1.5 Method

5.1.5.1 Study design

Quantitative cross sectional study using online questionnaires

5.1.5.2 Participants

Selection of populations

People with head and neck cancer who use OSGs.

Target population

The data for this study included people who use all existing OSGs for individuals with H&N cancer excluding:

- (1) The groups that were inactive with less than 25 message threads posted to the group within the past 30 days (January 2013).
- (2) The groups that contained less than 50 members at time of selection.
- (3) The groups that deal with other oral conditions other than of H&N cancer.
- (4) The groups in languages other than English.

Exclusion criteria for participants

People who have not been diagnosed with H&N cancer at any point during their life.

Inclusion criteria

- 1- People who have been diagnosed with H&N cancer at any point during their life.
- 2- Using H&N cancer related-OSGs.
- 3- Read the information sheet for the study and accepted the consent form.
- 4- Completed and submitted the questionnaire online.

5.1.5.3 Recruitment

A thorough Internet search was established to identify OSGs for people living with H&N cancer. The four most common Internet search tools, Google, Yahoo, Bing, MSN and Face Book were searched using the terms of online support group and Head and neck cancer (Head, neck, cancer, tumour, forum, online, message boards, support group, chat, blog, oral, pharyngeal, laryngeal, lip, tongue, tonsil, throat, gingival, gum, mouth, dental, cheek, epiglottis).

OSGs were selected based on two criteria (Mo and Coulson, 2012):

- (1) The OSG was active with at least 25 message threads posted to the group within the past 30 days.
- (2) The group contained at least 50 members.

The results of the search showed 75 OSGs (56 traditional OSGs and 19 Facebook groups) (Appendix 3 and 9). However, since some moderators manage more than one group, the total numbers of the moderators of 75 OSGs was only 37. Only ten H&N cancer-related OSGs fulfilled the criteria (Figure 10).

Following ethical approval, moderators from these groups were contacted by email, phone, post, Facebook or directly through their “contact us” form explaining the research study and asking for permission to recruit participants from their group. Out of the 10 OSGs contacted, four replied and provided permission to recruit participants (Appendix 10).

After having permission from the moderators, a pilot study was conducted (details below Section 5.1.5.7.), following which a message was placed in the groups explaining the objectives of the study (Appendix 11). The questionnaire was provided in the message in a form of hyperlink which contained the information sheet (Appendix 12), consent form (Appendix 13), instruction leaflet on how to complete the questionnaires (Appendix 14) and the questionnaires (Appendix 15). The aims and objectives of the study, inclusion criteria and confidentiality of data and rights of participant as well as instructions about the survey were explained in the information sheet which appears first when the participants click on the study link, and informed

consent was sought from participants before they were able to complete the questionnaire.

After reading the full information sheet and having accepted the consent form, participants were directed automatically to the questionnaire. The questionnaire was designed so that participants could not submit their answers until they answered all the required questions. This also ensured that the researcher only received full responses to the questionnaire, with no missing data.

All the questionnaires were delivered online, and the respondents were intended to complete them online, simply by following a link to the questionnaires and then by clicking on submit button after the questionnaires had been completed.

In order to determine inclusion criteria for participants and to avoid any misunderstanding or doubt, a message was placed at the beginning of the invitation that was posted to the group explaining the objectives of the study *“This posting is intended to reach people who are accessing this online support group and who have been diagnosed with head and neck cancer at some point. If you do not meet the above description, please ignore this and there is no need to continue”*. This message worked successfully when tested in the pilot study (Section 5.1.5.7); all of the participants who took part in the pilot study were people who were accessing that OSG and had been diagnosed with H&N cancer at some point during their life.

At the end of the questionnaire, participants were asked whether they were interested in participating in a short online interview regarding their use of the online H&N cancer support group. This formed the recruitment procedure for the qualitative part of the study (see Chapter 5, Section 5.2). Respondents who expressed an interest were asked to provide suitable means and time to contact.

Intended sample

People with H&N cancer who use the following four OSGs:

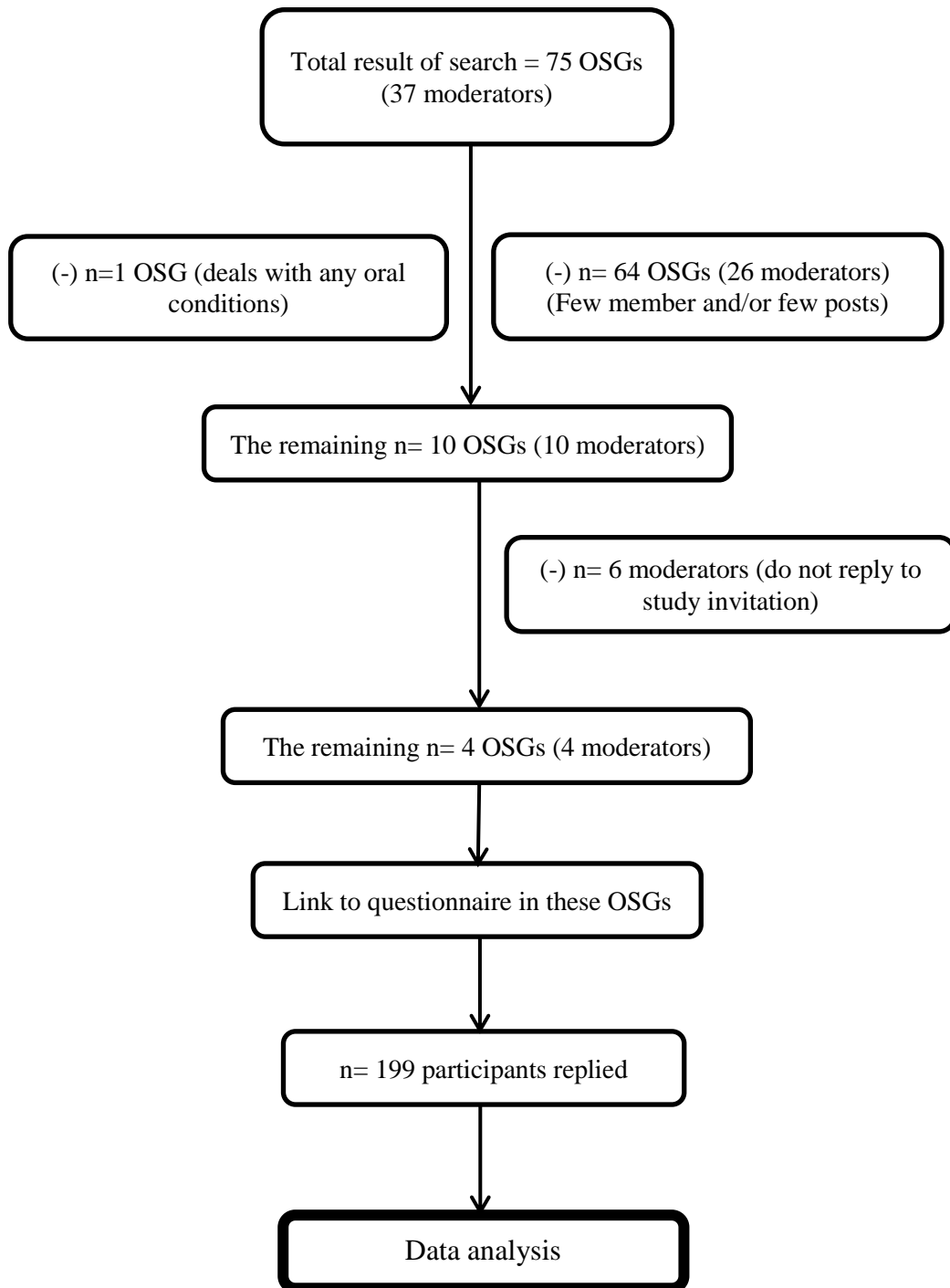
- (1) Macmillan Head and Neck Cancer Group
- (2) The Oral Cancer Foundation

(3) Survivors of Head and Neck Cancer

(4) Throat and oral cancer survivors

Brief descriptions of these OSGs can be seen in Appendix 10. Figure 10 shows the study profile from the initial 75 OSGs to the 4 included within the study.

Figure 10: Study 2 sample profile



5.1.5.4 Sample size

The sample size for the study was calculated using the software ‘G-power’ (Faul *et al.*, 2007; Faul *et al.*, 2009). The sample size calculation was based on a medium effect size of $f^2=0.15$, statistical power of 95%, a significance level of 0.05, and 15 potential variables in the analysis as follows (frequency of using OSG, social support, self-efficacy, depression, anxiety, helpless-hopeless coping, cognitive avoidance coping, fighting spirit coping, anxious preoccupation coping, fatalism coping, empowerment-receiving social support, empowerment-finding positive meaning, empowerment-receiving useful information, empowerment-helping others and quality of life). From this, the sample size calculation was 199 participants.

5.1.5.5 Ethics

The project involves people with H&N cancer, and since the contact with these people was only through the internet and there was no direct face-to-face contact with them, ethical approval was sought from University of Sheffield Research Ethics Committee (UREC) (Appendix 16). The project followed the ethical guidelines of the British Psychological Society (2013), including informed consent and confidentiality (see Table 20, Section 3.3).

- Moderators from the OSGs were contacted and informed about the study and permissions to recruit participants from their groups were obtained.
- All participants were informed about the study and they provided consent to take part in the study.
- To protect anonymity of individuals, the names or addresses or any other identifying information of the participants was not collected in the questionnaire.
- To protect confidentiality of OSG members, the original data that contained emails or any other contact means sent by the members in order to participate in the interview (see Section 5.2.5.2) were kept by the researcher in a password protected electronic document and could only be accessed by the researcher.

5.1.5.6 Variables

5.1.5.6.1 Demographic variables

Data on participant's age, gender, country, religion, marital status, house members and income status were collected by questions adapted from the Census (2011) and Survey Onics (2011) as follows:

Religion was categorised into eight groups; No religion, Christian (all denominations), Muslim, Buddhist, Hindu, Jewish, Sikh and others. Moreover, choice for people who "*prefer not to say*" was also given. Whereas "marital status" was recorded as married / living with a partner, widowed, single and other and again choice for people who "*prefer not to say*" was given.

House members were recorded as no-one (I live alone), children, siblings, other relatives (e.g. parents, grandparents), non-family members and anyone else. However, "income status" was investigated in a way to uncover how participants were satisfied with their income status and was recorded as; totally insufficient, somewhat insufficient, sufficient for essential needs, more than sufficient

5.1.5.6.2 Illness related variables

Illness related variables consist of cancer site, stage, spread, treatment type, treatment stage and time since diagnosis.

Cancer site was categorised into three main groups; Lip and mouth cancer (Lips, tongue, under my tongue, gum, jaw bones, roof of my mouth, cheeks and salivary gland), throat cancer and vocal cords. In addition there was an extra choice for people who "*were not sure*". Whereas cancer stage was recorded as Stage I, Stage II, Stage III and Stage IV according to Tumour Node Metastasis (TNM) staging system (Deschler *et al.*, 2008) and again there was an extra choice for people who "*were not sure*". This staging system was placed in the questionnaire, because it has been noticed in the first study (Chapter 4), which investigated the messages posted by people living with H&N cancer, that the vast majority of the posters were aware of

their cancer stage with this staging manner, since it was recorded in the patients' profile or from the messages itself where the member raised his/her problem.

Spread of the cancer (Cancer metastasis) was recorded as Yes, No question and there was a choice for people who "were not sure". In addition, questions about treatment type were modified from a questionnaire used for cancer by Susan and Clingman (2005), in which participants could tick as many as they liked, and were as follows:

- Chemotherapy
- Radiation
- Surgery
- Acupuncture/Oriental
- Naturopathy
- Herbology or Nutritional Consulting
- Online Support Groups
- Others_____
- Colour, Art or Music Therapy
- Spiritual Healing
- Prayer
- Medicine Meditation or Self-Healing
- Psychological Counselling
- Face-to-Face Support Groups
- Massage or other Bodywork
- I am not sure

Finally, Time since diagnosis was reported in years and months and treatment stage was recorded as pre-diagnosis, pre-treatment, under-treatment, post-treatment and there was a choice for people who "*were not sure*".

5.1.5.6.3 OSGs-related variables

These variables included number of days using OSGs per month, hours of using OSGs per day (in minutes), time since start using OSGs (in months), membership of OSG, time since becoming a member, number of posted and replied messages, reason for participating in OSGs, whether OSGs made any difference in coping, and whether there were any problems related to the use of OSGs.

Membership, whether OSGs made any difference in coping and whether there was any problems related to the use of OSGs were all recorded as Yes/No questions. Whereas reasons for participation were recorded using a modified list from (Mo and Coulson, 2010a), and participants could tick more than one reason.

- Because I was curious how other members were doing.
- It was part of my daily routine.
- When I had a question about my health condition.
- To enjoy myself.
- When I heard new information about my health condition.
- When I had a lot of symptoms.
- Before visiting a doctor.
- After visiting a doctor.
- When I had new symptoms.
- Because I felt lonely.
- Because other members expected me to be here.
- To stay in touch with other members.
- To help other members in their health condition.
- Other reason (please specify).

5.1.5.6.4 Psychosocial variables

Psychosocial variables included social network, self-efficacy, anxiety, depression, adjustment, empowerment and quality of life. All questionnaires used to measure these variables can be seen in Appendix 15.

1. Social network

Social network was measured using The Berkman-Syme Social Network Index (BSNI) an 11-item self-reported questionnaire (Berkman and Syme, 1979). The BSNI is designed to assess the type, size, closeness, and frequency of contacts in a respondent's current social network. This measure allows researchers to categorize individuals based on social connectedness and can highlight those at risk for social isolation.

It is a compound measure of four categories of social connections; sociability (frequency and number of contacts with close relatives, and close friends), marital status (not married vs. married), church group membership (no vs. yes) and membership in other community organizations (no vs. yes). The BSNI considers both relative importance and number of social ties among the four groups and unites this material into measure of summary ranging from 0-4 (NIH, 2002).

BSNI allows researchers to classify people into four stages of social connection; socially isolated (people with few close contacts, fewer than six friends or relatives, not married, and no membership in either community or groups church), moderately isolated, moderately integrated, and socially integrated. The most isolated category belong to scores summed; 0 or 1, whereas the other three categories of increasing social connectedness belong to scores summed; 2, 3, or 4.

A review of the literature found that BSNI is one of the most commonly used and reported research measures for social support/networks. The BSNI was cited in 209 articles found in MEDLINE, CINAHL, EMBase and PSYCinfo (Biordi and Nicholson, 2008).

The BSNI is a valid and reliable index (Cronbach's alpha ranged from .77 to .85) in assessing patient's social network as a factor known to influence morbidity and mortality in people with chronic disease, (Berkman, 1977; Lubben, 1988).

2. Self-efficacy

Self-efficacy was measured using The Cancer Behaviour Inventory-brief version (CBI-B), 12-item validated questionnaire (Heitzmann *et al.*, 2011) used widely as a measure of self-efficacy for coping with cancer derived from the longer 33-item version (Merluzzi *et al.*, 2001). Participants responded to each question on a 9-point Likert scale, with a possible score of "1" = 'Not at all confident' to "9" = 'Totally confident' reflecting the degree of confidence the patient has that he or she can perform that particular coping behaviour, (possible total scores ranged from 12 to 108).

The CBI-B has been used as a measure of self-efficacy for coping with cancer (Heitzmann *et al.*, 2011) and previous studies have indicated that the CBI-B has good internal reliability ($\alpha=0.84$) and construct validity (Heitzmann, *et al.*, 2011).

3. Anxiety and Depression

Anxiety and depression were measured using Hospital Anxiety and Depression Scale (HADS) 14-item questionnaire (Zigmond and Snaith, 1983); commonly used to determine the levels of anxiety and depression that an individual is experiencing in both hospital and community settings. Seven of the items relate to anxiety and seven relate to depression. Each question has 4 possible responses ranging from 0 to 3. The maximum score is 21 for depression and 21 for anxiety (0-7= Normal; 8-10 = Borderline abnormal; 11-21= Abnormal).

The HADS appeared to be a widely used measure to determine the levels of anxiety and depression that an individual is experiencing (Abrahams *et al.*, 1997; Johnston *et al.*, 2000; Mykletun *et al.*, 2001; Goldstein *et al.*, 2002; Barth and Martin, 2005; Martin, 2005; Goldstein *et al.*, 2006; Muszbek *et al.*, 2006; Wicks *et al.*, 2007; Gibbons *et al.*, 2011).

The author tested internal consistency of the scale, using data from 50 patients. The correlation for anxiety items ranged from 0.41 to 0.76. The depression items had correlations ranging from 0.30 to 0.60. Higher correlations were reported by Moorey *et al.* (1991). The criteria were then tested for reliability with a further 50 patients and results judged to be satisfactory. The severity ratings correlated with psychiatric judgments, with the results for depression: 0.70 and for anxiety: 0.74.

Previous studies have indicated that the Hospital Anxiety and Depression Scale (HADS) exhibits good construct validity (Goldberg, 1978; Zigmond and Snaith, 1983; Snaith and Taylor 1985; Aylard *et al.*, 1987; Fallowfield *et al.*, 1987; Wilkinson and Barczak 1988).

4. Adjustment to cancer

Adjustment to cancer was measured using The Mini-Mental Adjustment to Cancer (MINI-MAC) 29 item questionnaire (Watson *et al.*, 1994). The Mini-MAC is a revised version of the commonly used Mental Adjustment to Cancer scale (MAC) (Watson, 1988), that was created to measure mental adjustment to cancer generally.

The Mini-MAC involves 29 items and the psychometric properties of this scale have proved satisfactory (Ho *et al.*, 2003; Hulbert-Williams *et al.*, 2012; Fong, and Ho, 2015).

The Mini-MAC items are rated on a 4-point Likert scale ranging from “Definitely does not apply to me” (1) to “Definitely apply to me” (4) and measures patient’s experiences at present (possible total scores ranged from 29 to 116) . It also has five subscales; Helpless-Hopeless “8 items”, Anxious Preoccupation “8 items” (possible scores ranged from 8 to 32 for each), Cognitive Avoidance “4 items”, Fighting Spirit “4 items” (possible scores ranged from 4 to 16 for each), and Fatalism “5 items” (possible scores ranged from 5 to 20). Higher scores indicate higher endorsement in these coping strategies.

The MAC scale is one of the most commonly used tools to assess coping responses in people with cancer in both clinical practice and research fields. Since it is not specific for any cancer type it is widely used for many purposes (Lee, *et al.*, 2009; Johansson *et al.*, 2011; Hulbert-Williams *et al.*, 2012; Zucca *et al.*, 2012).

Several studies evaluating the psychometric properties of the Mini-MAC scale have supported its validity and reliability of all five subscales of this questionnaire (Ferrero *et al.*, 1994; Ho *et al.*, 2003; Grassi *et al.*, 2005; Anagnostopoulos *et al.*, 2006; Pallant and Tennant, 2007; Tennant *et al.*, 2007; Kang *et al.*, 2008; Watson, *et al.*, 2008; Boyes *et al.*, 2009; Hulbert-Williams *et al.*, 2012). Reported internal consistency ranged from 0.65 to 0.91, and construct validity was well-established (Ho *et al.*, 2003).

5. Empowerment

Empowerment was measured using the 39-item Empowering Processes Scale (Mo and Coulson, 2010). Items for this scale were adapted from the Empowering Processes Scale developed by van Uden-Kraan and colleagues based on their studies of online support group use for patients with breast cancer, fibromyalgia, and arthritis (van Uden-Kraan, Drossaert, Taal, Seydel *et al.*, 2008). The original scale had 29 items which measured 5 dimensions of empowering processes (exchanging information, encountering emotional support, finding recognition, helping others, and sharing

experiences). However, to reflect the broader aspects of empowering processes (e.g. finding positive meaning towards the diseases), 15 items were added to the scale by Mo and Coulson (2010a). Results from their factor analysis indicated the possibility of a four factor solution, since on closer inspection of the factor loadings, some items were eliminated because they cross-loaded on two factors. After that, they repeated the factor analysis stipulating a four-factor solution, using a Varimax rotation and the integrity of the four-factor solution was preserved. As result of these modifications, the Empowering Processes Scale had 39-items measuring 4 dimensions of empowering processes (receiving social support, finding positive meaning, receiving useful information, helping others).

Participants were asked the frequency in which each event took place in the OSG on a 5-point Likert scale ranging from 1 = never to 5 = very often, with higher scores indicating higher levels of empowering processes (possible total scores ranged from 39 to 195). The items were distributed on the 4 dimensions of empowering processes as follows; receiving social support “14 items”, finding positive meaning “14 items” (possible scores ranged from 14 to 70 for each) receiving useful information “9 items” (possible scores ranged from 9 to 45) and helping others “2 items” (possible scores ranged from 2 to 10).

The Empowerment Process Scale has been recently developed for using in OSGs (van Uden-Kraan *et al.*, 2008) and it has been used successfully to measure empowering processes from OSGs participation among patients living with HIV/AIDS (Mo and Coulson 2010).

The reliability of the original empowering processes scale was satisfactory (Cronbach’s alpha ranged from .70 to .95). The Cronbach’s alpha of the four subscales ranged from .87 (helping others) to .95 (finding positive meaning) (Mo and coulson 2010). However, Information about validity is not yet available.

6. Quality of life

Quality of life was measured using the 12-item University of Washington Quality of Life Questionnaire (UW-QOL) (Hassan and Weymuller, 1993; Weymuller *et al.*,

2001; Rogers *et al.*, 2002). Each question has from 3 to 5 answers, with participants choosing one appropriate answer that applies to them. Each of the domain-specific items is scored from 0 (worst QOL) to 100 (best QOL). The 'composite' score is created by averaging the scores from the 12 items, therefore the possible total scores ranged from 0 to 100.

The UW-QOL questionnaire is one of the most widely used instruments to evaluate the QoL of patients H&N cancer (Nazar *et al.*, 2010). It has been extensively and successfully used in research conducted for English-speaking populations; in addition, it has been translated and used in other languages (D'cruz *et al.*, 2007; Lowe and Rogers, 2008; Nazar *et al.*, 2010; Chang *et al.*, 2012).

The validity of UW-QOL questionnaire version 4 has been assessed in many study using translated version to other languages (Vartanian *et al.*, 2006; D'cruz *et al.*, 2007; Nazar *et al.*, 2010; Chang *et al.*, 2012), and the overall internal consistency ranged between Cronbach's alpha of 0.73 and 0.84.

5.1.5.7 Pilot study

A pilot study was conducted with 5 people with H&N cancer from an H&N cancer related- OSG (a different one to those used for the main study). Permission was gained from the moderator, and the same invitation message that was prepared for the main study was placed on the group's website. The message contained a link to the same questionnaire and information used in the main study except that there were two questions related to the pilot study in which participants were asked to calculate the time of completing the questionnaires, supply information at the end, and write their experience of the questionnaire and any difficulties they had encountered during their completion. There was no invitation question about participation in a further interview in the pilot study. After 5 responses to the pilot were received the invitation message was removed from the OSG.

The results of the pilot study suggested that the time required for completing the questionnaire was about 10-20 minutes. The participants reported that all the questions of the survey were clear and easy to complete and none of the participants

found any technical, language problems or any other difficulties in understanding and completing the questionnaire. This led to modifying the invitation message for the main study to indicate that the time required for completing the questionnaire would be approximately 10-20 minutes but no other changes were made to the study materials.

5.1.5.8 Data collection

The invitation message that contained the link for the online questionnaire and the objectives of the study were placed on the OSG's website in February 2013. This link remained active for six months until the required number of responses had been achieved. During this period, the invitation message was renewed several times in order to ensure that it was easily accessible and did not move too far down with the older messages. The administrators of the groups were asked from time to time to place the invitation message back on the top of their page. After the required sample size had been achieved, the online link to the questionnaire was removed.

5.1.5.9 Data analysis

All the questionnaires used for measuring the psychosocial variables have been computed for their total scores (Table 42). The internal reliability of the questionnaires was assessed by Cronbach's Alpha.

Data were analysed in three phases:

Phase 1 described the distribution of all demographic variables, Illness-related variables and OSGs variables using appropriate measures of proportions, spread and central tendency.

Phase 2 evaluated and prepared data to be used for the regression analysis in the next phase.

Phase 3 evaluated the relationship between using OSGs and QoL and explored the possible mediators in this relationship between these two variables using regression analysis.

Psychosocial variables	Score interpretation
Social network	0 = The most socially isolated 4 = The most socially connected
Self-efficacy	12 = Not at all confident 108 = Totally confident
Anxiety	0 = Not anxious at all 21 = The most anxious
Depression	0 = Not depressed at all 21 = The most depressed
Adjustment	29 = The lowest endorsement of the adjustment response 116 = The highest endorsement of the adjustment response
Empowerment	39 = The lowest levels of empowering processes 195 = The highest levels of empowering processes
Quality of life	0 = The worst QOL 100 = The best QOL

Table 42: Coding of the psychosocial variables

5.1.6 Results

5.1.6.1 Introduction

The results in this chapter are presented in three main sections:

Section I: descriptive analysis summarises the sample regarding demographic factors (age, gender, country, religion, marital status, house member and income status), Illness-related_demographics (cancer site, stage, spread, treatment type , treatment stage and time since diagnosis) and OSGs demographics (number of days of using OSGs per months, hours of using OSGs per day, time since start using OSGs, membership, times since become member, number of posted and replied message, reason for participation as well as whether OSGs made any difference in coping and whether there were any problems related to the use of OSGs). This section also discusses the reliability and validity of the questionnaires.

Section II: evaluated and prepared data to be used for the regression analysis in the next phase. In this phase, the measure for using OSGs was selected and assumptions of the regression analysis tested.

Section III: reports the regression analysis between using OSGs and the psychosocial variables (social network, self-efficacy anxiety, depression, adjustment, empowerment and QoL).

5.1.6.2 Section I: Descriptive analysis

5.1.6.2.1 Demographics

The demographic data of the participants are illustrated in Table 43. The mean age of the participants was 54.34 (SD =10.2, Range = 13 – 79 = 66). Although the range seems to be wide (13 – 79), more than 70% of the participants were over 50 years and only 1% were below 30 years, whereas the rest (28%) were between 30 – 50 years.

There were 101 females and 98 males (50.8% and 49.2% respectively) in the sample with participants originating from 7 countries, with the majority from the United States of America (USA) (55.8%). Christianity was the religion of 70% of the participants. With regard to marital status and house members, the majority of participants were married or living with their partner and 37% had children living with them. One hundred and thirty four of the participants (66%) were satisfied with their income status.

	Participants	Number	%
Age	10 - 19	1	0.50
	20 -29	1	0.50
	30 - 39	13	5.53
	40 - 49	43	21.60
	50 - 59	81	40.70
	60 - 69	48	24.12
	70 - 79	12	6.05
Sex	Male	98	49.24
	Female	101	50.75
Country	USA	112	56.28
	UK	45	22.61
	Australia	22	11.05
	Canada	15	7.53
	New Zealand	4	2.01
	France	1	0.50
Religion	No religion	43	21.60
	Christian (all denominations)	142	71.35
	Muslim	3	1.50
	Buddhist	3	1.50
	Hindu	0	0.00
	Jewish	1	0.50
	Sikh	0	0.00
	Prefer not to say	1	0.50
Other	9	4.52	
Marital Status	Married / Living with a partner	145	72.86
	Widowed	9	4.52
	Single	30	15.07
	Prefer not to say	2	1.00
	Other	16	8.04
House members	No-one, I live alone	31	15.57
	Children	73	36.68
	Siblings	5	2.51
	Other relatives (e.g. parents, grandparents)	18	9.04
	Non-family members	6	3.01
	Other*	75*	37.68
Income status	Totally insufficient	25	12.56
	Somewhat insufficient	40	20.10
	Sufficient for essential needs	91	45.72
	More than sufficient	43	21.60

Table 43: Demographic data of the study participants

*= Mostly spouse/partner

5.1.6.2.2 Illness-related variables

Table 44 shows that the majority of participants had been diagnosed with either throat cancer or lip and mouth cancer (40.7% and 38.2% respectively) and most of the participants were in the advanced stages of cancer (Stage III and IV). In addition, 23% of the participants indicated that their cancers had metastasised to other sites.

The majority of participants were treated with radiation, surgery and chemotherapy (88.9%, 77.4% and 51.2%) respectively, and the vast majority of them (87.4%) were in the post treatment stage. Approximately 30% of the participants were diagnosed more than 5 years ago (mean 53.7 months, SD = 54 months, Range = 1 – 420 months).

	Variable	Number	%
Cancer site	Lip and mouth	76	38.19
	Throat	81	40.70
	Vocal cords	34	17.08
	I am not sure	8	4.02
Cancer stage	Stage I	22	11.05
	Stage II	14	7.03
	Stage III	27	13.56
	Stage IV	94	47.23
	I am not sure	42	21.10
Spread	Yes	46	23.11
	No	143	71.85
	I am not sure	10	5.02
Treatment type	Chemotherapy	102	51.25
	Radiation	177	88.94
	Surgery	154	77.38
	Acupuncture/Oriental Medicine	18	9.04
	Naturopathy	5	2.51
	Herbology or Nutritional Consulting	10	5.02
	Online Support Groups	131	65.82
	Colour, Art or Music Therapy	5	2.51
	Spiritual Healing	9	4.52
	Prayer	80	40.20
	Meditation or Self-Healing	25	12.56
	Psychological Counselling	32	16.08
	Face-to Face Support Groups	32	16.08
	Massage or other Bodywork	33	16.56
	I am not sure	2	1.00
Other	16	8.04	
Treatment stage	Pre-diagnosis	1	0.50
	Pre-treatment	3	1.50
	Under-treatment	19	9.54
	Post-treatment	174	87.43
	I am not sure	2	1.00
Time since diagnosis	≤1 year	45	22.61
	>1 – < 5 years	91	45.72
	≥5 – <10 years	44	22.11
	≥10 years	13	6.53
	Unknown	6	3.01

Table 44: Illness-related demographic

5.1.6.2.3 Online support group variables

Table 45 indicates that more than half of the participants (58%) had been using OSGs for more than one year (mean = 31.4 months, SD = 33.2, Range= 0 - 240 months), and about 93% of the study participants were a member of such groups. Similarly, the table shows that more than half of them (52.7%) had been members for more than one year (mean = 30.2 months, SD = 32.7, Range = 0 – 180).

The data also indicated that around half of the participants were frequent users of OSGs (more than 20 days per month) with 37.2% of participants being daily users (mean = 18.1 day, median = 20 day, SD= 11.1, Range = 0 - 31). The majority of participants (70%) when they used the OSG, did so for at least one hour per day (mean 138 minutes, SD = 260 minutes) and some of them (10%) for extended periods of time (5 hours +).

The data for member activity and participation indicates that half of the participants had posted at least 10 support-seeking messages (mean = 38.4, SD = 129.4, Range = 0 - 1000) and more than half of the participants (63.3%) posted at least 10 messages as a reply to others (mean 125.4, SD = 360.1, Range = 0 - 3000). It appears from the data that members were more active in replying to others, perhaps indicating the willingness of those people to help and provide support when others asked them.

	Variable	Number	%
Days per month	0 - 9	57	28.64
	10 - 19	34	17.08
	20 - 29	32	16.08
	Daily	74	37.18
	Missed data	2	1.00
Hours per day	0 - <1	46	23.11
	1 - <2	88	44.22
	2 - <3	22	11.05
	3 - <4	6	3.01
	4 - <5	2	1.00
	≥ 5	20	10.05
	Missed data	15	7.53
How long using OSGs	≤1 year	81	40.70
	>1 – < 5 years	92	46.23
	≥5 – <10 years	19	9.54
	≥10 years	4	2.01
	Missed data	3	1.50
Membership	Yes	184	92.46
	No	15	7.53
How long member	≤1 year	87	43.71
	>1 – <5 years	84	42.21
	≥5 – <10 years	17	8.54
	≥10 years	4	2.01
	Missed data	7	3.51
Number of posted messages	1-9	72	36.18
	10-49	74	37.18
	50-99	11	5.52
	100-499	11	5.52
	500-1000	4	2.01
	>1000	0	0.00
	Missed data	27	13.56
Number of replied messages	1-9	53	26.63
	10-49	55	27.63
	50-99	23	11.55
	100-499	37	18.59
	500-1000	7	3.51
	>1000	4	2.01
	Missed data	20	10.05

Table 45: OSGs demographics: Frequency, duration, membership and activity

When asked the reason for participation in OSGs, 72% of the participants indicated that one reason was “*to help members in their health condition*” which was the second most frequent reason chosen by the participants (see Table 46). Curiosity on how other members were doing was the most common reason for participation as indicated by 77% of the participants. Two thirds of the participants (65%) reported that they used OSGs when they had a question about their health condition.

The data indicated that the vast majority of participants (about 90%) reported that being a member of an OSG had made a difference to their coping with cancer, and around 87% did not experience any problems during their participation in OSGs (Table 46).

Variable	Number	%
Reason for participation		
Because I was curious how other members were doing	153	76.88
It was part of my daily routine	38	19.09
When I had a question about my health condition	130	65.32
To enjoy myself	14	7.03
When I heard new information about my health condition	92	46.23
When I had a lot of symptoms	59	39.64
Before visiting a doctor	28	14.07
After visiting a doctor	52	26.13
When I had new symptoms	54	27.13
Because I felt lonely	55	27.63
Because other members expected me to be here	7	3.51
To stay in touch with other members	84	42.21
To help other members in their health condition	143	71.85
Other	29	14.57
Any difference		
No	21	10.55
Yes	178	89.44
Any problem		
No	172	86.43
Yes	27	13.56

Table 46: OSGs demographics: Reason for participation, any differences and any problems

5.1.6.3 Questionnaire reliability

The internal reliability of the questionnaires was assessed by Cronbach's Alpha (see Table 47). The means and standard deviations (SD) for each total scale and subscales can also be seen.

Cronbach's Alpha for all scales was excellent to good; 0.96 (EPS), 0.91 (HADS), 0.86 (CBI-B), 0.82 (MINI-MAC), 0.79 (UW-QOL) and 0.76 (BSNI). The means for the study participants were in the middle area of the range of the questionnaires, far from extremes, indicating no floor or ceiling effects.

Variable	Measure	Cronbach's Alpha	min-max score range	Mean	SD	Number of Items
Social network	Berkman-Syme Social Network Index(BSNI)	0.76	0 - 4	1.45	0.88	11
Self-efficacy	Cancer Behaviour Inventory (CBI –B)	0.86	12 - 108	81.80	16.13	12
Anxiety and depression	Hospital Anxiety and Depression Scale (HADS)	0.91		13.44	7.89	14
	- Anxiety	0.88	0 -21	7.88	4.41	7
	- Depression	0.86	0 -21	5.56	4.17	7
Adjustment	The Mini-Mental Adjustment to Cancer (MINI-MAC) Scale	0.82	29 - 116	69.34	10.44	29
	- Helpless-hopeless	0.90	8 - 32	13.25	5.09	8
	- Anxious preoccupation	0.88	8 - 32	19.26	5.73	8
	- Avoidance	0.63	4 - 16	9.85	2.30	4
	- Fatalism	0.48	5 - 20	14.44	2.57	5
	- Fighting spirit	0.53	4 - 16	12.53	2.09	4
Empowerment	A modified version of the Empowering Processes Scale	0.96	39 - 195	131.52	26.63	39
	- Factor 1: Receiving social support	0.93	14 - 70	41.54	11.81	14
	- Factor 2: Finding positive meaning	0.95	14 - 70	46.89	11.78	14
	- Factor3: Receiving useful information	0.95	9 - 45	35.17	6.70	9
	- Factor 4: Helping others	0.91	2 - 10	7.92	2.03	2
Quality of life	University of Washington Quality of Life Questionnaire (UW-QOL)	0.79	0 - 100	68.17	14.74	12

Table 47: Reliability, mean and standard deviation of the questionnaires

5.1.6.4 Section II: Data preparation

5.1.6.4.1 Selecting a measure for using OSGs

Since the aim of this study was to examine the relationship between using OSGs and QoL, a measure had to be decided upon for the variable ‘using OSGs’. Seven possible measures were prepared to represent the use of OSGs (see Table 48). To investigate the utility of these measures, a bivariate analysis (Table 48) was conducted between QoL and each measure. These were as follows:

- 1- Pearson’s correlations were used to investigate the association between the continuous measures of OSGs [Time since start using OSGs (TsU), Length of membership, Number of days of using OSGs per month and Number of hours of using OSGs per day] and quality of life.
- 2- Spearman’s correlations were used to examine the association between the discrete measures of OSGs [Membership, Number of posted messages and Number of replied messages] and quality of life.

Use of OSG measures	r-value	p-value
Time since start using OSG	0.16	0.02
Days of use per month	0.09	0.20
hours of use per day	-0.11	0.13
Membership	-0.06	0.36
Length of membership	0.19	0.00
Number of posted messages	0.12	0.09
Number of replied messages	0.14	0.06

Table 48: Relationship between OSG measures and quality of life

As it can be seen from Table 48, only “Time since start using OSG” ($p= 0.02$) and “Length of membership” ($p=0.00$) were significantly related to QoL, whereas other variable such as “Number of days of using OSGs per month” “Number of hours of

using OSGs per day” “Membership” “Number of posted messages” and “Number of replied messages” were not significant.

Visually inspecting the data showed that “Time since start using OSGs” and “Length of membership” measures appeared to represent the same thing (Table 45, Section 5.1.6). Therefore, “Time since start using OSGs” was chosen as the measure to assess the relationship between use of OSG and QoL.

5.1.6.4.2 Pre-regression tests

One simple linear regression model was conducted to answer the first aim of this study (*to examine the relationship between using OSGs and QoL*). This was followed by six multiple linear regression models to answer the second aim of the study (*to examine the psychosocial factors: social network, self-efficacy, anxiety, depression, adjustment and empowerment that may influence the relationship between using OSGs and QoL*) (see Table 49) below:

In order to carry out the regression analyses, a number of tests were undertaken to assess the assumptions of linearity, homoscedasticity, normality of the residuals (the differences between obtained and predicted dependent variable scores) (Tabachnick, and Fidell, 2007; Pallant, 2013) and reliability of measurement, (Osborne and Waters, 2002). In addition, tests for the absence of serial correlation (autocorrelation) between the residuals (Schwab, 2007; Zaiontz, 2014) and absence of multicollinearity between the variables (Mela, and Kopalle, 2002) were also considered as they are key assumptions in regression analyses. Some statisticians also recommend that significant outliers should be carefully examined if linear regression model is to be conducted (Bollen, and Jackman, 1990; Blatná, 2006; Lund and Lund, 2013). More details about each of these issues and how they have been tested in this study can be seen below.

Serial Correlation (Autocorrelation)

A key assumption in regression is that the residuals are not correlated serially from one observation to the next. This means the size of the residual for one case has no

impact on the size of the residual for the next case (i.e. independent from one another) (Schwab, 2007; Zaiontz, 2014).

In this study, the value of Durbin-Waston was used for each regression model to evaluate the presence of serial correlation (Table 49). According to Schwab (2007), a value between 1.50 and 2.50, as a general rule of thumb, indicates no serial correlation and we can presume that the residuals are independent. As it can be seen from Table 53, the value of Durbin-Waston indicates no serial correlations for all the models.

Model	Type of regression	Purpose: to investigate	Durbin-Waston value
Model 1	Simple linear regression	The relationship between using OSGs and QoL	1.995
Model 2	Multiple linear regression	Mediators between OSGs and QoL	1.940
Model 3	Multiple linear regression	Mediators between OSGs and depression	2.087
Model 4	Multiple linear regression	Mediators between OSGs and adjustment	2.180
Model 5	Multiple linear regression	Mediators between OSGs and anxiety	1.946
Model 6	Multiple linear regression	Mediators between OSGs and self-efficacy	1.823
Model 7	Multiple linear regression	Mediators between OSGs and empowerment	1.647

Table 49: Durbin-Waston value for each regression model

Reliability of measurement

In regression, unreliable measurement causes relationships to be under-estimated increasing the risk of Type II errors. In the case of multiple regressions, effect sizes of other variables can be over-estimated if the variable is not reliably measured. Therefore, before performing multiple regressions, it is important to ensure that the variables are measured without error (reliably) (Osborne and Waters, 2002).

Authors assume that reliability estimates (Cronbach alphas) of 0.7 or above are acceptable to perform multiple regression analysis (Nunnally, 1978; Osborne *et al*, 2001). In this study the Cronbach alphas for all of the measures used were found to be between 0.76 and 0.96 (see Table 47, Section 5.1.6, for details).

Multicollinearity

Multicollinearity is a phenomenon which occurs in a multiple regression model in which two or more independent variables are highly correlated (Mela, and Kopalle, 2002). In this study, to diagnose whether there is an issue of Multicollinearity between the variables, Tolerance and the Variance Inflation Factor (VIF) have been calculated (Table 50). The literature indicates that a tolerance of less than 0.20 or 0.10 and/or a VIF of 5 or 10 and above indicates a multicollinearity problem (O'Brien, 2007). As can be seen in Table 50, both measures indicate no multicollinearity.

IV \ DV	TsU		Social network		Self-efficacy		Anxiety		Depression		Adjustment		Empowerment		QoL	
	Tolerance	VIF	Tolerance	VIF	Tolerance	VIF	Tolerance	VIF	Tolerance	VIF	Tolerance	VIF	Tolerance	VIF	Tolerance	VIF
TsU			.882	1.134	.883	1.132	.896	1.117	.883	1.132	.887	1.128	.891	1.122	.881	1.135
Social network	.825	1.212			.825	1.212	.834	1.199	.875	1.143	.874	1.144	.826	1.211	.825	1.212
Self-efficacy	.429	2.332	.428	2.337			.441	2.269	.550	1.819	.437	2.288	.430	2.328	.434	2.303
Anxiety	.361	2.771	.359	2.785	.366	2.734			.390	2.567	.453	2.205	.360	2.776	.356	2.811
Depression	.252	3.971	.266	3.753	.323	3.097	.276	3.627			.252	3.974	.265	3.774	.336	2.974
Adjustment	.449	2.228	.473	2.115	.456	2.194	.570	1.755	.447	2.238			.453	2.207	.472	2.118
Empowerment	.911	1.098	.902	1.109	.905	1.105	.914	1.094	.950	1.052	.915	1.093			.913	1.095
Quality of life	.486	2.059	.486	2.059	.493	2.029	.486	2.056	.650	1.538	.514	1.946	.492	2.031		

Table 50: Tolerance and the variance inflation factor (VIF)

Assumption of linearity

In order to detect non-linearity, residual plots (plots of the standardized residuals as a function of standardized predicted values) were examined for each regression model (Cohen and Cohen, 1983; Berry and Feldman, 1985; Pedhazur, 1997; Tabachnick, and Fidell, 2007; Pallant, 2013). Appendix 17 indicates that the assumption of linearity holds for the main outcome variable in each model since data were distributed in a way where a fitted line looks straight.

In addition, Appendix 18 shows the regression plots for each of the independent variables with the dependent variable in each model, and, again, no curved relationship appeared for any variable indicating assumptions of linearity held.

Homoscedasticity (constant variance)

Homoscedasticity refers to a situation in which the variability of a variable is consistent throughout the range of values of another variable that predicts it (Taylor, 2013). Evaluating homoscedasticity in this analysis was dependent on graphical methods including investigating scatterplot, histogram and normal Probability plot (P-P Plot) of the residuals. Appendix 17 shows a scatterplot of the relationship between the residuals (or error) and the predicted value for each model. From the figures value, the plots of points appear roughly as a rectangular band in a scatterplots and according to Schwab (2007), this shape can indicate a consistent relationship between the residuals and the predicted variable. The spread of the residuals appears as roughly about the same throughout the plots (no systematic patterns). So, it appears that the error variance is consistent with varying values in the predicted variable in each model.

The histogram of the residuals associated with the dependent variables looks roughly normal for each model (see Appendix 19). In addition, in the P-P Plot of each model (Appendix 20), the data points are very close to the least-square fit-line.

The above points can support the presence of homoscedasticity and indicate little probability of heteroscedasticity.

Normality

Normality in regression analysis means that the residuals should be normally distributed about the predicted dependent variable score (i.e, not highly skewed or highly kurtotic) (Tabachnick, and Fidell, 2007; Pallant, 2013). Bulmer (1979) suggests the following rule of thumb; If skewness is less than -1 or greater than $+1$, the distribution is highly skewed. If skewness is between -1 and $-\frac{1}{2}$ or between $+\frac{1}{2}$ and $+1$, the distribution is moderately skewed. If skewness is between $-\frac{1}{2}$ and $+\frac{1}{2}$, the distribution is approximately symmetric. In addition, the values for kurtosis between -2 and $+2$ are considered acceptable in order to prove normal distribution (George and Mallery, 2010).

Table 51 shows the Skewness and Kurtosis of the residuals in each regression model in this study. According to the above rule of thumb, none of the distributions of the residuals in the models were highly skewed or highly kurtotic.

	Skewness		Kurtosis	
		Std. Error		Std. Error
Model 1	-.345	.174	-.121	.346
Model 2	-.119	.174	.597	.346
Model 3	-.010	.174	.648	.346
Model 4	-.372	.174	1.072	.346
Model 5	.158	.174	.965	.346
Model 6	-.561	.174	.747	.346
Model 7	-.112	.174	-.134	.346

Table 51: Skewness and Kurtosis of the residuals in each regression model

In addition, another recent and more accurate rule by Hae-Young Kim, (2013) indicates that for medium-sized samples ($50 < n < 300$), we can reject the null hypothesis at absolute z-value over 3.29, which corresponds with an alpha level 0.05, and conclude the distribution of the sample is non-normal.

The z-value (Z_{skew} and $Z_{kurtosis}$) has been calculated (see Table 52 below) and, according to Hae-Young Kim's rule (2013), the distribution of the residuals in all the models appeared to be normally distributed.

In addition, the histograms, Normal Probability Plots (P-P plots), Quantile-Quantile (Q-Q) plots and Box Plot of regression standardised residuals available for each model

(Appendices 19 - 22), show that the distributions of the residuals of all models appear to have a normal distribution in line with Hae-Young Kim, (2013). This indicates that the assumption of linearity holds for the residuals in each model.

	Z_skew	Z_kurtosis
Model 1	-1.982	-0.349
Model 2	-0.683	1.725
Model 3	-0.057	1.872
Model 4	-2.137	3.098
Model 5	0.908	2.789
Model 6	-3.224	2.158
Model 7	-.643	-.387

Table 52: z value for skewness and kurtosis for the residuals in each regression model

Outliers

Researchers indicated that outliers can lead to misinterpreting patterns in plots and can affect visual resolution of remaining data in plots (forces observations into “clusters”) (Jacoby, 2005). More importantly, unusual cases with both outliers and high leverage can have a strong influence on a statistical model, and can substantially influence the fit of the model (Lane, 2008). Therefore, some researchers have suggested that deleting outliers from a regression model can sometimes give completely different results (Jacoby, 2005).

Cook's distance is a commonly used estimate of the influence of a data point when performing regression analysis (Mendenhall and Sincich, 1996). Another measure is the leverage of an observation, which is based on how much the observation's value on the predictor variable differs from the mean of the predictor variable. The greater an observation's leverage, the more potential it has to be an influential observation (Lane, 2008).

There are different opinions regarding what cut-off values to use for spotting highly influential points. A simple operational guideline of Cook's distance >1 has been suggested (Cook and Weisberg, 1982). Some analysts suggest investigating observations for which Cook's distance is greater than 0.5 (Blatná, 2006).

As a general rule, a point with Cook's distance greater than $4/n$ and points with Leverage Value greater than $(2k+2)/n$ should be carefully examined. Where k is the number of predictors and n is the number of observations (Blatná, 2006; Bollen, and Jackman, 1990).

Cook's Distance and Centred Leverage Value have been measured for all the models to investigate for any extreme values that may require deletion before conducting the regression analysis (Table 53 and Appendix 23).

Using the above mentioned general rule (Blatná, 2006; Bollen, and Jackman, 1990) together with inspection of the scatter Plot of Cook's distance against Centred Leverage Value, indicated the presence of few outliers in the data. In addition, testing the models with and without these outliers neither affected the result nor the assumption of the regression. Therefore, since the issue of deletion of outliers is a controversial practice in the literature (Orr, *et al*, 1991; Barnett and Lewis, 1994; Zimmerman, 1995; Osborne, 2004) and since the assumptions of regression analysis have been met for all the models even without removing these outliers, a decision was made to keep these outliers in the data.

	Cook's Distance		Centred Leverage Value	
	Minimum	Maximum	Minimum	Maximum
Model 1	.000	.173	.000	.053
Model 2	.000	.079	.004	.117
Model 3	.000	.125	.002	.099
Model 4	.000	.128	.002	.096
Model 5	.000	.068	.002	.115
Model 6	.000	.074	.001	.101
Model 7	.000	.052	.001	.111

Table 53: Cook's Distance and Centred Leverage Value for each model

Shape of the distribution for each variable

Appendix 24 shows the shape of the distribution for each variable in a histogram. While most of the variables appeared to be normal, some of them appeared to have a skewed distribution (e.g. Time since start using OSG "TsU"). However, since the assumption of the regression suggest the normality of the residuals (Tabachnick, and Fidell, 2007; Pallant, 2013) which have already been met, no transformation was applied to the variables.

5.1.6.5 Section III: Regression analyses

A series of regression analyses were conducted using the Enter method. One simple linear regression model was conducted to answer the first aim of the study (*to examine the relationship between using OSGs and QoL*). Following this, six multiple linear regression models were conducted in order to answer the second aim of the study (*to examine the psychosocial factors: social network, self-efficacy, anxiety, depression, adjustment and empowerment that may influence the relationship between using OSGs and QoL*).

Research Question 1: Is there a relationship between OSG-use and quality of life?

To investigate the first research question, a simple regression analysis using Enter method was conducted with QoL as the dependent variable and OSG use as the predictor.

Time since starting using OSGs (TsU) was selected as a measure to represent the use of OSGs (see Section 5.1.6.4). This measure was used for all the regression models in this study to ensure the analysis was standardised.

5.1.6.5.1 Model 1: Relationship between OSG-use and quality of life

Regressing QoL on TsU indicated that *times since starting using OSGs* (TsU) was related to the QoL of participants (Table 54), such that those participants who had better QoL had been using OSGs for a longer time than those who had worse QoL. Although the results of bivariate correlation analysis showed that there was a relationship between *times since starting using OSGs* (TsU) and QoL, correlation only quantifies the degree to which the two variables were related but it does not fit a line through the data points, whereas linear regression finds the best line that predicts QoL from TsU (Zou *et al*, 2003).

	Unstandardized Coefficients (B)	Standardized Coefficients	<i>t</i>	<i>P</i>
OSG (TsU)	0.07	0.16	2.32	0.02

Table 54: Regressing QoL on TsU

Research Question 2: Is the relationship between OSG use and QoL mediated by social network, self-confidence, anxiety, depression, adjustment or empowerment?

To investigate this, the mediation regression tests outlined by Baron and Kenny (1986) were followed. Baron and Kenny (1986) proposed a model (Figure 11) which includes three paths; the direct path (c-path) between the predictor (e.g. TsU) and the dependent variable (e.g. QoL) and the indirect paths (a-path and b-path) that include the mediator (e.g. Social network).

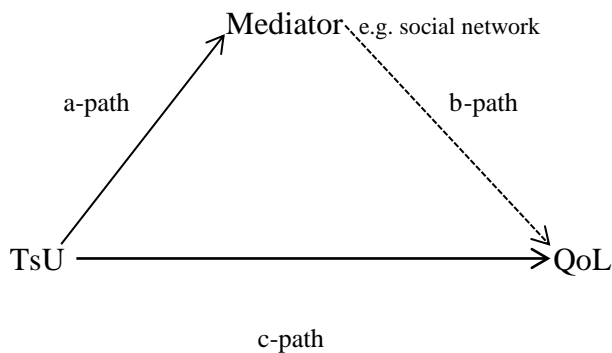


Figure 11: Example of process of mediation between OSG (TsU) and QoL

Baron and Kenny suggest that if the mediation requirements hold, using the example above, TsU should be a significant predictor of QoL (c-path), and TsU should be a significant predictor of the mediator variable (a-path). In addition, there should be a significant relationship between the mediator variable and QoL (b-path) while controlling for TsU. Baron and Kenny (1986) model also indicate that when the mediator (e.g. social network) and TsU are used simultaneously to predict QoL, the previous relationship between TsU and QoL should be reduced or become non-significant.

Following the Baron and Kenny model, the mediating role of the psychosocial variables was tested using SPSS using a tool by Hayes (2013). This allows for the testing of each step of the mediation effect and testing of the significance of the indirect path through the bootstrapping method with bias-corrected confidence estimates (Mackinnon, *et al.*, 2004; Preacher and Hayes, 2004). In addition, all

mediators (social network, self-confidence, anxiety, depression, adjustment and empowerment) were tested within the same regression analysis rather than separately.

5.1.6.5.2 Model 2: Mediators between OSGs and QoL

Proposed mediators were; social network, self-efficacy, anxiety, depression adjustment and empowerment.

Multiple regressions were conducted to assess each component of the proposed mediation model. In the first step, testing the c-Path, OSG usage (TsU) was positively associated with QoL ($B= 0.07$, $t= 2.32$, $p= 0.02$). The a-paths for each possible mediator were then tested (i.e. their relationship with OSG usage) and the results can be seen in Table 55.

	B (a-path)		t	p
	Unstandardized Coefficients (B)	Standardized Coefficients		
Social network	0.00	0.06	0.94	0.34
Self-efficacy	0.08	0.16	2.35	0.02
Anxiety	-0.03	-0.25	-3.72	0.00
Depression	-0.02	-0.21	-3.10	0.00
Adjustment	-0.07	-0.22	-3.18	0.00
Empowerment	0.13	0.17	2.41	0.01

Table 55: The relationship between OSG (TsU) and the six proposed mediators (b-path)

As can be seen, there was a significant relationship between OSGs and self-efficacy, anxiety, depression, adjustment and empowerment such that longer-time of using OSGs (TsU) was related to each of these mediators. However, social network was not related to OSG use and so, according to the requirements of Baron and Kenny, cannot be considered a mediator of OSG on QoL.

In the final step of the regression model, testing the b-path, whilst controlling for TsU, the results indicated that only depression and adjustment were associated with QoL (see Table 56). Therefore, self-efficacy, anxiety and empowerment, according to the requirements of the Baron and Kenny model, cannot be considered as mediators of OSG on QoL.

	B (b-path)		<i>t</i>	<i>p</i>
	Unstandardized Coefficients (B)	Standardized Coefficients		
Self-efficacy	-0.11	-0.12	-1.63	0.10
Anxiety	0.15	0.05	0.57	0.57
Depression	-2.46	-0.71	-8.44	0.00
Adjustment	-0.33	-0.24	-3.38	0.00
Empowerment	-0.03	-0.07	-1.16	0.24

Table 56: Indirect effect of the OSGs on QoL (b-path)

Because both the a-path and b-path were significant for depression and adjustment, mediation was tested using the bootstrapped CIs. The results confirmed the mediating role of depression and adjustment between length of time since using OSGs (TsU) and QoL (see Table 57).

	Effect	BootLL-CI	BootUL-CI
Depression	0.06	0.01	0.14
Adjustment	0.02	0.00	0.05

Table 57: Indirect effect of the OSGs on QoL, result of bootstrapping Confidence Interval

The results also indicated that the direct effect of the length of time since using OSGs (TsU) on QoL became non-significant ($B=0.00$, $t= 0.04$, $p= 0.96$) when controlling for depression and adjustment, thus suggesting full mediation. This suggests that the relationship between longer time using OSGs and better QoL was mediated by people having less endorsement in the negative adjustment behaviour toward their H&N cancer and lower levels of depression. Figure 12 summarises the direct and indirect (mediated) pathways between OSG use and QoL.

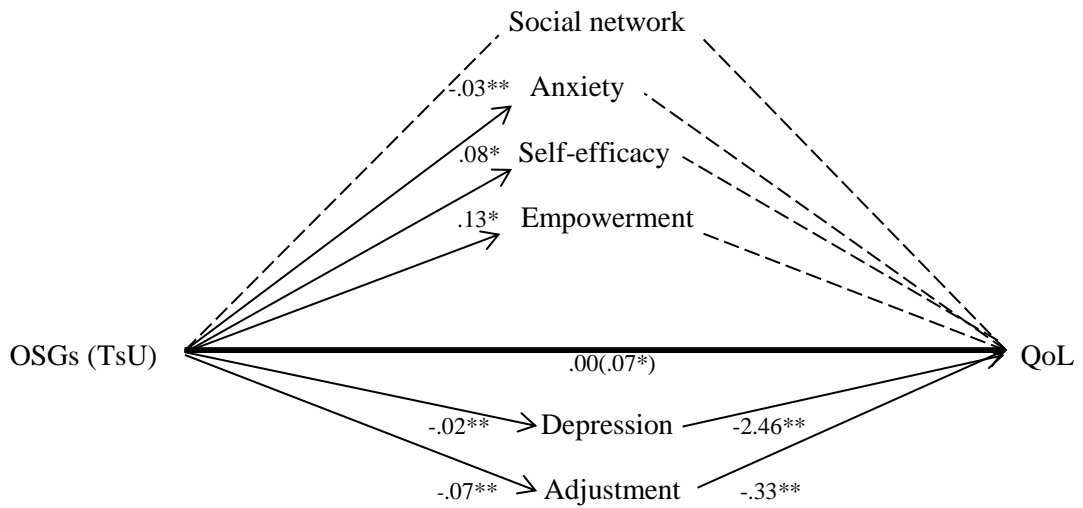


Figure 12: Summary of the possible mediators in the relationship between OSGs and QoL

**= Correlation is significant at the 0.01 level (2-tailed), * =Correlation is significant at the 0.05 level (2-tailed,) Sold arrows= c-paths or a paths, dashed lines = insignificant paths. The numbers= unstandardized regression coefficients (B), The number in brackets= B value before mediation.

Given that depression and adjustment were the only possible mediators in the relationship between the use of OSGs and QoL, the second stage of the analysis was to identify what the mediators were between the use of OSGs and depression, adjustment, anxiety, self-efficacy and empowerment.

In line with the requirements of Baron and Kenny’s model, the results of regression analysis (see Table 55 above) indicated that the c-path (the relationship with OSG “TsD”) was significant for each variable. The table also shows that the a-path was significant for all the proposed mediators except social network. The final regression step to confirm or exclude mediators for each variable is to test the b-path, by controlling for TsU as follows:

5.1.6.5.3 Model 3: Mediators between OSGs and Depression

Proposed mediators were; self-efficacy, anxiety, empowerment and adjustment.

All “b-paths” of the proposed mediators were significant except for adjustment (see Table 58).

	B(b-path)		<i>t</i>	<i>p</i>
	Unstandardized Coefficients (B)	Standardized Coefficients		
Self-efficacy	-0.11	-0.44	-7.65	0.00
Anxiety	0.35	0.37	5.62	0.00
Adjustment	0.01	0.03	0.42	0.67
Empowerment	-0.02	-0.13	-2.99	0.00

Table 58: Indirect effect of the OSGs on depression (b-path)

Because both the a-path and b-path were significant for self-efficacy, anxiety and empowerment, mediation was tested using the bootstrapped CIs. The results confirmed the mediating role of these variables between length of time since using OSGs (TsU) and depression (see Table 59).

	Effect	BootLL-CI	BootUL-CI
Self-efficacy	-0.01	-0.02	-0.002
Anxiety	-0.01	-0.02	-0.003
Empowerment	-0.00	-0.01	-0.000

Table 59: Indirect effect of the OSGs on depression, result of bootstrapping Confidence Interval

The results also indicated that the direct effect of the length of time since using OSGs (TsU) on depression became non-significant ($B=0.00$, $t= -0.37$, $p= 0.71$) when controlling self-efficacy, anxiety and empowerment, thus suggesting full mediation.

5.1.6.5.4 Model 4: Mediators between OSGs and adjustment

Proposed mediators were; self-efficacy, anxiety, empowerment and depression. In the final step; testing b-path, and controlling for TsU, the results indicated that none of paths of the proposed mediators (b-path) were significant apart from anxiety (see Table 60). This means self-efficacy, empowerment and depression, using Baron and Kenny's model, cannot be considered as mediators of OSG on adjustment.

	B (p-path)		t	p
	Unstandardized Coefficients (B)	Standardized Coefficients		
Self-efficacy	-0.09	-0.14	-1.86	0.06
Anxiety	1.29	0.55	7.27	0.00
Depression	0.09	0.04	0.42	0.67
Empowerment	-0.03	-0.07	-1.49	0.13

Table 60: Indirect effect of the OSGs on adjustment (b-path)

Because both the a-path and b-path were significant for anxiety, mediation was tested using the bootstrapped CIs. The results confirmed the mediating role of anxiety between the length of time since using OSGs (TsU) and adjustment (see Table 61).

	Effect	BootLL-CI	BootUL-CI
Anxiety	-0.044	-0.08	-0.01

Table 61: Indirect effect of the OSGs on adjustment, result of bootstrapping Confidence Interval

Furthermore, the results indicated that the direct effect of the length of time since using OSGs (TsU) on adjustment became non-significant ($B=0.01$, $t= -0.65$, $p= 0.51$) when controlling anxiety, thus suggesting full mediation.

5.1.6.5.5 Model 5: Mediators between OSGs and anxiety

Proposed mediators were; self-efficacy, depression, adjustment and empowerment.

The result of the regression (Table 62) shows that all “b-paths” of the proposed mediators were significant except empowerment. This indicated that self-efficacy, depression and adjustment, can be considered as mediators of OSG on anxiety.

	B (p-path)		t	p
	Unstandardized Coefficients (B)	Standardized Coefficients		
Self-efficacy	-0.04	-0.15	-2.27	0.02
Depression	0.40	0.37	5.62	0.00
Adjustment	0.17	0.41	7.27	0.00
Empowerment	0.01	0.06	1.70	0.09

Table 62: Indirect effect of the OSGs on anxiety (b-path)

Again, because both the a-path and b-path were significant for self-efficacy, depression and adjustment, mediation was tested using the bootstrapped CIs. The results confirmed the mediating role of these variables between the length of time since using OSGs (TsU) and anxiety (see Table 63); they also excluded the mediation effect of empowerment.

	Effect	BootLL-CI	BootUL-CI
Self-efficacy	-0.00	-0.01	-.0003
Depression	-0.01	-0.02	-.002
Adjustment	-0.01	-0.02	-.001

Table 63: Indirect effect of the OSGs on anxiety, result of bootstrapping Confidence Interval

The results also indicated that the direct effect of the length of time since using OSGs (TsU) on anxiety became non-significant ($B= -0.01$, $t= -1.68$, $p= 0.09$) when controlling self-efficacy, depression and adjustment, suggesting full mediation.

5.1.6.5.6 Model 6: Mediators between OSGs and self-efficacy

Proposed mediators were; anxiety, depression, adjustment and empowerment. In the final step; testing b-path and controlling for TsU, the results indicated that only anxiety and depression were associated with self-efficacy (see Table 64). Therefore, adjustment and empowerment cannot be considered as mediators of OSG on self-efficacy.

	B(b-path)		t	p
	Unstandardized Coefficients (B)	Standardized Coefficients		
Anxiety	-0.65	-0.18	-2.27	0.02
Depression	-2.07	-0.52	-7.65	0.00
Adjustment	-0.19	-0.12	-1.86	0.06
Empowerment	-0.02	-0.03	-0.67	0.50

Table 64: Indirect effect of the OSGs on self-efficacy (b-path)

Both the a-path and b-path were significant for anxiety and depression, therefore mediation was tested using the bootstrapped CIs. The results confirmed the mediating role of anxiety and depression between the length of time since using OSGs (TsU) and self-efficacy (see Table 65).

	Effect	BootLL-CI	BootUL-CI
Anxiety	0.02	.004	0.05
Depression	0.05	0.01	0.11

Table 65: Indirect effect of the OSGs on self-efficacy, result of bootstrapping Confidence Interval

Furthermore, the results indicated that the direct effect of the length of time since using OSGs (TsU) on self-efficacy became non-significant (B=- 0.00, $t = -0.36$, $p = 0.72$) when controlling anxiety and depression, suggesting full mediation.

5.1.6.5.7 Model 7: Mediators between OSGs and empowerment

Proposed mediators were; self-efficacy, anxiety, depression and adjustment. In the final step; testing b-path and controlling for TsU, the results indicated that only depression was associated with empowerment (see Table 66). Therefore, self-efficacy, anxiety, and adjustment cannot be considered as mediators of OSG on empowerment.

	B(b-path)		<i>t</i>	<i>p</i>
	Unstandardized Coefficients (B)	Standardized Coefficients		
Self-efficacy	-0.11	-0.06	-0.67	0.50
Anxiety	1.15	0.15	1.70	0.09
Depression	-2.11	-0.32	-2.99	0.00
Adjustment	-0.36	-0.13	-1.49	0.13

Table 66: Indirect effect of the OSGs on empowerment (b-path)

Both the a-path and b-path were significant for depression; therefore mediation was tested using the bootstrapped CIs. The results confirmed the mediating role of depression between the length of time since using OSGs (TsU) and empowerment (see Table 67).

	Effect	BootLL-CI	BootUL-CI
Depression	0.05	.007	0.14

Table 67: Indirect effect of the OSGs on empowerment, result of bootstrapping Confidence Interval

The results also indicated that the direct effect of the length of time since using OSGs (TsU) on empowerment became non-significant ($B=0.10$, $t= 1.78$, $p= 0.07$) when controlling depression, suggesting full mediation.

5.1.6.5.8 Summary of relationships

The regression analysis indicated that the relationship between OSGs and QoL was only mediated by depression and adjustment. Further regression indicated that some of the psychosocial variables mediated each other in their relationship with OSGs. For example, self-efficacy, anxiety and depression were found to mediate each other in their relationships with OSGs. Depression was also found to mediate and be mediated by empowerment. In addition, anxiety was also found to mediate and be mediated by adjustment. Figure 13 summarises the significant mediators between OSGs and QoL.

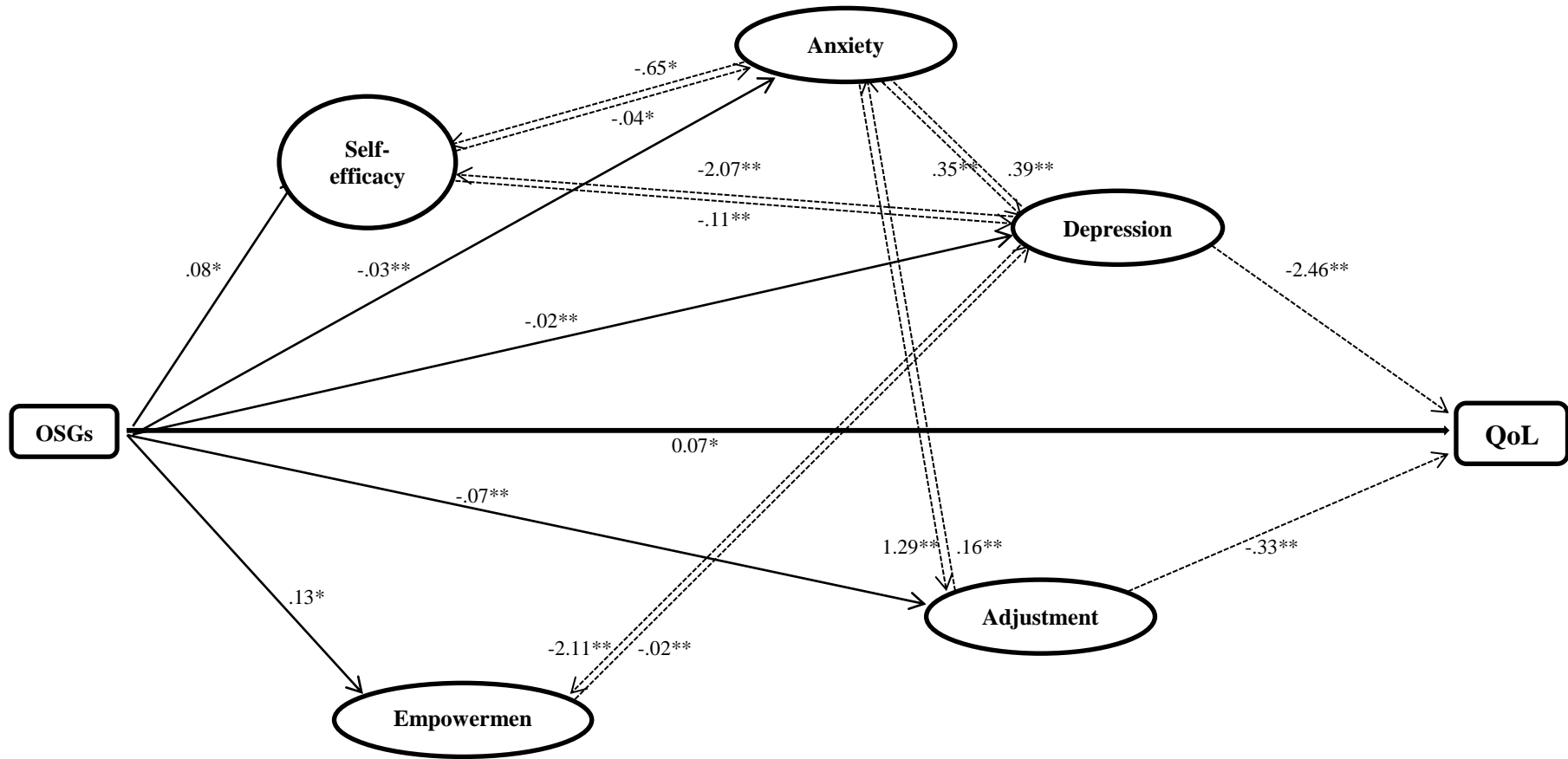


Figure 13: Summary of the mediating process in the relationship between OSGs and QoL, depression, adjustment and anxiety

**= Correlation is significant at the 0.01 level (2-tailed), * =Correlation is significant at the 0.05 level (2-tailed,) Sold arrows= c-paths or a paths, dotted arrows = significant b-paths. The numbers= unstandardized regression coefficients (B)

5.1.6.5.9 Summary of the model

The results of the regression analysis indicated that length of time since using OSGs (TsU) was related to QoL of the participants, together with depression, anxiety, adjustment, self-efficacy and empowerment. Participants who had been using OSGs for a longer time (measured in months) had better QoL, lower levels of anxiety and depression, lower endorsement of the negative adjustment behaviour (in terms of negative coping strategies such as helpless-hopeless, anxious preoccupation, avoidance and fatalism), higher levels of empowerment process (terms of receiving social support, finding positive meaning, receiving useful information and helping others) and greater belief that they were capable of performing well (i.e. self-efficacy).

Levels of depression and adjustment were found to mediate the relationship between length of time since using OSGs and QoL. Participants who had been using OSGs for a longer time reported lower levels of depression and adjustment and subsequently reported better QoL. In addition, depression and adjustment also mediated the relationship between length of time since using OSGs and anxiety such that participants reporting lower levels of depression and adjustment also reported lower levels of anxiety. Depression mediated the relationship between length of time since using OSGs and both self-efficacy and empowerment such that those who reported lower levels of depression reported greater empowerment and self-efficacy.

Anxiety was also found to mediate the relationship between length of time since using OSGs and depression and adjustment in a similar way; those participants who had been using OSGs for a longer time reported lower levels of anxiety and subsequently reported lower levels of depression and adjustment. Anxiety also mediated the relationship between length of time since using OSGs and self-efficacy and participants reporting lower levels of anxiety also reported greater levels of self-efficacy.

Similarly, self-efficacy mediated the relationship between length of time since using OSGs and both levels of anxiety and depression such that those participants who had been using OSGs a longer time reported greater levels of self-efficacy and subsequently reported lower levels of anxiety and depression.

Finally, empowerment mediated the relationship between length of time since using OSGs and depression. Participants who had been using OSGs a longer time, reported greater levels of empowerment and subsequently reported lower levels of depression.

5.1.7 Discussion

The analysis of the current study indicated that there was a relationship between using H&N cancer-related OSGs and QoL of the users. The analysis suggested that most of the proposed psychosocial variables included in the study may have a role in this relationship. The main finding was that longer use of OSGs was related to better QoL and this relationship was mediated by depression and adjustment. In addition, anxiety, self-efficacy and empowerment were found to have a role in the mediation process by mediating the relationship between the use of OSGs and depression and adjustment. In this section, two main questions are discussed:

- Is the use of OSGs for head and neck cancer related to quality of life?
- Who uses OSGs for head and neck cancer?

5.1.7.1 Is the use of OSGs for H&N cancer related to QoL?

This findings of the present study indicate that using OSGs (measured as the length of time since starting using such a group) was related to better QoL. This finding is consistent with previous studies that report a link between OSG use and better QoL for HIV/AIDS (Mo and Coulson, 2010b; Mo and Coulson, 2012). It also was consistent with a meta-analysis of 28 studies exploring the health-related outcomes related to contribution in a formal intervention dealt with computer-mediated support group (CMSG) (Rains and Young, 2009).

5.1.7.1.1 What factors mediate the relationship between OSGs and QoL?

Previous studies suggested that using OSGs including group communication and educational components led to an improvement in QoL directly or indirectly through increasing the use of adaptive coping and decreasing the use of maladaptive coping (Rains and Young, 2009; Mo and Coulson, 2010b, Mo and Coulson 2012).

The findings of the current study suggested that self-efficacy, anxiety, depression, adjustment and empowerment, were all found to mediate the relationship between length of time since starting using OSGs and QoL. The results relating to self-

efficacy, adjustment and empowerment are in line with previous literature (Mo and Coulson 2012), in which the authors have investigated the possible mechanism through which participation in OSGs might encourage user empowerment for people living with HIV/AIDS. Findings of that study proposed that OSGs participation results in empowering processes, which in turn have a positive influence on psychosocial outcomes as measured by coping, self-care self-efficacy, and QoL. This consistency in the findings is despite the difference in the nature of HIV/AIDS and H&N cancer. This might indicate that the mechanisms underlying the mediation process between using OSGs and QoL may be similar despite differences in the health condition.

With regards to the role of anxiety and depression, no previous studies have investigated the mediating role of anxiety and depression in the OSG-QoL relationship. A recent randomised control study by Griffiths *et al.*, (2012) indicated that participants of an OSG showed significantly considerable decrease in depressive symptoms at follow-up (6 and 12 months) than the control group. This result was supported by a previous study (Winzelberg *et al.*, 2003) which indicated that a web-based social support group was effective in reducing the scores of depression, stress, and cancer-related trauma in women with breast carcinoma participating in the group. In addition, studies by Coulson and Buchanan (2006, 2008) indicated that participation in OSGs appeared to reduce feelings of dental anxiety and concern. On the other side, the literature indicated that depression and anxiety are widely known to have a negative association with at least one aspect of QoL in people with H&N cancer (Horney *et al.*, 2011) or other cancers or non-cancerous health conditions (Reich *et al.*, 2008; Schram *et al.*, 2009; Brown *et al.*, 2010 ; Jouniaux-Delbez, *et al.*, 2010). Therefore, future studies to examine the mediation role of anxiety and depression in the relationship between duration of using OSGs and QoL might be beneficial.

The length of time since starting using OSGs was also found to be directly related to depression, anxiety, adjustment, self-efficacy and empowerment. Those participants who had been using OSGs for a longer time (measured in months) had lower levels of anxiety and depression, lower endorsement of the negative adjustment (in terms of negative coping strategies such as helpless-hopeless, anxious preoccupation, avoidance and fatalism), higher levels of empowerment process in (terms of receiving

social support, finding positive meaning, receiving useful information and helping others) and a greater belief that they are capable of performing well (i.e. self-efficacy). Although, so far, no study has investigated the relationship of all of these variables with OSGs, the results of this study were in line with some previous studies conducted for other conditions (non-H&N cancer including breast cancer, dental anxiety, depression, arthritis and fibromyalgia and HIV-AIDS) and which investigated the relationship of at least one of these variables with OSGs (Winzelberg *et al.*, 2003; Klemm *et al.*, 2003, Coulson and Buchanan, 2006; Coulson and Buchanan, 2008; van Uden-Kraan *et al.*, 2008; van Uden-Kraan, *et al.*, 2009; Høybye *et al.* 2010; Griffiths *et al.*, 2012; Mo and Coulson, 2012). These studies supported the relationship between OSGs with depression, anxiety, adjustment, self-efficacy and empowerment in a similar way to those found in the present study.

In terms of adjustment, the length of time using OSGs was related to the total score of the MINI-MAC scale (Watson *et al.*, 1994) used to measure adjustment in this study. This scale consist of 29 items distributed within five subscales all of them deal with negative strategies except one (Fighting spirit). Given the small number of positive items (4), it may be difficult to investigate whether OSG are related to positive coping strategies, and further research using another adjustment or coping scale is required. The result relating to negative strategies is consistent with Mo and Coulson (2012) who suggested that using OSGs was negatively related to maladaptive coping strategies. However, other previous research (Fogel *et al.*, 2002), could not find a significant relationship between using the Internet for health information and psychological coping in patients with breast cancer.

In the present study, there was no relationship between length of time since using OSGs and social network. These results are in contrast with previous research in which an association between health-related Internet use and higher scores of social support in patients has been reported (Fogel *et al.*, 2002; Kalichman *et al.*, 2003). Nevertheless, other studies have also found a lack of association between OSGs use and social support (Eastin and LaRose, 2005; Mo and Coulson 2010b) where there was no direct relationship seen between time spent on the online support levels of social support. One possible explanation might be that the scale used for measuring social networks, which was designed to measure social networks in personal

relationships, might not be suitable for online relationships (Mo and Coulson 2010b). It is possible that people with H&N cancer might be part of real social networks and receive social support from other sources, apart from OSGs. Thus, future work should use another social network scale designed to be used in OSGs, given that there are likely to be different types of support from different sources available for individuals living with H&N cancer (Cancer care, 2014).

5.1.7.1.2 Mechanism of the mediation process

Although all the proposed mediators were found to play a role in the relationship between OSGs and QoL (except social network), the results indicated that, while controlling for all the proposed mediators, only levels of depression and adjustment were found to be direct mediators, such that participants who had been using OSGs a longer time reported low levels of depression and adjustment and in turn reported better QoL.

Whilst the other variables were not mediators of the OSG-QoL relationship, they were found to play a role in other relationships within the pathway (see Figure 13, Section 5.1.6). For example, self-efficacy, anxiety and depression were found to mediate each other in their relationships with OSGs. Depression was also found to mediate and be mediated by empowerment. In addition, anxiety was also found to mediate and be mediated by adjustment. In general, participants who had been using OSGs a longer time were less depressed, less anxious, had fewer tendencies for the negative adjustment behaviours, and confident that they were capable of performing, felt more empowered to react better with their illness and in turn had better QoL.

5.1.7.2 Who uses OSGs for head and neck cancer?

The present findings revealed that users of H&N cancer-related OSGs were more likely to be older and from both genders. This is not consistent with previous research on use of OSGs and Internet for other health-related purposes, in which users of OSGs were more likely to be female and younger (Fox and Rainie, 2002; Rahmqvist and Bara, 2007; Mo and Coulson, 2010b). However, results for age were consistent with

the previous study (Chapter 4) that analysed messages posted to H&N cancer-related OSGs.

The disparity in age between this study and previous research can be attributed to the fact that the incidence of H&N cancer increases with age particularly after 50 years (Ridge *et al.*, 2004; Chidzonga and Mahomva, 2006; Warnakulasuriya, 2009). Therefore, it would be expected that older participants would be predominant users of H&N cancer-related OSGs. In terms of gender, the worldwide incidence of oral cancer is more prevalent in males than females in the majority of countries (Warnakulasuriya, 2009) and the general male: female ratio is about 3:1 for these tumours (Ridge *et al.*, 2004; Freedman *et al.*, 2007). In the present study the male: female ratio was approximately equal (49% male: 51% female). It may be that women are more likely to use the Internet for the purposes of interpersonal communication (Weiser, 2000; Boneva *et al.*, 2001) and more interested in the topics that relate to health (Green and Pope, 1999) which may explain the disproportionate number of females.

In contrast with a previous study that used a similar methodology in relation to HIV-AIDS (Mo and Coulson 2010b), individuals who were married / living with a partner were more likely to participate in H&N cancer-related OSGs than those who reported that they were single, widowed, divorced or separated. This can also be related to the age-group of people who use this kind of OSGs (older age), since it has been believed that older men are more likely to be married compared with young people (Statistics' New Zealand, 1996).

Although a previous study implicated socio-economic deprivation as an important factor for H&N cancer (Conway *et al.*, 2010), around two thirds of the participants in our study were satisfied with their income status. This might be because the sample in this study was taken from people with H&N cancer who were using OSGs, which reflected their education and income levels (Diaz *et al.*, 2002; Kalichman *et al.*, 2002; Kalichman *et al.*, 2005), whilst Conway *et al.* (2010) included the wider general H&N cancer population. Another reason may be because this study used a subjective measure of SES whilst Conway and colleagues used objective measures. Beside satisfaction with their income status, participants also have the ability to access and

use the Internet, which may reflect their income and education level “at least to own and use a computer and Internet”. This was consistent with the literature that suggests that people with higher socioeconomic classes are more likely to search for health-related information through the Internet than the lower socioeconomic classes (Diaz *et al.*, 2002; Kalichman *et al.*, 2002; Kalichman *et al.*, 2005).

The majority of participants had been diagnosed with either throat cancer or lip and mouth cancer. This result was consistent with the previous study (Chapter 4) in which the most common type of cancer reported by both support seekers and providers were cancers of the tongue followed by cancers of tonsil. In addition, it was consistent with cancer incidence in the USA and the UK, to which most the members in the sample belonged, as oral cancer was noticed to be more common than other subcategories of H&N cancer in these two countries (IARC, 2008).

In contrast to a previous study (Mo and Coulson, 2010), in which OSGs users were recently diagnosed, this study found that people who accessed H&N-related OSGs were diagnosed with cancer a long time ago, and the majority of them were in advanced stages of cancer and post-treatment. However, this finding supports results from the first study (see Chapter 4) that revealed that the majority of support providers were in their post treatment stage whereas people who were under treatment, in pre-treatment stage or in pre-diagnosis stage tend to be support seekers. The results also suggested that more than half of the participants had been using OSGs for more than one year and many of them were members for a longer time (> 5 years). Thus, it may be the case that users of H&N-related OSGs joined the group for the first time to seek support then continue to use the group after they recover.

In line with this, although the majority of participants were treated with radiation, surgery and chemotherapy, two-thirds of them also considered OSGs as part of their treatment. This was consistent with previous literature investigating OSGs for other health conditions and indicating using online support as having positive impacts, such as better adjustment, support and encouragement, less anxiety and depression and better QoL (Page *et al.*, 2000; Huws *et al.*, 2001; Houston *et al.*, 2002; Coulson *et al.*, 2007; Mo and Coulson, 2008; Mo and Coulson, 2010).

In this study, participants of H&N-related OSGs would be defined as heavy users, in that more than half of them were frequent users of more than 20 days per month. Furthermore, when they used OSGs, they did so for at least one hour per day. Indeed, the participants appeared to be more frequent users than participants of other online groups for other health conditions such as HIV/AIDS and depression (Houston *et al.*, 2002; Mo and Coulson, 2010b). The exact reason for this is not clear; it may be related to a more general gradual increase in the use of the internet for health purposes (Cohen, and Adams, 2011).

5.1.7.3 Limitations

The most important limitation was the cross-sectional nature of the study design. This is particularly important when discussing mediation. Whilst mediation was tested using techniques outlined within the literature (Baron and Kenny, 1986), the data were cross-sectional and so temporality cannot be assumed. The pathways proposed here are therefore exploratory and need to be tested longitudinally and, if possible, through a more precise design such as controlled trials.

The study used an online survey because it felt that it might be a convenient way for collecting data from people who are in various geographic areas in the world and have access to internet. However, the literature suggests that there are some disadvantages for online surveys, including issues of non-representativeness of the sample, low response rates, nonresponses, and lack of validity of the data (Couper, 2000; Nosek *et al.*, 2002; Kraut *et al.*, 2004; Matsuo *et al.*, 2004). For example some researchers (Couper, 2000) suggested that there is no equivalent way for researchers to access the population within the online environment. It has also been suggested that response rates are generally lower for online surveys than for mail or telephone surveys (Kraut *et al.*, 2004). In addition, it is possible for individuals to affect the quality of the results by deceptively or falsely answering questionnaire items (Nosek *et al.*, 2002) or by simply submitting their response multiple times. Moreover, it is still likely to obtain a small significance level even with a large sample size, which may require additional statistical tests to validate the results (Matsuo *et al.*, 2004).

Participation in the study was optional and participants were self-selected, and from a limited number of OSGs. It may be that only people with positive experiences of OSGs agreed to participate, or perhaps those who were adjusting better to their condition or treatment. In terms of the OSGs, practicalities meant the study could only incorporate four sites. It may be that differing results would have been obtained if more sites had been included.

This study aimed to collect data from online users who were people with cancer (not caregivers or other users). However, as there was no clear distinction in the definitions of cancer survivors compared to current patients (National Cancer Institute, 2014; NCCS, 2014; Macmillan Cancer Support, 2015), the inclusion criteria for this study included people who used OSGs and had been diagnosed with H&N cancer at any point during their life. Indeed, the results of the study showed that the majority of participants (87.43%) were in their post-treatment stages. This strategy may have drawbacks in that people at different stages of cancer and/or its treatment may have different perspectives from each other and may differ from people who have already finished their treatment in terms of their use and relationship with OSGs, and their questionnaire responses.

Although several measures were used to assess the use of OSGs, (See Table 45, Section 5.1.6), only “Time since start using OSG” and “Length of membership” were significantly related to QoL, whereas other variables such as “Number of days of using OSGs per month”, “Number of hours of using OSGs per day”, “Membership” “Number of posted messages” and “Number of replied messages” were not significant. The reasons for this are not clear. It could be because most of these variables (except membership) were based on estimation. Since many people using the OSGs had been doing so for a very long time, it could make it difficult for them to give precise estimation for how many days they were using the group per month, how many hours per day and how many messages they had sent.

Visually inspecting the data showed that “Time since start using OSGs” and “Length of membership” measures appeared to represent the same thing (Table 45, Section 5.1.6). It looked as though most of the people who started using OSGs were registered as members from the beginning. Therefore, “Time since start using OSGs” was

chosen to be the main measure in assessing the relationship between OSGs and QoL. However, since this measure is reported by the participants it could be subject to self-reporting bias. It is also a rather crude measure and does not consider the level of participation within the group; including the number of messages posted and participant activity in different periods, or their daily use. In addition, since participants were different in terms of stages of cancer and treatment stage, this measure does not fully account for this difference. Future studies should investigate more closely the relationship with the actual levels of participation in terms of posting messages as well as the daily and monthly rate of use, preferably with participants who have similar stages of cancer and treatment.

As was the case in Study 1, most of the respondents (56.28%) in this study were from the USA and this may make the results difficult to generalise to other countries. Namely in terms of differences between countries in treatment pathways but also help-seeking behaviours as well as emotional reactions, coping strategies and role of social support and relevant support networks. Also, most of the participants in this study were in advanced stages of cancer (60.79% were in stage III and IV) and in post-treatment stages (87.43%). Thus, it is still not clear whether people who are in initial stages of cancer and/ or treatment or untreated will respond similarly.

One other limitation was that the results suggested more than two thirds of the participants were satisfied with their income status, and it is clear that they have access to the internet and were educated enough “at least to use the computer”, which may reflect their higher socioeconomic status. Therefore, the generalisability of the results to people with a lower socioeconomic class is still unclear, which may raise a need for further research.

In spite of these limitations, the present study presented a potential model of pathways linking OSG use and QoL for those with H&N cancer. It remains to be tested in future studies and the relationships proposed explored in greater detail with other participants.

5.2 Study 2 - Part 2 (qualitative component)

5.2.1 Introduction

Searching the literature indicated that head and neck cancer is commonly cited as the most emotionally traumatic of all tumours (Dropkin, 2001) and often results in the development of a series of functional and psychosocial problems (McDonough *et al.*, 1996; Penner, 2009). There are a growing number of OSGs available for different health conditions including cancer (Eysenbach *et al.*, 2004). The previous studies in this thesis suggested that there were several OSGs available for H&N cancer (see Appendices 3 and 9). From these studies, it was understood that H&N cancer OSGs were used frequently by some people, from many different countries; sometimes both patients and carers used the OSGs. Importantly, many types of social support were being sought and offered within these OSGs – for example, informational, emotional, esteem, social network and tangible support. It also was understood that longer use of OSGs was related to better QoL and this relationship was mediated directly by depression and adjustment and indirectly by anxiety, self-efficacy and empowerment.

The previous two studies in this thesis have described aspects of the experience of people with H&N cancer using OSGs, both of the studies used pre-existing measures or frameworks. To date, there have been no studies that have explored, in depth, OSGs user's experiences and gave participants the opportunity to talk about their experiences with cancer and OSGs in a detailed and unrestricted manner.

5.2.2 Aim

The aim of this study was to explore, in depth, the OSG experiences of people with H&N cancer

5.2.3 Objectives

The objectives of this part of study 2 were to

- explore, in depth, people's experiences of using OSGs for H&N cancer

- analyse the data using a narrative thematic experience analysis to identify the emergent themes

5.2.4 Strategic choices for method

The most commonly used method of data collection in qualitative research is interviewing (Creswell, 2007). Time and financial restrictions, geographical constraints, and medical condition boundaries of the research participants are often cited as obstacles for traditional face-to-face interviews (Cater, 2011). Recently, with the technological development of the Internet, the experience of online interviewing in qualitative inquiry has been developed and the problems related to face-to-face interviews have been somewhat reduced (Hooley *et al.*, 2012). Cyberspace has been viewed as a useful way of creating an interview venue (Kennedy, 2000), and the majority of work has been conducted using asynchronous or non ‘real time’ interviewing (Gaiser 1997) with more recent studies arguing in favour of the benefits of ‘real time’ online interviews (Chen and Hinton 1999; Davis *et al.*, 2004; Opdenakker 2006; Kazmer and Xie 2008; Hinchcliff and Gavin 2009). Online interviews are now utilised for Internet-mediated research to collect original data through the Internet in order to analyse them and provide new evidence related to a particular research question (Hewson, 2010). This type of interview can be conducted without the expense and time of travel (Salmons, 2010). With this method, it is possible to have an increased pool of participants, including geographically distributed, disabled, or socially isolated people (Mann and Stewart, 2003; Ahern, 2005; Connor, 2006; Bowker and Tuffin, 2007). Its appropriateness has also been claimed for when participants cannot easily access face-to-face settings such as a closed workplace or hospital where focus groups, interviews, or even support groups may occur (Salmons, 2010). Online participants may possibly be more relaxed in the comfort of their familiar surroundings, not have to deal with interpersonal communication in face-to-face transactions and therefore more willing to discuss sensitive issues, such as disorders or emotions that may be harder to disclose in person (Cabiria, 2008; Hunt and McHale, 2007; Mann and Stewart, 2003). Participants who speak different languages or who have difficulties with spoken language can also participate more easily (Salmons, 2010).

Some researchers (James and Busher, 2006; Seymour, 2001) claim that online interviews can develop greater mutuality, disclosure and reciprocity between the participants and the researcher. Online interviews might be more appropriate compared to face-to face interviews which might be influenced by other interpersonal issues associated with gender, age, class, ethnicity, prestige and standards of ability because these distinctions are less overt in the online environment (Seymour, 2001).

Yet, using online interviews can have some drawbacks, for example, some researchers have suggested that establishing an online relationship between the interviewer and interviewee is difficult or can be impossible (Fontana and Frey, 2003). This is because they feel that researchers need to be able to observe the research setting and the interviewee which is all a part of the interview environment and derived from ethnographic approaches to research. Other researchers propose that verbal and non-verbal communication is essential to interviews, only available with face-to face interviews and that it is only possible to detect distress and provide comfort in this type of environment (Salmons, 2010).

In this study, the type of online interview was one-on-one and could be established synchronously (real-time) and asynchronously (non-real-time). Asynchronous online interviewing is usually performed through bulletin boards, emails, and discussion groups (Salmons, 2010; Hooley *et al.*, 2012) while text-based instant messenger protocols, chat rooms, and video conferencing are the most commonly used methods for synchronous approaches (Stewart and Williams, 2005; Stieger and Gortiz, 2006).

The online interview used narrative methods (Reissman, 2008). Narrative is both a method and phenomenon of research (Connelly and Clandinin, 1990). There are no preset questions and instead an aide memoire is used to guide the researcher and keep them focused (Mishler, 1986). Narrative interviewing is different to the stimulus/response model using preset questions which are frequently used in qualitative research and instead becomes a space where participant and interviewer work together to create meaning around events (Reissman, 2008). Part of the method involves clarification and probing parts of stories in depth and this helps a participant's complete narrative to develop. The method also allows for the participant's voices to emerge.

5.2.5 Method

5.2.5.1 Study design

Qualitative study using narrative thematic experience analysis to facilitate online interviewing

5.2.5.2 Sampling

A convenience sample of 30 men and women self-selected from participants who participated in the quantitative online questionnaire (see section 5.1) and agreed to be contacted to discuss their experiences in more depth in an online interview. The sample is not intended to be representative of the wider population of people with head and neck cancer. It does, however, constitute a sample that is fit for the purposes of this study.

Thirty participants formed the sample. When contacted some participants had changed their mind, and so the process consisted of working through the questionnaires and contacting people until self-selecting willing participants were identified. Sampling continued until the data captured were considered to have produced a range of experiences whereby there were enough similarities and differences produced to claim saturation and when emergent themes became repetitive (O'Reilly and Parker, 2013).

5.2.5.3 Sample characteristics

A convenience sample of thirty participants who indicated their willingness, were selected from participants who participated in the quantitative questionnaire. The age of the participants ranged from 41 – 76 years, and they originated from the UK, Australia, Canada, France and the USA (Table 68). Participants were computer literate either using the computer for work, or for home use for shopping, organising the home finances, or online social networking.

Gender	Number (n)	Age range	Country	Yahoo messenger	MSN	Email	Face-book	Skype
Male	14	50- 76	UK =2 USA= 12	1	-	3	9	1
Female	16	41- 67	Australia = 2 Canada = 1 France = 1 UK= 3 USA= 9	1	1	3	9	2
Total	30	41 - 76		2	1	6	18	3

Table 68: Sample characteristics of the qualitative component

5.2.5.4 Types of technology used as research tools

This small-scale study used synchronous online and asynchronous interviewing and a variety of tools such as MSN, Facebook, yahoo messenger, Skype or email to conduct the interviews. Synchronous online interviewing used the chat technology through MSN, Facebook or Yahoo messenger and asynchronous used email, although the emailing followed a synchronous pattern because it was direct response rather than a considerable time lag. The aide memoir used for the interviews can be seen in Appendix 25.

Facebook

Facebook is an online popular free social networking service that allows registered users to create profiles, upload photos and video, send messages and keep in touch with friends, family and colleagues (Eldon, 2008; Ryun, 2010). This site was founded in February 2004 (Carlson, 2010) and is available in many different languages.

It allows anyone who aged 13 years or above to become a registered member of the website (Face book, 2013). Facebook includes some public features that allow users to read, post, and respond to classified advertisements, and enables users who have common interests to find each other and interact in cyberspace. Users can also create a public page around a specific subject, although in this study a separate page around H&N cancer was not created specifically (Ryun, 2010; Fowler, 2012). Face book has been ranked as the most used social networking website by monthly users worldwide (Kazeniak, 2009).

Facebook provides a range of privacy options to its members. Such as private communication, visibility, and being searchable (Rouse, 2009). The majority of people taking part in the qualitative section of this study chose Facebook as the preferred medium of interaction.

Skype

Skype is a free communication service offers instant messaging and voice conversation to client. The name was derived from "sky" and "peer", and is developed by the Microsoft Skype Division (Tanavsuu, 2013). This service was first launched in August 2003 (Andreas, 2008) and by of the end of 2010 had 663 million registered users (Telecompaper, 2011).

Users of this service can speak with each other through a microphone, see each other through a webcam or just chat through instant messaging over the Internet; all these services are free of charge. In addition, Skype also allows phone calls to mobile phones or landlines, but this service is not free. Skype has additional characteristics such as videoconferencing and file transfer (Linton, 2011).

Registered users of Skype are identified by a unique Skype Name, and there is a list of expressive emotions from which users can choose during chat communications (Skype, 2009). For this study chat through instant messaging was used.

Yahoo messenger

Yahoo Messenger was originally released under the name Yahoo Pager on March 9, 1998 (Internet archive, 2010). It is an advertisement-supported instant messaging client and associated protocol provided by Yahoo.

Similar to Skype, yahoo messenger offers free voice and video calls, file transfers, instant messaging service and can be downloaded from internet free of charge. Also registered users should have "Yahoo ID" which also allows access to other Yahoo services, such as Yahoo Mail (yahoo, 2008). The instant messaging service was used for this study.

MSN

MSN (derived from The Microsoft Network) is a group of Internet services and sites provided by Microsoft. This range of services has changed since its initial release in 1995. MSN was primarily a popular Internet portal (Nations, 2012).

In the late 1990s, numerous popular web-based services had been promoted to become a part of MSN, most notably Hotmail and Messenger service, and these have subsequently reorganised again in 2005 (Alexa, 2009). Only one person chose MSN but it is important to note that it was still a useful medium of interaction.

MSN Messenger

In 1999, MSN released an instant messaging service “Initially known as 'MSN Messenger Service’” The underlying technology later called as the 'Microsoft Messenger service', while the main program used to access the service became known as Windows Live Messenger. Nevertheless, the term 'MSN' has come to be synonymous with the service in Internet slang (Microsoft, 1999). Windows Live Messenger has similar features to that available in Skype and yahoo messenger such as voice and video calls as well as instant messaging service and registered members employ a unique name to use the service.

5.2.5.5 Conduct of interviews

Three participants did not use any software or any similar software that facilitated conversation in the same way as other software tools. These interviews were conducted through emails in which the interviewer emailed a question and the interviewee emailed the answer back and so on; both parties were online at the same time.

The majority of the interviews took from 30 – 60 minutes. Three interviews took from 2-3 hours; one was due to the internet/computer crashing, the second was due to the typing skills of the interviewee and the third was due to the extensive responses of the interviewee, although not all responses focused on responding to the question and veered wildly off track, this was a limitation of using cyberspace.

The procedure for using the text-based online chats was conducted in rounds; after some introductory words (thanking the respondent for participation in the interview, introducing oneself repeating the aims of the study, the option to terminate at any time without question, assuring anonymity, and regaining consent) the interviewer started the online interview by typing the first question in a small text box of the chat software. By clicking a “send button”, the question was immediately sent to the interviewee who can read the question in a larger text box. The interviewee then sent a reply to the interviewer in the same method.

5.2.5.6 Method Strength

As the flow of conversation is broken into text “chunks” with a time-lag between questions and replies, online interviews conducted in this way may appear more structured and ordered than traditional face-to-face interviews (Chen and Hinton, 1999). The interview transcript is automatically generated by the online chat software, which enabled quicker analysis of data because the interviewer did not have to spend time transcribing. Another advantage of this method is that participants can chat in an environment in which they feel most comfortable; it may be less stressful because there is a ‘virtual’ person to talk to, it is anonymous and faceless and so the participants cannot be influenced by the interviewer’s face, body language, or vocal cues. This aims at reducing interviewer/interviewee bias (Duffy *et al.*, 2005). For many people with H&N cancer, there is also the issue of being able to verbalise clearly and articulate words. Using the chat software enabled them to ‘talk’ without having to physically verbalise their words; this was undoubtedly a benefit. Another benefit was that the interviewer did not have to consider the geographical distance and could interview participants in Australia, Canada, America, and France, as well as different areas of the UK, and it was a cheap way of interviewing without the expense and time of travelling.

5.2.5.7 Method limitations

Although there were obvious benefits, there were also limitations of this type of interviewing for example; sometimes the interview took longer than normal either due to the computer and/or internet crashing, typing skills of the participants, or

distractions in the home. Other pitfalls of this type of communication can be the absence of social cues, lack of facial expressions and verbal communication together with other body responses which make it easier to interpret meaning (Opdenakker, 2006). Some researchers propose that verbal and non-verbal communication essential to interviews is only available with face-to face interviews and that it is only possible to detect distress and provide comfort in this type of environment (Salmons, 2010). Others have suggested that establishing an online relationship between the interviewer and interviewee is difficult or can be impossible (Fontana and Frey, 2003). Although all the used tools give the opportunity to create some advanced emoticons that can be put straight into a message, these emoticons have been culturally constructed and can only reflect culturally specific meanings (Morris, 1994). In addition, geographic variations associated with time disparity led the interviewer to conduct some interviews out of regular working hours, for example some interviews were conducted between the hours of 11pm and 7 am.

5.2.5.8 Analysis

The original aim of using the type of questioning was to code sequences of attributes, consequences and values (the ladders) to make comparisons across participants. The researcher aimed to use the decision-support software program LADDERMAP (Gengler and Reynolds, 1993) to insert up to ten chunks of meaning per ladder with the classification of each phrase as a consequence, attribute, or value, then identify and group meaningful categories. Problems arose with the LADDERMAP software, which was not compatible with Windows 7 and would only work with Windows 98. Gaining access to a computer with Windows 98 proved extremely difficult and the software had not been updated. Researchers were contacted who had used the software and moved on to other similar types; they explained that the site licenses for similar types of software were excessive and not practical for one small-scale study.

A method of analysis was needed which was not tied to any particular theoretical framework therefore, a narrative thematic experience analysis was conducted on the emergent data (Braun and Clarke, 2006; Riessman, 2008, Bold, 2012). This was in contrast to a deductive thematic analysis because it was 'bottom up' or driven by the data rather than 'top down' or driven from the original research question. A narrative

thematic experience analysis is more flexible and allows for a broader analysis rather than concentrating on a discrete area. Transcripts were read and re-read in order to identify the underlying narratives (Sparkes, 2005).

Although narrative is not a new concept and has been around since the time of Aristotle and Greek tragedy plays, it is now considered to be both a method and phenomenon, having been adapted from the arts over time for use in the social and behavioural sciences and health. The diversity in its development means that it exists on a continuum; at one end stands the work of Labov and Waletzky (1967) which is a more structuralist approach and reliant on social linguistics with a definite beginning, middle and end. At the other end is a more social anthropological and historical approach with authors such as Studs Terkel who won the Pulitzer Prize for ordinary American people's narrative recollections of the Great Depression; 'Hard Times; An Oral History of the Great Depression'. The power of Terkel's work is that he managed to include a selection of rich narratives from across the socioeconomic spectrum, from young to old, poor to rich and the ways that they survived. Other work in this genre is Tony Parker's 'Life After Life: Interviews with 12 Murderers', derived from interviews with 12 people serving life in the UK. Parker concentrates on presenting the 12 chapters as monologues, giving the narratives quality and depth. In the middle of this continuum sits a variety of work from sociology and social psychology which are not only about narratives of life but about the way they interact with life (Reissman, 2008, Daiute 2014). My work sits firmly in the middle of the continuum. Narrative in this study is not a set of features similar to Labov's work, neither is it solely about life similar to Terkel and Parker's works. Instead it is about the interactions of expressions, emotions and contexts and the complex ways in which relationships and their stated and implied meanings between people become prominent.

During analysis, the narratives were kept intact for interpretation. The aim here was twofold; to inductively analyse the narratives as a whole and identify the themes and concepts firmly embedded within them (Holstein and Gubrium, 2012). This means that the theme arises is constituted for each participant in their narrative rather than through the usual process of analysis which disembeds the themes and treats them as

equal across participants (Riessman, 2008, Holstein and Gubrium, 2012). For example, if we look at 2 contrasting narratives of Terry and Claire:

Terry: *“I first came to the online group three years post treatment because another member who I knew and trusted recommended I join. I was lonely because I was on my own and the treatment centre was 200km from where I lived. I was going through treatment with virtual strangers. If I hadn’t found the group I would have had an empty space inside me. I joined two groups at the same time but stuck with one because it was more active. I think the activity is important because there is more support for those who need it. There is more information shared. Even to just read the posts it is reassuring for people to know they are not the only one thinking or feeling a certain way, or perhaps experiencing some difficulties (as head and neck patients do). I think I felt relieved after joining because it goes back to not feeling alone...being able to share and knowing that you are not the only one who found the treatment hard, or found the recovery difficult. Or even living with the side effects difficult. Not that you want people to feel these things; just that we need validation of our own feelings and everyone needs that in life. Of course, in giving, we receive. So by me frequently using the groups and giving I am receiving. Just knowing that I have possibly helped to take the edge off someone else makes me feel good.”*

Terry’s narrative is about the loneliness he feels, partly because of his geographical isolation and partly because he did not know anyone with his type of cancer. The metaphor of the empty space inside him if he had not found the group gives us a keen sense of his isolation. The need to share experiences and information was apparent, as was the level of altruism he displayed by frequently using the groups and giving although he admits that through giving he also receives. The key theme that is embedded in Terry’s narrative is altruism which is driven by his loneliness and his feeling that in giving he is also receiving.

Claire: *“I had been through treatment when I found the group by Googling. I joined this group because it was the only one that I found, although I do*

feel like a bit of an outsider. Most of the people are from the USA and have had Chemotherapy. I was lucky to miss that. I was curious to see if anyone had the same cancer as me and how they had dealt with the after effects of radiotherapy. In the early days it was helpful to find answers to annoying side effects; the dry mouth, poor appetite and sore jaw joints. Now I'm used to the new normal and am happy as someone who has passed the 5 year point because it means that I am well. My family were very supportive but wanted to put the whole thing out of sight after my treatment had finished and I didn't want to upset them any more. Now I check the site most days because I have a lot of free time, although I don't feel my participation adds anything. An online support group makes you feel supported and you can get information about symptoms and general advice without it being too invasive. You can dip in when you want to and hear about others journey through this horrible illness."

Like Terry, Claire had also been through treatment before she found the online group. Her motivation for joining was very different from Terry's and she did not discuss the same level of isolation because she had a supportive family network. Post-treatment, she still felt the need to discuss her cancer journey with others whom she identified with which has echoes of Terry's need to share with others. However, her need was more about sharing particular experiences of the side effects of radiotherapy and she did not feel the need for the same level of involvement as Terry with the group. The key theme that is embedded in Claire's narrative is the transactional nature of trust which she places in the information and advice that others give as being accurate and relevant.

These two narratives exhibit similarities and differences even though these two people are post-treatment and their social environments are different, they each felt the need to relate to others, for different reasons and in different ways. The narratives of all participants were considered in this way and this was how the main thread that ran through the majority of the narratives was arrived at.

Table 69 below shows the initial emotions, behaviours and feelings that emerged from the narratives at the beginning of the analysis.

Initial Feelings	Behaviours	Relationships	Wants
Uncertainty	Help/develop ability to help	Friendship	Wanting/not wanting medical professionals involvement
Fear	Giving and receiving Encouragement	Family/ big/close	
Hope	Giving and receiving Support	Comradeship	
Loneliness	Giving and receiving Advice	Band of brothers	
Anxiety	Giving back, paying forwards	Part of something	
Love	Giving and receiving Knowledge		
Despair	Sharing stories and experiences		
Isolation	Giving and receiving Empathy		
Relief	Ways of coping with new reality		
Normal/ being normal	Lurking/participating		
Reassurance	Identifying with others		
Feeling secure/safe			
Cynicism			
Mistrust			
Encouragement			
Vulnerable			

Table 69: Initial table of emotions, feelings and behaviours that became important in the data

This table is important because it highlights the range of emotions and behaviours that run through the narratives, but they only make sense when they are embedded within the narratives themselves. I was guided by my supervisors to consider that the OSGs

provided a platform for a form of relationship to be developed between participants. This emerged from the narrative descriptions of relationships between participants in the OSGs which were often termed as family, implying extremely close relationships. I was encouraged to think about relationships in terms of interpersonal transactions and after much discussion and reading around the area, the main theme from all the narratives that arose was that of trust. I arrived at trust by further close reading of the narratives and sequentially organising them as Reissman (2008) suggests and as I have demonstrated in the results section.

When I returned to the original research and thought about the individual themes that had previously been discussed in Study 1 (Chapter 4); informational, emotional, esteem, social network and tangible support, it appeared that they were all embedded in the narratives this particular component of the study. After discussing the narratives in more detail with my supervisors it became apparent that there was more depth to what people had been describing and I read further around the formation of interpersonal relationships, both face-to-face and online.

Work in social psychology, sociology and management studies all discussed the complexity of social relationships but the work of Nikolas Luhmann (1988) was instrumental in guiding my thinking. Luhmann discusses the situation of risk and that an individual can avoid risk if they are also willing to waive the advantages of engaging in a situation. The process of taking a risk engenders trust to develop; in choosing an action where there is a level of uncertainty, but where we also have expectations around the outcome of our actions, means we are engaging in trusting behaviour. Luhmann also equates trust with a reduction in complexity and uncertainty which enables people to cope in situations of uncertainty and complexity (Luhmann 1979). I then reflected back to the initial narratives exhibiting the uncertainty that people felt on first encountering the OSGs and reasons they offered which all had an element of risk attached, I then related this to trust and distrust.

Luhmann also suggests how individuals can have trust in institutions or institutional trust. In the field of medicine, workers may be said to be working within an institution because it has its own set of rules and regulations. Institutional trust can also be linked with individual trust of its members because it is difficult to separate one from the

other. I originally used the term professionalisation to describe why people used OSGs because there was a medical professional present, but after reading Luhmann I decided to use 'institutional trust'. This was mainly because participants did not know the medical professional but the status of being a medical professional gave OSGs credibility in the eyes of 7 participants.

There is little conceptual clarity around the meaning of trust, but it is argued that if the term is treated as a set of transdisciplinary concepts rather than an unitary concept then it becomes easier to define (Kee and Knox 1970, Mayer *et al.*, 1995). Within the occupational psychology literature, different forms of trust are often discussed and a typology of trust has been developed (McKnight and Chervany, 2001). In McKnight and Chervany's typology, trust is developed over time and involves acts such as information sharing and altruism; beliefs about the benevolence of the other party to tell the truth and to be honest, to care and act in the interest of the other and that they are willing to help. The notion of sharing is about exposing yourself through divulging personal information which is apparent in OSGs (Putnam, 2000). There is also the sub construct of relational trust developed by Lewicki *et al.* (2006) where repeated interactions over time reinforce the idea that the people dealt with are credible, reliable and dependable, producing positive expectations and this is where emotion enters the relationship. These factors develop and maintain bonds between specific others. Identification-based trust is also described by Lewicki and Bunker (1995, 1996) and Lewicki *et al.* (1998) and this is where mutual understanding occurs around a particular area or situation of relevance to both parties and is only available through experience.

Other research outlines the stages of building trust in OSGs which exist on a continuum from thin trust to thick trust (Radin 2006). Radin discusses thin trust which promotes de-lurking arising from welcome posts and helpful messages; this evolves into greater trust through self-disclosure and openness and sometimes off-line communication; thick trust develops from OSG users initiating or supporting projects, for example fund-raising or virtual support campaigns for members. All these aspects were present in the narratives of participants in my study. Various elements combined have also been suggested for developing trust; reciprocity, moral obligation,

familiarity, trustworthiness all leading towards creating a sense of community (Miszta 1996).

The reading about interpersonal relationships and how various acts transformed the relationship and allowed or enabled trust to develop gave me greater insight as to what I was exploring and this was how the overarching theme of trust was firmly embedded in all the narratives I read. This gave more depth and originality to the study, rather than repeating findings from previous studies and developed an area that has not been explored in any great depth in relation to OSGs.

5.2.5.9 Triangulation

Triangulation refers to using more than one method to investigate a research question so as to enhance confidence in the ensuing results (Bryman, 2003). It has also been described as "the combination of methodologies in the study of the same phenomenon" (Denzin 1978, p.291). Denzin (1978) argues that the advantages of using triangulation are that it may also capture a more complete and contextual portrayal of the area being studied. It may also uncover some unique factor about the area which may have been overlooked using single methods. Qualitative methods, in particular, enable more depth to emerge and suggest conclusions which other methods may not be able to access. Triangulation may be used not only to examine the same phenomenon from multiple perspectives but also to enrich our understanding by allowing for new or greater depth to emerge from existing dimensions.

Furthermore, Denzin (1970) draws a distinction between within-method triangulation and between-method (or across) triangulation. Within method triangulation uses varieties of the same method to investigate a research area. Between-method triangulation uses contrasting methods and sometimes research paradigms to investigate an area. This study used between-method triangulation.

Triangulation can occur in four forms (Denzin 1970); it can occur if the data has been collected through several sampling strategies (data triangulation), being collected and interpreted by more than one researcher (investigator triangulation), interpreted by more than one theoretical position (theoretical triangulation) or collected using more

than one method (methodological triangulation). Methodological triangulation is considered as the most common strategy employed in studies and this study also used methodological triangulation.

Triangulation is not without its critics and it has often been accused by constructivists of subscribing to naïve realism because there is more than one account of the social world, and the issue of comparing different sets of data from different paradigms appears problematic because to compare hints that somehow there is equivalence in their capacity to address a research question (Bryman 2012).

This position is reinforced by another form of triangulation proposed by Cicourel (1974) this is 'indefinite triangulation'. Indefinite triangulation aims towards 'generating divergent interpretations, rather than for checking the validity of inferences from data' (Hammersley 2008, p.24).

The main thesis was titled as "Exploring the experiences of individuals with head and neck cancer using online support groups" and had three main aims; the first aim was to assess the types of social support, sought and offered, within online support groups for H&N cancer, and this was investigated in the content analysis study. The second aim was to examine the relationship between using OSGs and QoL and examine the psychosocial factors that may influence this relationship, and this was investigated in the quantitative study. The third aim was to explore, in depth, the OSG experiences of people with H&N cancer.

We could claim that for this study, methodological triangulation cannot be applied perfectly with the qualitative research. However, the 5 dimensions of the empowerment process were present in the initial rough ideas; exchanging life experiences, emotional support, identification, sharing and coping. Time and length of membership were also validated because using OSGs for a longer time did offer greater QoL, but the qualitative study emphasised that it was the quality of the relationship that was an important factor in increased QoL. The quality of the relationship in this study appeared to be enhanced by different aspects of trust, which added another dimension and more depth. Likewise, depression was mediated by empowerment and adjustment in the quantitative study. In the qualitative study,

empowerment was present in the ways that people were enabled to cope with their new ‘normality’ and fight rather than just passively accept their diagnosis. We could claim that to some extent this supported the first part of the study but that a more complete view of participants in OSGs was offered by the qualitative dimension of the study, rather than calling it a divergent interpretation. Even though the quantitative and qualitative approaches appeared initially incommensurate they were in fact complimentary and captured different aspects of the same phenomena, similar to the arguments around mixing qualitative and quantitative methods by Sale *et al.* (2002). The different methods within this study have perhaps given the area under exploration more depth. Triangulation has involved both methodological and divergent forms and reinforced the description by Erzberger and Kelle “[...] *Empirical research results obtained with different methods are like the pieces of a jigsaw puzzle that provide a full image of a certain object if put together in the correct way*” (Erzberger and Kelle 2003:461).

5.2.5.10 Reflexivity

Reflexivity involves reflecting on the ways in which the research process and the researcher may impact on collection, analysis and interpretation of the data (Pope and Mays, 2006). A reflexive attitude was adopted in this study including consideration of power imbalance, language use, research settings and data analysis.

Power imbalance

I am a dentist with basic knowledge about H&N cancer and have conducted previous studies about OSGs, one of them related to H&N cancer. I was therefore concerned about a power imbalance resulting in response bias. I was guided by existing studies in order to minimise any potential bias from this source (Thomas, 2010)

- Ensuring that the interviewee is relaxed and free from anxiety prior to commencing the interview. To ensure this, participants were allowed to choose the time and the method of online interviewing and the process was kept as informal as possible.
- Assuring the interviewee that the interview would be completely confidential and their true identity would only be known to the interviewer.
- Striving to analyse and report the research in an open and honest way so as to be an accurate reflection of the data.

I tried to interject as little as possible and used probes and clarification to invite additional storytelling in order to try and minimise researcher power.

Language use

I tried to make every effort to avoid using dental language and terminology. Since participants were from different places in the world and with different socioeconomic statuses, languages that reflect cultural or socioeconomic background were avoided to reduce the possibility of misunderstanding as much as possible. The meanings of the words or phrases were also clarified with participants when necessary.

Research setting

All interviews took place online and the participants were given the freedom to choose a convenient time and method of the online interviewing. The majority of the participants (60%) chose Facebook, 20% chose direct response through email (synchronous pattern), 10% chose Skype, 6.6% chose Yahoo messenger and 3.3% chose MSN as a tool of interviewing. The flexibility of choosing a suitable time for the interview led me to conduct some interviews out of regular working hours and some interviews were conducted between the hours of 11pm and 7 am. There was a potential problem with the confidentiality when the interviewee was distracted in the home by family members, in order to avoid this situation I paused the interview and waited until it either became more convenient to talk, or postponed the rest of the interview if it was required. It was hoped that using an online interview at a convenient time for participants would put them at an ease.

Data analysis

Although the aim of this study was to explore, in depth, the OSG experiences of people with H&N cancer, I was aware that the results represented my inductive interpretation. However, the interpretation did represent the voices of people with head and neck cancer who have so far remained virtually absent from oral health and cancer research. My background as a dentist and experience with the OSGs and H&N cancer in other studies may have influenced the ways in which I interpreted the data. It is because of this that the analysis and interpretation of the data were discussed with and checked by supervisors with differing academic backgrounds and I was encouraged to read literature from contrasting disciplines in order to develop a

multiplicity of different insights around the data. It was hoped that these actions would mitigate the influence of my background and previous experience.

5.2.5.11 Ethics

As in the quantitative part of the study ethical approval was sought from University of Sheffield Research Ethics Committee (UREC) (Appendix 16) and the project followed the ethical guidelines of the British Psychological Society (2013), including informed consent, confidentiality and the right to withdraw (See Table 20, Section 3.3).

All participants were given a pseudonym to protect their identity which was only known to the researcher, and all data were kept on a password protected computer but it was also anonymised on the computer as a further precaution. Identifying email addresses were removed.

Participants were given the option to terminate the interview at any point without explanation and withdraw, even after they had been interviewed. Although the research was designed to involve minimal risk, there was the potential for the reflective process of the interview to create distress about H&N cancer. I felt I enabled participants to disclose issues with which they felt most comfortable, and a process of informal chat at the end of the interview was used to ensure the participant did not feel distressed. I left my email address with the participant should there be any further questions about the study, or their participation.

5.2.6 Results

5.2.6.1 Trust

Online social relationships have previously been found to provide camaraderie and social support, as well as building and maintaining social ties (Butler *et al.*, 2007). Social relationships have also been found to create trust and increase credibility of group information exchange (Sproull and Faraj, 1997). Indeed, trust has increasingly become viewed as important for managing online relationships (Hossain and Wigand, 2004). Trust appears to be an important variable in all forms of social relationships and arises in and through social networks that infuse in people the ‘social virtues’ of reciprocity, honesty, obligation, reliability and altruism (Hearn 1997:97; Fukuyama, 1995:43). Trenholm and Jensen (2000) suggest that trusting relationships develop in stages; initially there are perceptions of similarity and this is where people first identify with each other, then reciprocal acts such as self-disclosure promotes greater understanding and deeper levels of trust, then people get to know more about each other through various shared or compared experiences.

Trust has been explored widely and defined in many ways in the literature; the best definition that was found to be suitable for use in this study is that

“[...] trust is a medium of interaction with the abstract systems which both empty day-to-day life of its traditional content. Trust here generates that ‘leap into faith’ which practical organisation demands” (Giddens 1991, p.3).

Abstract systems are a generalised term derived from the process of disembedding which lifts social relations from their local contexts and restructures or stretches them indefinitely across time and space. Abstract systems are used to denote 2 areas: symbolic tokens which are mediums of exchange that are relatively stable and interchangeable across a plurality of contexts with money being the best example. The second area is expert systems, which is simply the disembedding of social relations from their context and providing a sort of guarantee of expectations across time and space. Trust mediates these systems but is complex because you can have trust in the symbolic token of money as a method of exchange, but not necessarily trust the person

in the transaction. Another example is having trust in a doctor because they are part of the expert system of the medical profession. We trust doctors to be medically competent, to be concerned for our health and well-being and to be non-exploitative, but we often know little about them socially. Giddens argues that expert systems penetrate all aspects of social life and are not merely confined to technological expertise but can be extended to social relations and self intimacies.

For Luhmann, social trust is a stabiliser of social order because “[...] is an effective form of complexity reduction [...]”, (Luhmann, 1979, p. 8). Luhmann suggest that trust is subjective and allows an individual to take a consequential action as a result of accepting some (subjective) level of uncertainty or risk and implies a certain level of vulnerability. Social trust also mediates cooperation because it mutually enforces perceptions around reciprocity (Scott, 1999). Goffman further asserts that social life and social relations are rule governed and this enables people to attribute a sense of meaning to a situation which when defined as normal permits them to trust others who are present in that context (Goffman, 1967, 1971, 1983). Trust for Goffman is an unintended outcome of routine social life and the essential component of everyday interactions, because it enables us to cope by simplifying information and reducing complexity whilst simultaneously protecting us from the uncertainty that surrounds situations.

The narratives that participants provided emphasised the complexity of online social relationships. From the narratives, it was noticed that some participants progressed from positions of uncertainty and distrust which promoted ‘lurking’ to positions of trust through the process of identification and sharing. Other participants began with immediate participation and sharing. Overall, this process appeared to underpin the cohesiveness of the group and develop solidarity.

5.2.6.1.1 Distrust

The binary opposite of trust is distrust and the continuum from distrust to trust is embedded in some people’s narratives of their perceptions of OSGs for H&N cancer.

John: *“The day I was told ‘you have cancer’ I thought was the beginning of the end of my life and if I had not have found this group I would probably have sat in a corner and disappeared into oblivion. When I first joined, I was curious as to what happened to people who had cancer and I was and am still a reader. This is because at first I was not sure if people were genuine or just a set of idiots who wanted to see people suffer. I did feel people were real after watching the site for a few weeks because of the words, phrases and terms that they used which were quite individual but summed up the way I was and how I had felt and still do. One of the phrases that someone used was ‘we are cancer warriors’ and this just stuck in my mind. What more could I do...not sit in a corner and worry about it so I got up and started to shout about it. I felt very insignificant with the problems that other members have gone through which is why I just do the reading but I don’t feel I have anything to offer these wonderful people. I had my own support from friends away from the online group who I trust to talk to, anyone else I just tell them I was attacked by a shark. I also joined a community head and neck cancer group in the area where I live. I meet them regularly because I prefer face-to-face contact and feel you can express more.”*

John initially described himself as a ‘reader’ who posted infrequently because he felt others had greater levels of pain and that his experiences were not as important as those of others. His response also hints at a level of distrust as to the intentions of people in the OSG and a sense of guilt because other people were getting on with their lives and appeared to have far worse experiences. Even though John was in his own words a ‘reader’, he felt the online group had given him a push to fight rather than giving in and giving up. The OSGs had also enabled him to seek support in a face-to-face group for H&N cancer which he preferred because of the higher level of interpersonal interaction but the level of distrust he feels is evidenced by his lack of engagement online, compared to his interactions with the face-to-face support group.

Tammy’s narrative is similar to John’s but distrust changes to trust with her leap of faith about the group:

Tammy: *"I was first diagnosed with OC in 2005 and had many many questions. My own doctor had a terrible bedside manner and I would not go back to him if my life depended on it. When I finally found the support group (website) it was like an answer to my prayers. Initially, I was a "lurker" – I would read the posts on the forum, but did not make a post myself. I never had participated in an on-line forum before. This forum stores all conversations (years' worth) and has search capabilities, so I was able to search for answers to my questions. After a while, I felt comfortable enough to ask questions and the folks on the forum were great - willing to answer the same question over and over again. They were either patients or caregivers, and very willing to help and very compassionate...I wasn't sure what to expect of an on-line support group. Now I feel I help the 'newbies' providing answers to their questions...the same questions I had many years ago. There are many posters who have been a member of this forum for years and we've become like a family sharing both the good news and the setbacks. Any cancer is horrible but H&N or oral cancer has a number of unique problems not faced by others and unless you have walked in our shoes you don't understand the many QOL issues we face (which are often permanent). This group gets it, can offer advice or just a shoulder to cry on, they are there 24x7 and just having someone to talk to that understands my issues is reassuring (better than a psychiatrist!)"*.

The initial lack of willingness indicates a level of distrust but also uncertainty as to expectations around the OSGs. Previous research has implied that lurkers 'do not profit to the same extent as posters with regard to "enhanced social well-being"' (van Uden-Kraan *et al.*, 2008). Tammy developed over time from a 'lurker' to a regular poster and it is perhaps the length of time that people take to undergo the transition and develop a level of trust before they may experience the enhanced social well-being that van Uden-Kraan *et al.*, identify as being of importance. For Tammy, the notion of kinship through the use of the word family indicates the generative potential of trust in creating more trust through the closeness of the relations that she has formed with the group.

The narratives of these participants demonstrate that engaging with an online community such as an OSG entails risk for them because they feel they are exposing a part of themselves to faceless strangers. This may appear unusual because of the benefits of anonymity that OSGs provide, but it is also strongly linked to the initial lack of trust that individuals may have in developing this type of social relationship. A process of decision-making probably occurs where individuals weigh up the costs and benefits of engaging with OSGs and this may be more predictive of those who engage more readily compared to those who either 'lurk' or 'read'. It may also be the point at which some people choose to disengage with the group when they balance the costs of building or maintaining a relationship with the group against the costs of severing it. There is always the possibility that people who feel vulnerable because of their cancer may be exposing themselves to more psychological harm by engaging with OSGs. Conversely, there is also the possibility that their vulnerability may be reduced as a result of the support offered. Although there appear to be many benefits of OSGs, the advice for people who have conditions that increase their vulnerability might be to proceed with caution and only engage with OSGs when like Tammy, they feel comfortable enough.

5.2.6.1.2 Institutional trust and forms of knowledge

One issue that became apparent as being an important factor for joining an OSG for H&N cancer was the presence of a knowledgeable professional who was leading the group. This aspect of institutional trust was contrasted with other OSGs users who wanted to be away from a medicalised perspective and experience a more 'real world' approach to their problems.

Susie gave the input of a medical professional as an initial reason for joining an OSG:

Susie: "When I first searched for information about my type of cancer I wasn't specifically looking for a forum, more knowledge, but it was great when I found it. If I had not found the forum I would certainly have suffered from far worse depression, I may have given up, I think I would have found it harder to fight. I could see from reading the posts that there were lots of people who had been through similar to me. So I knew I would get the

understanding and the support, but also the fact it was run by a doctor. I saw some of his posts which were giving information from a medical point of view, not just from a sufferer's experience. I found them interesting and reassuring. I looked into him online and saw he was a respected expert and that made the site more serious in my eyes. I wasn't new to online forums but was desperate to get some contact with people who could understand what I was suffering. So I was really pleased and eager to start posting and reading. It gave me a lot of reassurance at a time when I felt alone and very scared. I didn't feel able to talk to my partner who had his own issues dealing with my illness. I take part in online social forums just for fun, but the cancer one was for emotional survival because I felt isolated. People are embarrassed by cancer-scared of it; 'I don't want to talk about it'. The forum was open, welcoming, not embarrassed. When you are alone in the house you feel shite, you are scared, you are exhausted, you are crying, there is no-one you can turn to: having the forum there is just wonderful. The forum offered me a sense of comradeship, made me feel not alone; it cheered me up; it informed me, helped keep me sane and helped me think of others instead of being self-obsessed. Although I have frequently been disappointed that the Drs input is not more frequent."

The credibility of medicine and the medical professional encouraged Susie to join the OSG because she saw it as being somehow more authentic and hence more trustworthy. This level of credibility and trust facilitated her postings and interactions within the OSG. She articulates the roller coaster of emotions that she feels able to express, but comes back to the fact that she routinely wants more input from the medical professional involved.

Derek's view values medicine similar to Susie but he differs in how he sees the OSG:

Derek: "I first came to this online support group through another group; I tend to trust these things without the need for verification. The group was open to non-clinical answers and humorous jibes which made me feel VERY comfortable, like I was talking to friends. The CONCEPT of the

group provides anonymity which is important when you are different from others. You don't have to speak and you can ask all the questions you want without being personally known for asking it. The PROBLEM with online groups is that few are truly 'experts' -- so the advice you get is -- if medically, may be wrong. But then few medical people really know the ins-and-outs of living a day-to-day existence of being a lary so they lack the skill set to know the little tricks that make life more comfortable - - nor do they concern themselves with problems that are social, cultural, or sociological in origin -- but other lary's do have that information -- and when you have an open on-line group -- those tips and how to deal with cultural perceptions can be passed on far easier, and with personal FIRST HAND information - and, yes, what's right for one, is wrong for another. There is a balance that the groups can offer, Kurt Vonnegut coined two terms: a Faloon and a 'grand-faloon'. A faloon is a group of people who have one small thing in common say they like the colour red or clouds. Then there is a Grand-faloon like being British or American or Indian etc, they are all illusions. An online group gives people the feeling of being in a faloon; that is the perception that we all have something in common; cancer and some of the trouble it causes us. So it's simply a faloon. We range the full spectrum of humankind and the only thing that binds us is our cancer. We don't even speak of the cultural perceptions of the thing, nor the HORRID trials of a woman who is forced now to speak with a man's voice! There are divisions within divisions yet we form this faloon to offer whatever support we can, even in ignorance to know that life can be normal, or not. That some people get cancer more than once; that some people die from stage 2 cancer. The anonymity creates the faloon; a false group of dissimilar objects".

A 'lary' is someone who has had a laryngectomy. Derek insightfully points to the issue of what you want to know as being of more importance. For example, if it is medical information then you need a qualified medical professional, but he insists that medical professionals cannot offer experiential advice and then the types of knowledge that OSG members possess becomes of greater importance. Personal first-hand information in this situation takes precedence. So reasons for engaging with

OSGs may differ for individuals and it may be that OSGs need to be set up with sections that may fulfil everyone's needs. Derek views the OSG as a faloon or a false group where the only thing people have in common is the fact they have cancer. His narrative of an OSG appears mostly functional, however, he is still engaging in social relationships evidenced by his perception that it is like talking to friends.

Karen emphasises the value of talking to others and gaining a perspective that medical professionals can sometimes fail to exhibit because they have not had the same experiences:

Karen: "I chose this group because a trusted friend recommended it. I found it useful to talk to others and get an understanding for things the doctor didn't say and things my speech therapist didn't seem to know. It was the questions that I asked the group that helped, I had also asked the speech therapist, but her advice was "it will get better", which is of very little help, but the group told me that just by lowering the base plate a few mms from the bottom of my stoma, it will not irritate so much, and reduce coughing. And it works! [...] They offer an insight and advice. They know what you have had done and what you are going through and thinking. Unless your doctor/therapist has actually had the same operation, they can't really prepare you for what is to come. Phrases such as "life changing" are tossed around by doctors, but the group is getting me through those changes. The group are not telling me that life will be all fine and rose-coloured after the operation. They are telling me the truth and how to handle it. The doctors say that they will remove this or that, and you will learn to cope. That is not really helpful; joining the group has been life changing for me".

These participants emphasise the usefulness of different forms of knowledge that enabled them to cope with the more practical day-to-day aspects of having H&N cancer. This ranged from the medicalised knowledge of the medical professional based on biomedical accounts constructed from cases; the experiential knowledge of people with head and neck cancer that focused on the practical aspects of living with the disease; person knowledge which refers to individual personal circumstances and

how an individual relates not only to their physical but also to their social environment. This further emphasises the complexity of the social relationships within the OSG.

What appears a little disconcerting is how medicalised some professionals are in relation to their profession with little idea of a patient-centred approach to treatment, and appear to be relying on a biomedical response to patients and their questions. Enabling people to cope with the everyday grind of life with H&N cancer, emphasising that things may be difficult from time to time, and giving a ‘warts and all’ account appears to develop a more trusting relationship with the OSG in comparison to the medical professionals in some cases. This is where institutional trust can possibly become thinner. This reinforces the idea that care needs to be taken with identifying what exactly an individual expects from an OSG and how best to meet their needs.

5.2.6.1.3 Identification-based and relational trust: the complexity of social relationships in OSGs

Part of building trust was through the process of sharing and comparing experiences and identifying with others who were perceived as similar. The level of mutual understanding increased through these interactions and repeated interactions over time appeared to increase positive expectations and emotions and developing the will to live and fight was often mentioned, as was the language of war with words like battle and fight regularly used in participant’s narratives.

Bob emphasises the importance of sharing and the interactions he has:

Bob: *“I first joined this group from another site when someone mentioned it. This group is more personal; it has more direct communication and interaction and is less formal. It felt right because there were others there who endured what I did and it made it appealing to join them. Sharing had an appeal. I enjoy one-on-one interaction and conversation on a variety of topics including politics so this was a natural fit for me. It also made sense for others in the same situation to talk to one another*

because even though I knew no-one when I joined, the group was a collection of people from all over the world with similar experiences and that was compelling. The people made up the group, not the other way around. I read their postings everyday and respond when I see reason to. I also post some of my own milestones and experiences because they help others understand that some of what they encounter is the same as I have and I believe adding my experiences helps others. For me, the group is a safe place to vent and to ground my thinking regarding my situation. In my case, I can see how miserable others have it compared to me so I feel more fortunate knowing that. I think this group offers emotional and material support and without it coping with this illness and the aftermath would have been tougher. None of us lives our lives alone and having support is important to mental health.”

Bob clearly articulates that the OSG is a place or space within which the relationships he has formed provide a safe environment where he trusts others to support his thinking and his venting. The notion of sharing with others, who were perceived to have similar experiences even though Bob had never met them, indicates a willingness to place his trust in others, as is feeling safe. The complexity of Bob’s relationship with this group is apparent from his narrative.

Simon’s narrative contains elements of the closeness of relationships derived from 36 years of comparing experiences with others on the OSG:

Simon: “My cancer was in 1978. As a cancer survivor I ran a business, raised a family, participated in marathons and Ironman competitions. Being a survivor gave the feeling I could help. Plus I had normal friends who encouraged me to share my experiences of a successful battle to help and inspire others. I had head and neck cancer and had lost friends to the disease, I wanted to help survivors or those undergoing treatment know what to expect. I also lost co-workers to the disease and I felt for their caretakers. I feel this group is like a band of brothers. Like military war veterans. I felt comfortable dealing with people who have had similar struggles. I now have about 70 friends online and their

caretakers and talk to them about diet, feeding and exercise. I tell them about dry mouth, burned facial skin, tooth loss and implants. I talk to individuals daily, multiple times. Although, not everything is about the patient and so many caretakers are frustrated and upset trying to take care of someone who was once robust but now in pain and can only eat baby food. I try and support them. For me, this group offers friendship and camaraderie. Many people are very nice. Many are busy bodies. Many fight amongst themselves; like a community or schoolmates. The internet allows me to sit and chatter and leave my own timetable for a few minutes or for hours. Ideas on life, not just cancer, are exchanged. Cancer isolates the person, you feel very separate from mainstream life. The support group acts as a 'placebo' to force the cancer victim to talk and socialise what they are feeling and where it may or may not lead. It offers comfort. Some will die, many won't, but physical damage is life changing and it is better mentally to know it."

Simon is a cancer survivor and with survivorship come more unique ways of living with cancer (Feuerstein 2007). Simon has developed a high level of altruistic behaviour in response to living with his cancer, even though he has been in remission for an extended period of time. His involvement is highly altruistic, his narrative emphasises the diversity and complexity of the relationships in the OSG. The extent of kinship is highlighted from phrases like 'community', 'schoolmates', 'friendship'. Kinship in this sense is more fluid than the biological notion and refers to the complex web and patterns of social relationships that exist between people who form an OSG community. The OSG becomes a vehicle for developing and organising social relationships by enabling people to explore their illness in a supportive environment.

The metaphor of war against cancer and survivorship is underlined with the terms 'band of brothers', 'military war veterans' and 'battle'. Here the use of metaphorical language bridges the gap between the technical treatment and medicalised world of cancer and the patient's experience of the disease. It clarifies and adds depth of meaning to the experience. In constructing patients as military war veterans it displays them not as victims who are passive and uninvolved but as fighters and survivors who are active and in control. It may also suggest that not winning the war (on cancer) is a

symbol of not fighting hard enough and this can leave people feeling guilty or inadequate, so care perhaps needs to be taken with metaphors. Simon also draws attention to the other aspects of living with and beyond cancer and the psychological and social aspects that may sometimes be disregarded if the focus is maintained on the 'war'.

One unusual aspect of Simon's narrative is the description of the OSG as a 'placebo' and if we consider that a placebo is something that is considered to be real but isn't and does not really have any effect on health, then the benefits of the virtual aspect of the group appears to be being questioned initially. Within the context of his narrative, what Simon appears to be saying here is that even though the OSG is a virtual group it still provides a space that facilitates and encourages social interaction through gently supporting the individual to explore their worst fears.

Building trust for these participants was apparent in the complexity of their narratives but trust occurs as a product of social relationships with other OSG participants. This reflects Goffman's (1967, 1971, 1983) work on trust as it being a necessary part of and at the same time a product of social relationships.

5.2.6.1.4 Power relationships and normalisation

Online support groups appear to offer a place that can mitigate the traditional power relationships between patients and health professionals.

Michael: *"The only support I had was the Macmillan nurse assigned to my case and the dentist I was referred to for reconstructive work suggested the online support group. Curiosity drove me to take a look and the first posting I read was a man with a persistent mouth ulcer who was afraid to see his doctor. I was recovering from ignoring a mouth ulcer which was in fact cancer and needed drastic surgery to deal with it. So I felt an obligation to encourage the man to see his doctor without delay. Since then I have made over 500 postings. I offer help and comfort to people who are at the start of their cancer journey. Many people have difficulty communicating with anyone in authority, particularly medical staff who*

they see as having authority over life and death. Often they leave the consulting room having remembered nothing of what was said (consulting room amnesia). However, they are at ease with someone on the same level as themselves, particularly someone who has experienced and survived the illness they have been diagnosed with. I personally have no difficulty communicating with people in authority and I have a very supportive wife and family. I've never felt the need to seek support. I joined the OSG for what I can give, not what I can get out of it. It gives me satisfaction knowing I have helped a fellow human being and just one thank you letter is worth all the effort I put in. One woman was convinced her husband's diagnosis was a death sentence and was very surprised that I was alive after a few years. She had earlier that day, seen her GP for advice and it was clear from our conversation that she had not comprehended what the doctor had told her (consulting room amnesia). I gave her my number and spoke to her on the phone. After our conversation she accepted that her husband had every chance of surviving and their life together would continue, albeit with difficulties over the coming months. She rang me 6 months later with profound thanks; she said I had put her mind at rest and both of them faced the difficult period because they knew what to expect and it happened as I explained. In a 20 minute phone call she went from expecting to be a widow to having hope for the future."

Although Michael had not need the OSG for support, he felt able to offer support and comfortable handing over his telephone number to a stranger. His narrative mentions consulting room amnesia twice and appears to feel quite strongly about reducing the power imbalance for others. It would appear that in this context the support group space acts as a leveller because of the sense of commonality between participants, the internet also masks social status and any other markers of class and socio-economic status. Although he insists he does not need support, the transactional nature of Michael's relationships with others displays altruism and a level of trust.

Another benefit of OSGs was the reported normalisation of people's experiences to a 'new normal' and the benefit of privacy and anonymity, particularly for individuals

with speech and facial impairments resulting from surgery and radiotherapy. One unexpected aspect that was reported was the effect of being able to socialise online when visible difference inhibited face-to-face interaction.

Sandra's narrative exhibits the benefits of online interaction:

Sandra: "I found a blog while looking up stories of people with head and neck cancer, I think it was called something like 'cancer sucks' and this led me to the forum. I joined the group because I was anxious, depressed and worried that I wasn't going to get any better. I felt alone. I needed more information about what was 'normal'. I needed to talk to people who not only shared the experience but who weren't part of my daily support system. I didn't want to bore my family and friends or use up their good will. I was lonely because I'd never heard of this kind of cancer and treatment, knew nobody with experience of it. Couldn't eat, swallow, taste, talk, dry mouth, sore throat, no energy. Felt like crap. Couldn't work or socialise. Everyone in my world was busy with their lives. After the treatment was done everybody disappeared; even the docs who I'd seen daily for months. In the beginning because I felt so isolated I needed reassurance and I was on there daily, several times a day sharing, asking, telling about my story and offering comments to others. Then I started getting to know people and it was fun to chat a little. Over time it decreased, although I still check-in several times a week. I enjoy hearing news from people who were on it from the time I arrived. If us 'old-timers' don't keep supporting the newcomers the site becomes less useful to those visiting. This offers hope that we can survive because the docs do their thing but they don't know what it is like to go through this and live with it. We do. We offer a sort of normalising experience because everybody has been through something similar. The group offers a degree of privacy and anonymity and you are not likely to meet anybody unless you choose to. There is no geographical limit and because of this the group normalises even the most difficult of experiences because somebody out there will have dealt with it in some way. Even when people cannot get out of the house because they are sick or weak or

cannot face others they can get support on their own schedule. I felt I could say things to people without being judged, they really understand.”

Sandra had acquired speech impairment as a direct result of her cancer treatment; this meant that her identity had also changed. She was once a confident and outgoing young woman, but cancer had altered this perception of self. Cyberspace had enabled her to reclaim her identity because she was not verbalising, developing a new ‘self’ through cyberspace was obviously of importance for her in the initial stages of her cancer journey and enabled her to express her identity in another format.

The issue of normalising an experience is important in Sandra’s narrative and she mentions it twice. Again, we can reflect back to Goffman’s work because when a situation is defined as normal it permits people to trust others who are present in that same context. This appears to be what is occurring in the OSGs. The participants are normalising the experiences of others through identification, comparison and sharing experiences with one another.

Summary

Trust was an embedded theme that emerged after reading the narratives as a whole, organising them sequentially and then reading the associated academic literature. The degree of trust appeared to develop through continuous online interactions which developed relational trust through identification, sharing and feelings of kinship denoted by the terms ‘family’, ‘community’, ‘friendship’ and ‘schoolmates’. The generative potential of trust in developing more trust during the repeated interactions was apparent in some narratives. Trusting relationships also appeared to foster transformations in how people considered cancer and developed coping strategies, creating a more positive perception of their cancer journeys.

What was unknown in this part of the study was the degree of trust people had in the website and whether it was in any way related to information and communication technology (ICT) ability and familiarity with online systems or whether it was merely the process of building a relationship with people in cyberspace. What was also unknown was the degree to which individual differences (the propensity to trust) may

facilitate online relationships in OSGs and to what extent trust was a phenomenon of the OSG, or something that generally exists in the world. This is an area worthy of further exploration. Furthermore, there is little research around cross-cultural understandings of trust and whether there is a difference across cultures; this may be yet another area for exploration.

The OSG for the participants in this study is a third place, the first place is physical, the second place is virtual and the third place is a networked place that can be accessed by remote users either synchronously or asynchronously. This shared electronic or virtual third place extends the notion of the real and the virtual; it is a hybrid space that enables remote participants to engage in social relations with one another through sharing, comparing and identifying. Ray Oldenburg would call a third place an anchor of community life because it facilitates and develops broader interaction (Oldenburg, 2000) he proposes that a third place has eight similar characteristics. Although Oldenburg was discussing the physical realm when suggested the concept of a third place, his concept fits very neatly with OSGs and the following characteristics of OSGs have been adapted from his suggestions:

- i. Neutral ground because members have no obligation to be there and can come and go at will
- ii. A leveller because social and economic status do not matter and there is a sense of commonality amongst participants
- iii. Social interaction is the main activity through some form of communicative exchange
- iv. Accessibility and accommodation are essential in that everyone can access the space, feels welcome there and has their wants and needs met
- v. Regulars create the interactions between existing members and welcome new members
- vi. Inclusive and welcomes people from all of life's different strata, it does not emphasise or highlight difference
- vii. It is somewhere to feel safe, like a home where you can let off steam and feel supported by the unconditional positive regard of members
- viii. Respectful; treats people with dignity, is never hostile towards them and normalises people's experiences

Of course, it could be suggested that an OSG may create a somewhat hollow effect because people do not know one another initially; they may never meet in the physical world and only ever interact virtually. This reflects back to Derek's narrative of the OSG being a faloon. In contrast to Derek's narrative, some of the participant's narratives in this study indicate that they have varying needs and relationships are being formed, some of which are extremely complex and illustrate high levels of trust and reciprocity. We could therefore adapt and use Oldenburg's concepts to consider and evaluate the role and contribution of OSGs for people with head and neck cancer. The benefit of OSGs as a third place of social interaction for people with head and neck cancer could be further explored qualitatively around some key areas:

- Generating trust
- Supporting and developing social relationships
- Promoting a sense of belonging
- Reducing loneliness and isolation
- Enabling people with head and neck cancer to feel part of something bigger than themselves and regain a sense of purpose for some

This small scale study has given us a great deal of insight regarding the social relationships that people engage in online. Further research around Oldenburg's concept of third place and the importance of trust in social relationships could form part of a larger study.

5.2.7 Discussion

This study is the third part of this thesis. This first study was a content analysis aimed at increasing our understanding of what types of social support are available within OSGs for H&N cancer, it showed that H&N cancer OSGs were used frequently by some people, from many different countries; sometimes both patients and carers used the OSGs. Importantly, many types of social support were being sought and offered within these OSGs – for example, informational, emotional, esteem, social network and tangible support. The second study examined the relationship between the use of these OSGs and other key factors which have been shown, in the literature, to mitigate or aggravate the impact of cancer on psychological wellbeing and QoL, and suggested that longer use of OSGs was related to better QoL and this relationship was mediated directly by depression and adjustment and indirectly by anxiety, self-efficacy and empowerment.

Whilst these two parts of the thesis enabled a greater understanding of social support available within OSGs and the relationship between using OSGs and key factors, nevertheless, it was felt that there were a number of limitations of using content analysis of the existing messages or using pre-existing questionnaires (see Section 4.7.4 and Section 5.1.7.3). For example the content analysis was based on the SBSS with a priori framework (deductive in nature) and the results focussed on these specific aspects of the data that were determined prior to data analysis. Some of the data could not be coded by that framework, which led the researcher to make an inductive analysis and add some items to the framework. In addition, using a quantitative method appeared to be insufficient to understand some forms of information such as changes of behaviour, emotions or feelings because it requests a limited amount of information without providing a deeper explanation (Popper, 2005).

Thus, alongside the quantitative study, a small-scale companion qualitative study was carried out using narrative methods and unstructured interviews with participants who had responded to the questionnaires. This study was conducted to satisfy the third aim of the thesis which was to explore, in more depth, the OSG experiences of people with H&N cancer. These interviews gave a more comprehensive view of the area under exploration and greater details about the benefit of using OSGs that could not be

achieved from the previous two studies and of the phenomena. It also allowed the ability to interact with the users of OSGs on their own terms and give them voice as they provided detail and depth on their behaviours, feelings and attitudes which opened up new themes related to trust which had not been initially considered.

The overarching theme of trust added new knowledge around the experiences of people with H&N cancer participating in OSGs. Different levels of trust have already been defined in previous research (Radin, 2006) which ranges in stages from lurking to de-lurking, thin trust, to thick trust. What Radin did not identify was that these stages do not occur linearly, nor are they a prerequisite for one another. Indeed, this study appeared to imply that prior experiences of OSGs may also play a role in participation in OSGs. What could not be explained was why some people did not engage at a deeper level compared to others and this further highlights the complexity of the social relationships in OSGs.

Using the work of Oldenburg (2000) added a new dimension regarding the position of an OSG as a third place where social relationships occur and although much of Oldenburg's work has taken place in face-to-face settings this has yet to be explored in relation to OSGs.

Another important theme emerged in the analysis of results of this study was related to some aspects of the benefits of OSGs that people with H&N cancer employed as part of the coping process they use for their cancers. People with H&N cancer used the narratives of others to cope with their situation as they try to reformulate into a more positive perception, especially when they perceive other experiences as worse than theirs

The analysis also expressed the concern of the people with H&N cancer who used OSGs for the welfare of others (altruism). Those people felt that their participation in these groups has enhanced their ability to help others and allowed them to give back and pay forward what they have received from the groups when they were in need of that help. This characteristic appeared to be rooted in the experiences of people in the OSGs which gave them an ability to adopt the perspective of others in a similar situation.

This characteristic, together with cohesiveness and solidarity that been expressed by the participants, might give an answer of why members of OSGs stay in contact with the group even after they survived from their cancer, as some of them were found to be members in the OSGs over very long periods of time (Table 48, Section 5.1.6).

5.2.7.1 Study strengths and limitations

This study has some strengths; for example, it used an online interviewing technique based on chat system which has a list of advantages (see Section 5.2.5.6). In addition, the study used narrative thematic approach in the analysis which has the advantages of generating new information compared with using a deductive approach that is limited by a specific framework and does not allow for new information and themes (Dudovskiy, 2014). In spite of this, the study was limited by some disadvantages, for example, as in the case in the quantitative study, this study is limited by its cross-sectional nature which only allowed exploring the participants experience about H&N cancer in the time of the interview. It does not allow for re-exploring their experience after a period of time of using the OSGs as they may have different opinion with time. The majority of people with positive experiences of OSGs agreed to participate and those who were adjusting to their condition or treatment. Therefore, the opinions of those who opted not to participate remain unknown. The study used a convenience sample which makes it difficult to defend the representativeness of the sample (Brink 1996; Mugera, 2013). In addition, using online interviews for data collection has also been limited by a list of disadvantages (see Section 5.2.5.7). Although participants were using English Language during the interview, there were language misunderstandings probably due to differences in cultural backgrounds between the interviewer and interviewees (Hofstede, 1996; Deeks, 2004), since participants in this study were from different areas in the world.

5.2.7.2 Summary

The results suggest that building trust in using OSGs was influenced by many factors. The study therefore reinforces and adds to previous research into the

importance of trust in managing online relationships and further emphasises the complexity of online social relationships. This is an area of potential work for the future. There is also the issue of the OSG as a third place which is a hybrid space that extends the real and the virtual worlds and enables remote participants to engage in social relations with one another through sharing, comparing and identifying. We could use Ray Oldenburg's work here and extend the notion of a third place for OSGs for people with head and neck cancer and explore relationships in more depth.

Chapter VI: General Discussion

6 General discussion

6.1 Introduction

Reviewing the literature indicates that H&N cancer is commonly cited as the most emotionally traumatic of all tumours (Dropkin, 2001) and can often result in the development of a series of functional and psychosocial problems (McDonough *et al.*, 1996; Penner, 2009) which may exert severe impacts on QoL of patients (Morton and Izzard, 2003; Rogers *et al.*, 2007; Penner, 2009; So *et al.*, 2011; Rogers *et al.*, 2007; Penner, 2009; So *et al.*, 2012).

However, some factors may mitigate or aggravate the impact of cancer on patient's psychological wellbeing (McDonough *et al.*, 1996). These factors include coping strategies (Sherman *et al.*, 2000), anxiety and depression (de Leeuw *et al.*, 2001; Massie, 2004; Archer *et al.*, 2008; Haman, 2008; Haisfield-Wolfe *et al.*, 2009), and social support (Baker, 1992; Ma, 1996; De Leeuw *et al.*, 2000 a and b; Hassanein, 2001; List *et al.*, 2002; Katz *et al.*, 2003; Karnell *et al.*, 2007; Chueh *et al.*, 2009; Howren *et al.*, 2011).

The mechanisms through which social support might affect well-being and health have been detailed throughout this thesis. For example, social support may have an influence on an individual's health through enhancement of self-efficacy (Berkman *et al.*, 2000). Factors such as self-efficacy and social network have been shown to be related to better coping (Benight *et al.*, 1997; Relic *et al.*, 2001) and relatively low levels of psychological distress (Goodwin *et al.*, 1991; de Ruiter *et al.*, 1993; Benight *et al.*, 1997; Guidry *et al.*, 1997; Michael *et al.*, 2002; Sapp *et al.*, 2003; Bauer *et al.*, 2005; Kroenke *et al.*, 2006; Pinguart and Duberstein, 2010; Beasley *et al.*, 2010).

Over the past three decades, with increase in number of people who use the internet, there are an escalating number of OSGs available for different health conditions including cancer (Eysenbach *et al.*, 2004). Many studies have suggested that these support groups can be useful for patients to obtain support and may be associated with a variety of positive psychosocial outcomes such as better health, better management

of the disease and better use of active coping strategies (Winzelberg, 1997; Braithwaite *et al.*, 1999; Finn, 1999; White and Dorman, 2000; Fogel *et al.*, 2002; Coulson, 2005; Kalichman *et al.*, 2005; Mo and Coulson, 2008). Moreover, it has been argued that participation in OSGs might foster patient empowerment in a range of ways, such that greater use of OSGs have been associated with more frequent occurrence of such empowerment processes (van Uden-Kraan *et al.*, 2008; van Uden-Kraan, *et al.*, 2009; Mo and Coulson, 2012), which are subsequently related to better coping and enhanced self-efficacy (Mo and Coulson, 2012).

In spite of numerous research studies to date on OSGs, there have been none that have explored OSGs for people with H&N cancer. Therefore the aims of this research were; firstly to assess the types of social support, sought and offered, within OSGs for H&N cancer. Secondly, to explore the relationship between using these groups and QoL and to identify some of the psychosocial factors that may influence this relationship. Thirdly, to explore in depth the OSG experiences of people with H&N cancer.

6.2 Main findings of the thesis

The aims of the present research were met with two studies utilising three different methods; the first study was a content analysis of posted messages within H&N cancer-OSGs. The second study was a cross-sectional study consisting of two parts; an online questionnaire using pre-validated questionnaires and an unstructured online interview. The results of these studies indicate that H&N cancer-OSGs appear to be a valid source of exchanging different types of social support particularly informational and emotional support for people with H&N cancer. The results also suggest that there may be a relationship between using these groups and the QoL of users, such that longer use of OSGs was related to better QoL. Moreover, this relationship appears to be mediated by a range of psychosocial factors including depression, adjustment, anxiety, self-efficacy and empowerment. In addition, the findings reinforced previous research in to the importance of trust in managing online relationships and further emphasised the complexity of online social relationships.

Although each study with these three different methods was intended to address one aim of the thesis, it appears that, generally, the results of these studies support each other with little conflict or disagreement.

Study 1 involved a content analysis of messages exchanged in H&N cancer OSGs using pre-validated coding frames to code both support-seeking and support-offering messages. Although the frames managed to code the social support sought and offered in the vast majority of the data, some modifications and new subcategories were added (see Section 4.7.3).

The content analysis of exchanged messages through H&N cancer OSGs suggests that these groups were used by individuals to seek and offer various types of support but particularly informational and emotional. The predominance of these two types of support in the findings of this study is consistent with previous research into social support for other health issues in both face-to-face and OSGs (Winzelberg; 1997; Braithwaite *et al.*, 1999; Preece, 1999; Loader *et al.*, 2002; Coulson, 2005; Coulson *et al.*, 2007; Mo and Coulson, 2008; Coursaris *et al.*, 2009; Elwell *et al.*, 2011; Coulson and Greenwood, 2012). The present findings therefore add further validity to these studies and suggest that OSGs can be a good source for informational and emotional support.

Study 2 was complementary and supportive to Study 1. Study 1 suggested the presence of several forms of social support exchanged with H&N cancer-OSGs. In addition, social support has been thought to represent the highest component (25%) of the whole coping efforts used by H&N cancer patients (List *et al.*, 2002) and can be beneficial to users. Thus, Study 2 attempted to investigate the benefits of these OSGs for the QoL of users and the possible mechanisms by which using OSGs might influence QoL. The first part of Study 2 illustrated the relationship between using OSGs and QoL and the potential psychosocial mediators of this relationship. The qualitative part of Study 2 added a new theme to the experience of people with OSGs which was not addressed in Study 1; that is, the role, of “trust” in using OSGs and creating or maintaining online relationships.

Indeed, during the analysis of the qualitative findings, trust gave depth to the previous quantitative findings (see Section 5.2.6 for details). The results suggest that building trust in using OSGs, was influenced by the quality of the relationships with OSG users and the quality of the relationships also engendered more trust in the process. The suggestion that the OSG was a third place is an area worthy of more exploration and this may also link strongly to other areas in the social science literature, for example the notion of social capital which is poorly defined.

Some demographics, cancer-related and OSGs-related variables were reported in both Study 1 and 2, showing consistency throughout. For example, both Study 1 and Study 2 showed that many members of H&N cancer-OSGs posted high number of messages (up to thousands), indicating that members of these online groups were considerably active in term of exchanging support regarding symptoms, treatment and management of H&N cancer. In addition, the predominance of oral and throat cancer appeared to be another consistency between the two studies and is also consistent with H&N cancer statistics (IARC, 2008 and 2012) and this can added to the validity of results of each study.

6.3 Different online methodologies for OSGs

The thesis utilised a number of different methodologies. Study 1 was a content analysis of posted messages within H&N cancer-OSGs. This analysis was intended to assess the characteristics of the communications between users of these groups (Holsti, 1969). These messages were posted by the users of the groups subjectively and by their will either to seek help or support or to reply to others and provide them with support. Therefore, these messages were not there as responses to researcher's questions in which the researcher tends to direct their questions to fulfil specific study aims.

The quantitative part of Study 2 utilised traditional self-reported questionnaires delivered online accessed through H&N cancer-OSGs. This methodology differs from that of the first study as participants responded to pre-validated questionnaires

containing questions directed to gain specific answers that could then be coded numerically to provide a score which is then easy for assessment and comparison in order to meet specific aims.

The qualitative part of Study 2, which used unstructured online interviews and narrative methods, gave participants more opportunities and freedom to talk about their situation and experiences of cancer and OSGs in a more detailed and unrestricted manner throughout. They produced detailed narratives of the experiences that they felt were of importance to them whilst in real time online.

Using these three different complimentary methods have allowed for an understanding of participant's feelings towards and experiences of their condition. It has also allowed for an examination of OSGs and given more comprehensive knowledge about the benefits and drawbacks of using OSGs and their possible relationship to QoL of people with H&N cancer.

6.3.1 Change in using OSGs with the development in the technology

The data for the first study was collected in 2011 from OSGs for H&N cancer after a thorough search was performed using Google as the search engine for a set of key words related to H&N cancer and online support groups. At that time, Google search showed OSGs for H&N cancer to be available as web forums (Appendix 3) which worked by posting messages though a website on a specific topic to be read by others. These messages appear immediately on the website after being posted and are usually classified under a specific topic and sometimes termed as "threads" (Sharp, 2000). Other people can see the topic when they log into the group, and choose to reply to or just read. Data for the second study (quantitative and qualitative) were collected in 2013 after a thorough search was performed on Google, Yahoo, Bing and MSN, as search engine for a set of key words related to H&N cancer and online support groups. The results of the search shows that, in addition to the traditional web forums that had been found in the first study, there were several H&N-related OSGs available on Facebook that had many advantages such as ease of use, convenience, instant interaction, comprehensive participation and encouragement to share (Saikaew *et al.*, 2011).

This led the researcher to perform a comprehensive search using the same key words for H&N cancer and OSGs on Facebook; the search showed that there were approximately 19 H&N cancer-related OSGs which were available from Facebook at the time of the search (Appendix 9). Most of these groups appeared to have been created recently after the search for the first study was performed. Some of the groups appeared to be administrated by the same people who managed the old groups, and links to these facebook groups had been placed in the main pages of the old groups. The activity of the old groups appeared to have decreased whilst the activity of the Facebook groups was on the increase (this was inferred from the number of messages posted per month over time). On reading through the postings it became apparent that many of the users of the Facebook group were the same people who had used the old groups.

This change of shared space may be attributed to the dramatic increase in the users of Facebook recently, which has increased by 22% from 2012 to 2013 and the total number of monthly active Facebook users reached 1.11 Billion in March 2013 and increased to 1.31 Billion by the beginning of 2014 (Harden, 2014). An increasing number of people began to use Facebook as an application on their smart phones, and the total number of mobile Facebook users reached 680 Million users at the start of 2014 (Harden, 2014). Facebook appears to have many advantages over a traditional OSGs and seems to be more convenient to users because of ease of connection to others, staying updated and aware, since the mobile phone can act as a notification tool, in addition to the context and connectivity as well as the simplicity of the this tool in the social interaction (Borneo and Barkhuus, 2011).

One other factor in using Facebook is that people can have access to the status of others without any direct interaction which appears to facilitate a sense of connection (Humphreys, 2007). Facebook may be said to have a wide but selective reach and users can choose to develop weak or strong ties (Baym, 2010). When people use Facebook to develop strong ties this provides another range of options for exchanging bonding resources, for example advice or support, but developing weak ties may also be said to increase people's access to bridging capital which refers to the building of connections between social groups and may be more fragile but simultaneously more likely to enable social inclusion by expanding the range of resources on which they

can draw (Ellison *et al.*, 2007). As a mode of communication, this more contemporary form of digital media may be said to enable people with H&N cancer to remain in continuous contact with one another, but also on their own terms as to the level of ties they wish to foster. With Facebook recently ranked as the most used social networking website by monthly users worldwide (Kazeniak, 2009), these properties might be the reason behind users of H&N cancer-related OSGs moving from the old form of OSGs to use Facebook groups as OSGs.

6.4 Who uses OSGs for H&N cancer?

Although it appeared that the majority of OSGs users were people with H&N cancer, other people such as family members, friends and colleagues were also recorded to use these groups for themselves or for the person with cancer. This may point to the benefits of OSGs for people other than those with H&N cancer, for example carers, family and close friends (Coulson and Greenwood, 2012).

The demographic results of the studies within this thesis appeared to be consistent with each other and with cancer statistics and previous literature (in spite of some inconsistency) in many aspects related to the features of users of online H&N cancer groups. Such consistency can added to the validity of results of each study in this thesis.

For example, both studies of the thesis were consistent in terms of users' age; most of the online H&N cancer support groups users were older people and these results were also consistent with H&N cancer patients' ages as provided by the literature (Ridge *et al.*, 2004; Chidzonga and Mahomva, 2006; Warnakulasuriya, 2009). However, although the worldwide incidence of oral cancer is more prevalent in males than females in the majority of countries (Warnakulasuriya, 2009), our results indicated that male: female ratio was almost equal (study 2) or more females (in Study 1). It may be that women are more likely to use the Internet for the purposes of interpersonal communication (Weiser, 2000; Boneva *et al.*, 2001) and more interested in the topics that relate to health (Green and Pope, 1999).

Both studies within the thesis were consistent in terms of types of cancer, since the majority of participants of the quantitative study had been diagnosed with either throat cancer or lip and mouth cancer and the most common type of cancer reported by both support seekers and providers in Study 1 were cancers of the tongue followed by, cancers of the tonsil. These results were consistent with cancer incidence in the USA and the UK, and to which most of the sample belonged, as oral cancer appeared to be more common than other subcategories of H&N cancer in these two countries (IARC, 2008).

The results of both studies were also consistent in defining participants of H&N-related OSGs as heavy users, in terms of number of the postings, number of days using OSGs per month and number of hours using OSGs per day. The participants' activity in these groups appeared to be more than that in other online groups for other health conditions such as HIV/AIDS and depression (Houston *et al.*, 2002; Mo and Coulson, 2010b). In addition, the results of the two studies were consistent in terms of cancer stage and treatment stages since both of them revealed that the majority of people who accessed H&N-related OSGs were diagnosed with cancer a long time ago (range: 1 – 420 months, mean: 53.7 months, with 30% of them were diagnosed before 5 years) and the majority of them were in their advanced stages of cancer and post-treatment (current patients and survivors). However, these results were in contrast to a previous study (Mo and Coulson, 2010), in which OSGs users were recently diagnosed. This inconsistency might be attributable to the difference in the nature of the disease (HIV/AIDS) that Mo and Coulson dealt with in their study.

6.5 Advantage of OSGs

When we consider the advantages of OSGs mentioned in the literature (see Chapter 3, Section 3.3.4), the present research achieved comparable results. For example, participants of H&N cancer-related OSGs were from different countries so in spite of the geographic distance they managed to participate and derived benefit from these groups, describing them as family.

The content analysis of the messages exchanged in these groups indicated that these groups can be a supportive rather than a competitive resource for face-to-face groups. This is because they provide different types of social support especially informational and emotional, but without the necessity of people having to engage in the intimacy of face-to-face interactions. Using mediated forms of communication, such as OSGs may enable people with H&N cancer to experience social contact on their own terms, even though it may be more reduced than face-to-face contact (Fulk and Collins-Jarvis 2001).

We can suggest that online groups have many advantages with specific regard to people with H&N cancer, for example, the consequences of H&N cancers and treatment may lead to several physical and psychosocial problems such as impaired speech, altered physical appearance, problems related to coughing and blowing the nose, breathing difficulties, embarrassment and feelings of shame (see Table 10, Chapter 2.5.2). All of these issues may act as a barrier for people to participate in face-to-face groups. However, the qualitative section of the present research suggests that OSGs can, to some extent, mediate these issues and people with H&N cancer can choose the level of personal identity and aspects of self that they wish to reveal without the regulation of implicit social norms present in face-to-face interactions. The mediating effect of OSGs and their ability to support and normalise identity appeared in several interviews which discussed changed identity and alluded to the normative perceptions of others.

These points link directly to the level of anonymity and privacy offered by online groups. Although few H&N cancer-related OSGs ask for the individual's real identity to register as a member, most of the groups allowed people to employ any username and most of the participants used usernames other than their real names (for example, some people used symbols, numbers or letter that did not reveal their identity), which may indicate that members of these groups feel more comfortable when they participate under the cover of anonymity. This anonymity can hide visual distractions such as gender, age, dress and socioeconomic status, which mediate conventional face-to-face interactions (Madara and White, 1997; Martin and Youngren, 2002). The use of OSGs may therefore be said to blur the social boundaries between the groups, but little has been written about the social norms and levels of appropriateness for

interactions. In line with the previous literature (Sharp, 2000), the anonymity provided by H&N cancer-related OSGs appears to enable participants to discuss their anxieties and difficult feelings and experiences with cancer in a less stressful way, since the content analysis of the messages showed that about 14% of the support-offering messages and 32% of the support-seeking messages were coded as “Sharing own experience” and some of the messages appeared to be very long and detailed. Even though OSGs can provide an anonymous space where people can choose how to present themselves, they also provide a space where people can share a common identity, H&N cancer, so it could be inferred here that part of their social identity is shared.

Another advantage is that, compared with face-to-face groups, the number of members of OSGs for H&N cancer appeared to be very high. For example, some of them contained nearly 6000 participants (see Appendix 9). This finding is consistent with the literature that suggests that size of the group no longer represents a barrier to the members (Scott, 1999).

Finally, the current research indicated that H&N cancer OSGs may, at times, have the potential to reduce feelings of loneliness and increase feelings of peace and support, which in turn might give people, as one participant put it, *‘the power to fight my illness’*. This advantage was in line with previous literature (Sharp, 2000) which indicated that people with uncommon or rare cancer who use OSGs may have the opportunity to feel the sense of “they are not alone”.

6.6 Disadvantage of OSGs

In spite of the previously mentioned advantages, this research has showed that OSGs can also have some disadvantages. For example, findings of this research (Study 1) suggested that approximately 10% of the support provided by the OSGs for H&N cancer was factual or technical information supplied by members of H&N cancer OSGs. In addition, during the process of recruitment and contacting the moderators of the groups, it was noticed that many of these groups were led by none-professional moderators. Therefore, the quality of this information is still in doubt (Klemm, *et al.*,

1998), since the information might be based only on personal experience or unproven methodologies and not on scientific evidence or medical advice, it may, therefore provide wrong or misleading information (Sharp, 2000).

In addition, although some OSGs make it mandatory for its members to provide their correct identity and their actual names and details for the admin during the process of registration (e.g. Survivors of Head and Neck Cancer), others (e.g. Macmillan Head and Neck Cancer Group) do not have such obligations. Therefore, the credentials of the message posters are hard to be verified and it is possible that anyone can post messages posing as a cancer survivor. This may reduce the credibility of OSGs (Martin and Youngren, 2002).

Trust can be an issue for some members, for example the results of Study 2 suggested that while some participants began with immediate participation and sharing, others required a long time to display a level of trust great enough to interact with OSGs, as they took such time to progress from positions of uncertainty and mistrust which promoted 'lurking' to positions of trust, de-lurking and participation.

The content analysis of the posted messages, specially the support-seeking messages showed that, as in the case of conventional support groups, some support seekers in OSGs express and reinforce negative emotions during the process of support seeking and sharing their problems and their personal experience with cancer. Such action can be unsupportive to other members (Sharp, 2000).

Furthermore, since H&N cancer is fatal disease and many people die because of this disease, the findings showed that this issue appeared in the messages posted for OSGs for H&N cancer, especially when some caregivers sought support after losing their family members or friends or when a member of the group died. While such messages may have negative impacts on the other members emotionally, the fear of a similar fate in the future is still an issue (Sharp, 2000).

6.7 Strengths

There were several strengths to the methods and techniques employed in this research. Firstly, the research was a multi-method project incorporating two studies which explored aspects of OSGs that have not been examined before. The research also sheds light on a number of processes that may be important for users of these groups and for those designing such websites/groups for users.

In this research, attempts were made to make the selection, design, conduct and processing of data a systematic process. For example, electronic software called RANDOM.ORG was used in the randomisation process in the sample selection for Study 1. In addition, the sample size for the quantitative part of Study 2 was calculated using sample size software (Buchner *et al.*, 2007) and the methodology chosen was appropriate and ensured that the required sample was obtained in the shortest time possible. In addition, the electronic transfer of the data that was used in this study prevented traditional researcher error during data transfer and coding and saved the researcher time. Moreover, sending and completing the questionnaire online saved the time and efforts and reduced the chance of missing data due to the design of the questionnaire which require completion of all the required questions.

Indeed, the online nature of the study reduced the cost compared to offline studies such as personnel training, papers, printing, posting or personal disturbing and entering the information into a database. It also facilitated access to the intended sample in an easier, economical, faster, more accurate, more honest, more selective, more convenient and more flexible way (Naser, 2002).

6.8 Limitations

In spite of the strengths mentioned above and the effort and precautions made to improve the quality of the research, there were some limitations. Firstly, although the research was based on three different methodologies, all of them were cross-sectional in nature which can only evaluate the situation at certain points and cannot evaluate both the short and long term impact of OSGs on its users. In addition, although the

data for Study 1 was selected from 18 OSGs, only four OSGs were used for data selection in Study 2 in which participation was optional and participants were self-selected. Therefore, it may be that differing results would have been obtained if more sites had been included or if the responses of people who opt not to participate were obtained. Therefore, future research using longitudinal methods and, if possible, a randomly selected sample might be beneficial in evaluating both the short and long term impact of OSGs on its users.

Secondly, since the research dealt with people who were using OSGs, it means that the participants were people who had a level of education and skills “at least to use the computer”, and moreover could afford to buy a computer and pay for the Internet service. This may reflect the higher socioeconomic status of those participants which can also be inferred from the results of the study in which more than two-thirds of participants reported that they were satisfied with their income status. Therefore, it is not clear whether people with H&N cancer but lower socioeconomic status will respond similarly.

Thirdly, although every effort was made to select reliable and valid measures to be used in the studies in the thesis, the measures used in both studies (e. g. SSBC framework in Study 1 and Time since start using OSGs in Study 2) had some limitations (see Section 4.7.4 and Section 5.1.7.3 for details). This might make the results of this study questionable and emphasise the need for validation of the present results using more reliable measures in future studies. For example, most of the questionnaires that were used in this research were primarily designed for measuring concepts in personal relationships. It may be that these scales are not suitable, or do not measure the same concepts as accurately or in the same way when used to assess online relationships. Future research needs to validate such measures for use in the online environment or new measure developed for this purpose.

Most of the respondents taking part in the studies in this thesis were from the USA and this may make the results and resulting interpretation based on one culture questionable.

There was an inconsistency in the sample between the studies in the thesis; while the sample in the Study 2 (both parts) was purely from people with H&N cancer, the sample in Study 1 (the content analysis) appeared to be a mix from the OSGs users, although the majority (70%) of the sample were people with H&N cancer, the remaining were mainly caregivers and a few classified as friends, colleagues or healthcare professionals. Since non- cancer uses might have different perspectives about OSGs and their experiences may dramatically differ from the experience of people with cancer, the results might not completely represent the experience of people with H&N cancer.

Moreover, although it is appeared that there is no clear cut in the definitions of cancer survivors to be differentiated from the current patients (National Cancer Institute, 2014; NCCS, 2014; Macmillan Cancer Support, 2015), all studies in this thesis included people who use the OSGs and they have been diagnosed with H&N cancer at any point of their life. Therefore, people at different stages of cancer or treatment have been included. We could suggest that people who are at initial stages may respond differently from those who are at final stages of cancer and /or treatment, and people who already finished their treatment might have different perspectives from those who are current patients. Therefore, variations in responses might arise and issues of representativeness of the sample might appear. In this thesis (all the studies) most of the participants were in advanced stages of cancer (stage III and IV) and in post-treatment stages (see Section 4.6.1.1, Section 4.6.2.1 and Section 5.1.6.2.2). Therefore, the results of this thesis seem to represent this group of people, whereas it is still not clear whether people who are in initial stages of cancer and/ or treatment or untreated yet will respond similarly.

6.9 Future work

6.9.1 Implications

Since this research indicated that the use of OSGs was related to improved QoL for people who live with H&N cancer, this might have some implications for health care professionals who are concerned with providing support and care for people with

H&N cancer. Those professionals may want to encourage patients to use OSGs to seek support and information related to their conditions. They may also be given the help to make patients aware of the internet for support and about how to facilitate patients' skills with this technology, or provide training themselves.

6.9.1.1 Access to the internet for older people (Digital divide)

The findings of this research as well as previous literature suggest that most of the people who live with H&N cancer and most of the users of H&N cancer-OSGs were older people. It has been thought that older people are less expected to access and use the internet compared with younger people, with only 37% of those who are above the state pension age have accessing to the Internet compared with 79 % of those who are below this age (Berry, 2011). The reasons for this exclusion of older people can be material such as cost or lack of physical infrastructure or non-material such as lack of interest, lack of skills, or other reasons such as psychological barriers (Kim *et al.*, 2009). This disparity may raise the concept of the “digital divide” between those who can access and enjoy using the internet and those who cannot. If we consider that most of the people who live with H&N cancer were older people, then we could argue that the significant benefits of the using the OSGs, efforts should be directed toward providing access to the internet among those people, especially those who cannot afford, by providing them with subsidised equipment, training and free internet access for people with H&N cancer and their supporters, and someone who can direct them on how to use this technology and inform them about the relevant OSGs and websites. This may widen their participation and since older people can be a target for many chronic diseases, not only H&N cancer, then OSGs may be beneficial to them. Such strategies have already been suggested by some researchers to be applied to the digital divide between older and younger people in using the Internet (Berry and Berry, 2006; Berry, 2011).

Besides the different types of support being given through OSGs, the results suggested that high factual and technical information were exchanged between users of OSGs for H&N cancer therefore, it may be beneficial for medical professionals to explore and monitor those OSGs regularly and correct any false or misleading health information that might negatively affect the users' QoL. Finally, it may be that health care

professionals could educate, and enable patients into using OSGs as part of their continuing treatment.

6.9.2 Future research

The results of the current research appear to have opened a pathway for future research from more than one aspect. Firstly, the validity of the relatively high amount of factual information (information that contains facts or news about the situation or about skills needed to deal with the situation) exchanged between users of H&N cancer online groups is an important area for further research, particularly in relation to groups run by and for lay persons.

The limitations of the current research could be a target for future research and some of these could be addressed using different methodologies. For example, the limitation of the cross-sectional nature of the studies in the thesis could be addressed in a future longitudinal study following OSG users and assessing key variables evidenced here over time. Comparing responses on these variables between new and longer-term users would be of interest, particularly in relation to development of social support and online social networks.

It might also be of interest to carry out more qualitative research along the lines of that reported here, particularly in relation to types of social support online. For example, the study here utilised a pre-formulated social support behaviour coding framework originally devised for stressful events and satisfaction with spousal support. It may be that the stressful nature of events associated with marriage are somewhat removed from those of H&N cancer. Future research might be aimed at exploring the nature and types of social support on offer online through interviewing OSGs users.

Future research could also explore further the generalisability of the results to people with lower socioeconomic status. In addition, future work might investigate the use of other scales designed specifically for use in OSGs or indeed tested the validity of the available scales to be used in online relationships. Future studies should also use other measures for participation in OSGs other than “the length of time since start using OSGs” in order to investigate more closely the relationships with the actual levels of

participation in terms of posting messages as well as the daily and monthly rate of use. In addition, future research should consider the possible influence of cultural differences in the social support offered in OSGs. For example, most of the participants in the present research were from the USA; are there differences between users of OSGs in the USA compared to other countries in terms of the social support offered and sought? Future research might also consider the possible influence of difference in treatment stage and/or cancer stage, and therefore, if possible, data should be collected from participants who are within similar stages of cancer and treatment. Finally, a comparison should be made in the use of OSGs between people who are current H&N cancer patients and those who have survived and no longer have cancer or are having treatment.

In this thesis, the selection strategy meant that messages for the content analysis were chosen from the even months only, rather than throughout the year. This may have biased the results, as well as leading to a relatively low number of messages being analysed. Therefore, it might be worth for future studies if the selection strategy incorporated messages from both even and odd months, and utilised existing OSG study data to aid future power calculations.

The present study presented a potential model of pathways linking OSG use and QoL for those with H&N cancer. The model remains to be tested in future studies (randomised-controlled or longitudinal studies) and the relationships proposed need to be explored in greater detail with other participants, both with H&N or other types of cancer.

The new theme of trust that arose from the qualitative part of the thesis appeared to influence participation in the OSGs. This needs to be investigated in more depth in future studies. New items and modifications have been added to the frameworks used in the the content analysis part of the thesis, a further study would need to validate the framework before firm conclusions could be drawn on its applicability to OSGs for H&N cancer.

A qualitative exploration of the role of an OSG as a third place using the following key areas to guide the study would add significantly to Oldenburg's work which so far has tended to focus on face-to-face relationships:

- Generating trust
- Supporting and developing social relationships
- Promoting a sense of belonging
- Reducing loneliness and isolation
- Enabling people with head and neck cancer to feel part of something bigger than themselves and regain a sense of purpose for some

Finally, future research should examine the generalisability of our findings (the frequency and dimensions of social support in OSGs and a model that summarises the relationship between OSGs and QoL as well the demographics of the users of these online groups) in representing face-to-face groups.

6.10 Conclusion

The internet has become a source of health information for many people experiencing different illness, including H&N cancer. The number of people who use the internet for health purposes has increased dramatically with increased publicity and ease of access to the Internet. The present research indicated that prolonged participation in H&N cancer-related OSGs can provide users with different types of social support; predominantly informational and emotional. Participation in OSGs was found to be related to better QoL either directly or indirectly through decreasing depression, anxiety and the negative adjustment behaviours and increasing self-efficacy and empowerment of the users. Moreover, this research reinforces and expands previous research in the importance of trust in managing online relationships and further emphasises the complexity of online social relationships.

With the increasing number of OSGs for different health issues, more research is required in terms of randomised-controlled or longitudinal studies to evaluate the impact of these groups on its users in both the short and long term. One thought is that

the availability of many well administrated OSGs can mediate the concerns of many people with different illness and assist in improving their health-related QoL.

6.11 Key advances in the field of OSGs

The present thesis has supported previous work about the role of OSGs in providing different types of social support to its users and identified a positive relationship between duration of using this type of support group and the QoL of the users. In so doing, the thesis has provided some key advances in this area:

- 1- OSGs can be valued as a source of support and have a favourable influence on QoL including conditions such as H&N cancer with low survival rates and often poor prognosis.
- 2- Participation in OSGs was found to be related to better QoL either directly or indirectly through decreasing depression, anxiety and the negative adjustment behaviours and increasing self-efficacy and empowerment of the users.
- 3- OSGs may be of particular benefit to people with H&N cancer who have complications because of the cancer or its treatment, especially those who cannot speak or cannot attend face-to-face support groups because of facial differences.
- 4- Users of H&N OSGs appear to be not only people who have the condition and be affected directly, but also other people such as caregivers or patient's friends who might be affected indirectly.
- 5- Most of the users of OSGs for H&N cancer were in post-treatment stages. This can show that either there is a shortage in directing people to this kind of support groups or people do not usually prefer to use these groups until they reach a certain point in the disease and/or treatment pathway.
- 6- With the increased number of different social networking groups such as Facebook and Twitter, people are shifting from using conventional OSGs that are usually available as a forum to more easily-accessible and practical kinds of OSGs such as, Facebook groups.
- 7- Trust appeared to play an important role in participation in OSGs and managing online relationships

- 8- The OSG could be potentially considered as a third place where social relationships are developed over time

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Appendices

Appendices

**Appendix 1: Types and ingredients of alcohol (adapted from;
Mosedale and Puech, 1998; Scalbert and Williamson, 2000)**

Beers	Wine	Spirits and liqueurs
<ul style="list-style-type: none"> - Carbone Dioxide - Minerals <ul style="list-style-type: none"> • Potassium • Phosphate • Sodium - Amino acids - Organic acids - Inorganic acids - Poly-phenols - Carbohydrates 	<ul style="list-style-type: none"> - Carbone dioxide - Minerals <ul style="list-style-type: none"> • Potassium • Iron • Phosphates • Calcium - Organic acids - Vitamins - Poly-phenols - Carbohydrates <ul style="list-style-type: none"> • Sugar • Pectin - Alcohols 	<ul style="list-style-type: none"> - Esters - Aldehydes - Terpenes - Ethereal oils - Acids <ul style="list-style-type: none"> • Fatty acids • Acetic acids - Alcohols

Appendix 2: Brief descriptions for studies conducted on the issue of racial disparities in survival for patients with H&N cancer

Author	Aim	Study design	Sample	Method	Result or conclusion
Franco <i>et al.</i> (1993)	To verify the actual prognostic effect of race and gender in survival among patients with cancer of the mouth	Retro-spective	4527	-Analysis of 15-year survival over 28 year period -Proportional Hazard Regression to control stage and treatment method	Race: survival difference for lip cancer Gender: survival difference for gum, floor of mouth and other oral sub sites
Caplan and Hertz-Picciotto (1998)	To investigate the relation between race and survival for patients with oral and pharyngeal cancer and to assess whether this association differ by stage at diagnosis	Retro-spective	1272 White: 961 Black: 311	-include all blacks and whites registered between 1978- 1990 -proportional Hazard Regression Model to calculate hazard ratio for all-cause mortality within 18 month of diagnosis - adjusting for site, grade, age and time dependent interaction	Blacks have higher all- cause mortality than whit people diagnosed at the same stage of oral and pharyngeal cancer
Moore <i>et al.</i> (2001)	To assess whether age and race are independent prognostic factors for survival in patients treated for oral and pharyngeal cancer	Retro-spective	909 Whites: 815 African Americans: 94	-Kaplan-Meier survival estimate to analyse survival time after diagnosis - Cox Proportional Hazard Model and log Rank test to analyse the effect of risk factors in association with survival	African Americans had poorer survival results with age and race rising as independent prognostic factors of survival after treatment for cancer of oral cavity and pharynx
Shavers <i>et al.</i> (2003)	To assess if racial disparities in pattern of care might have a role in survival disparities in African Americans and Hispanics	Retro-spective	471 White: 224 African Americans: 163 Hispanics: 84	-Data obtained from SEER and from US census 1970. -SEER summary stage for all for al stage analysis -Charlson's Co-morbidity Score for racial difference in Co-morbid conditions - SUDAAN for all data analysis	- There are racial disparities in diagnosis, tumour stage and treatment of selected H&N cancer. - African Americans are less frequently received treatment for cancer than both white and Hispanic
Morse and Kerr (2006)	To review statistics and long-term trends in incidence, survival and	Retro-spective		-Data obtained from SEER (1975- 2002) -Data analysed by joint point Regression Programme	Although the incidence and mortality rates of oral and pharyngeal cancer have declined recently in the US, racial

	mortality of oral and pharyngeal cancer among American Whites and Blacks				disparities still exist
Ho <i>et al.</i> (2007)	To investigate the pattern of oropharyngeal cancer among variation of ethnic groups in Taiwan	Retro-spective	Mortality sample: M (8858) F(1320) Incidence sample: M(15949) F(2465)	-Data obtained from Taiwanese Cancer Registry and the Taiwan Vital Statistics (1979- 1997) - Sample divided into 3 ethnic groups -both ages standard incidence and mortality rates were estimated	There is an ethnic difference in the pattern of oropharyngeal tumour in Taiwan could be due to difference in exposure to risk factors or as result of genetic differences
Shiboski <i>et al.</i> (2007)	To investigate the distribution of survival rate and stage at diagnosis among adults with oral cancer in relation to race and overtime	Retro-spective	46855	-Data obtained from SEER (1973- 2002) -analysis by tumour size, stage at diagnosis and 5- year relative survival rates	There are significant racial differences among adults with oral cancer regarding stage at diagnosis and survival. The possible explanation for lower survival among Blacks is difference in access and use of health care services
Goodwin <i>et al.</i> (2008)	To review data in disparities in H&N cancer focusing on the possible cause of this issue	Retro-spective	27451 Whites: 24569 M(16726) F(7843) Blacks 2882 M(2034) F(848)	-Data obtained from SEER (1975- 2003) to assess incidence, mortality and survival of H&N cancer	Greater burden of H&N tumour was observed among black Americans. The actual cause is unknown, but some factors such as accessibility to and quality of health care, incidence of co-morbid conditions, biologic/ genetic factors, diet and exposure to carcinogen were implicated.
Molina <i>et al.</i> (2008)	To identify the impact of ethnicity, race and socioeconomic status on H&N cancer patients	Retro-spective	20915 White: 89.7% African Americans: 8.4%	-data obtained from Florida Cancer Data System and Florida Agency for Health Care Administration (1998- 2002) - SSPS was used for statistical analysis - Chi- Square Test for correlation between variable and Kaplan Meier Method to calculate 5- year survival	H&N cancer s has general high mortality with uneven impact on African-American and poor patients. Significant disparities by race and SES are not completely explained by under- treatment, co-morbid conditions or demographics.

Du and Liu (2010)	To assess whether racial disparities continue in Medicare- insured old patient with H&N tumour	Retro- spective	7840 White; 6108 African American: 522 Hispanic: 376 Asian: 252 Other: 222	<ul style="list-style-type: none"> -Data were obtained from SEER (1991-2002) -Chi- Square Test was used to test distribution of characteristics among racial/ ethnic groups - Kaplan Meier Method to calculate survival rate - multivariate Logistic Regression analysis to evaluate the Odd ratio of various treatments and adjusted for other variables - the Cox proportional Hazard Regression model to Analyse the survival using SAS system 	There is no significant difference in the risk of mortality among African Americans and Hispanics compared with white in particular locations of H&N cancers except a slight elevation in all-cause mortality risk in African Americans with oral cancer.
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Appendix 3: List of head and neck cancer OSGs available in 2011

OSG	URL
1. The cancer forums	http://www.cancerforums.net/forums/40-Head-and-Neck-Cancer-Thyroid-Cancer-Forum/page3?order=desc
2. Head & neck cancer (CancerCompass)	http://www.cancercompass.com/message-board/cancers/head-and-neck-cancer/1,0,119,39.htm
3. Jaw Cancer (CancerCompass)	http://www.cancercompass.com/message-board/cancers/head-and-neck-cancers/jaw-cancer/1,0,119,39,41.htm
4. Laryngeal Cancer (CancerCompass)	http://www.cancercompass.com/message-board/cancers/head-and-neck-cancers/laryngeal-cancer/1,0,119,39,22.htm
5. Pharyngeal Cancer (CancerCompass)	http://www.cancercompass.com/message-board/cancers/head-and-neck-cancers/pharyngeal-cancer/1,0,119,39,28.htm
6. Salivary Gland (CancerCompass)	http://www.cancercompass.com/message-board/cancers/head-and-neck-cancers/salivary-gland-cancer/1,0,119,39,43.htm
7. Squamous Cell (CancerCompass)	http://www.cancercompass.com/message-board/cancers/head-and-neck-cancers/squamous-cell/1,0,119,39,44.htm
8. Throat Cancer (CancerCompass)	http://www.cancercompass.com/message-board/cancers/head-and-neck-cancers/throat-cancer/1,0,119,39,6.htm
9. Cancer Survivors Network	http://csn.cancer.org/forum/164
10. Cancer Focus	http://cancerfocus.org/forum/forumdisplay.php?f=25
11. Merseyside Regional Head and Neck Cancer Centre	http://www.headandneckcancer.co.uk/Forum.aspx
12. Med Help	http://www.medhelp.org/forums/Head--Neck-Cancer/show/323
13. Macmillan	http://community.macmillan.org.uk/cancer_types/head-neck-cancer/discussions.aspx
14. Introduce yourself (OCF)*	http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=2&page=1
15. General Board (OCF)	http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=1&page=1
16. Symptoms and Diagnosis (OCF)	http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=3&page=1
17. Coping / Anger and Fear (OCF)	http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=5&page=1
18. Medications, Treatment, Procedures (OCF)	http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=6&page=1

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|-----|---|---|
| 19. | Currently in Treatment (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=7&page=1 |
| 20. | After Treatment Issues (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=12&page=1 |
| 21. | Eating, Speech, Swallowing, and Alternative Feeding (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=17&page=1 |
| 22. | Caregiver / Co-Survivor Forum (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=9&page=1 |
| 23. | Insurance and Financial Forum (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=10&page=1 |
| 24. | Oral Cancer Recurrence (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=19&page=1 |
| 25. | Activism (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=8&page=1 |
| 26. | Adjunctive Therapy (OCF) | http://oralcancersupport.org/forums/ubbthreads.php?ubb=postlist&Board=11&page=1 |
| 27. | Introduce yourself (MCF)** | http://rdoc.org.uk/eve/forums/a/frm/f/75510549 |
| 28. | General chat (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/55510549 |
| 29. | Survivor Stories (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/78510549 |
| 30. | Patient Based Research (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/3381064033 |
| 31. | Medications, Treatment, Procedures (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/19510549 |
| 32. | Questions & Answers (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/46510549 |
| 33. | Laryngectomees Forum (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/415104212 |
| 34. | Spiritual Bouquet (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/109102483 |
| 35. | Light Humour (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/455107774 |
| 36. | Adult Humour (outrageous - not for the sensitive) (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/3761023803 |
| 37. | Helpful Tips (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/26510549 |
| 38. | Recipes and Food Tips (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/9001080951 |
| 39. | Chat about Sport, TV, Movies, Books, etc (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/5761077532 |
| 40. | Useful Websites & Books (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/66510549 |
| 41. | Projects, Fund & Awareness Raising (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/541103626 |
| 42. | Participate in a Poll (MCF) | http://rdoc.org.uk/eve/forums/a/frm/f/3441004042 |
| 43. | Topix | http://www.topix.com/forum/health/oral-cancer |
| 44. | Wrong Diagnosis [WD] or Better Medicine | http://forums.wrongdiagnosis.com/forumdisplay.php?f=3169 |
| 45. | Acor.org [association of cancer online resource] | http://listserv.acor.org/SCRIPTS/WA-ACOR.EXE?A0=HEAD-NECK-ONC |

46. Daily Strength <http://www.dailystrength.org/c/Head-and-Neck-cancers/support-group>
 47. Stupid cancer <http://forums.stupidcancer.com/forumdisplay.php?44-Head-Neck-Cancer&s=80082e68fd03c129765da0a459b21e7b>
 48. Throat cancer (Health boards) <http://www.healthboards.com/boards/forumdisplay.php?f=208>
 49. Oral cancer (Health boards) <http://www.healthboards.com/boards/forumdisplay.php?f=204>
 50. Tonsil Cancer Support Forum <http://www.tonsilcancersupport.com/bboard/>
 51. Throat cancer (MDJunction) <http://www.mdjunction.com/forums/throat-cancer-discussions>
 52. head and neck cancer (MDJunction) <http://www.mdjunction.com/forums/head-and-neck-cancers-discussions>
 53. mouth cancer (MDJunction) <http://www.mdjunction.com/forums/mouth-cancer-discussions>
 54. Lip and oral cancer (MDJunction) <http://www.mdjunction.com/forums/lip-oral-cancer-discussions>
 55. Dreddy Clinic.com <http://www.dreddyclinic.com/forum/viewforum.php?f=77&sid=f75bb4eeb1d94f78d2a0bbe94fa4f40d>
 56. Inspire <http://www.inspire.com/groups/head-and-neck-cancer-alliance/>
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** OCF (Oral Cancer Foundation), *MCF (Mouth Cancer Foundation)

**Appendix 4: Brief definitions of Social Support Behaviour Code
(Cutrona and Suhr, 1992).**

Support type		Purpose of Communication
Informational support		
1	Suggestion / advice	Offers ideas and suggest actions
2	Referral	Refers the recipient to some other source of help
3	Situation appraisal	Reassure or redefine the situation
4	Teaching	Provide detailed information, facts, or news about the situation or about skills needed to deal with the situation
Tangible Assistance		
5	Loan	Offer to lend the recipient something (including money)
6	Direct task	Offers to perform a task directly related to the stress
7	Indirect task	Offers to take over one or more of the recipient's other responsibilities while the recipient is under stress
8	Active participation	Offers to join the recipient in action that reduce the stress
9	Willingness	Express willingness to help
Esteem support		
10	Compliments	Says positive things about the recipient or emphasize the recipient's abilities.
11	Validation	Express agreement with the recipient's perspective on the situation
12	Relief of blame	Tries to alleviate the recipient's feelings of guilt about the situation
Network support		
13	Access	Offers to provide the recipient with access to new companions
14	Presence	Offers to spend time with the person, to be there
15	Companions	Reminds the person of availability of companions, of others who are similar in interests or experience.
Emotional support		
16	Relationship	Stresses the importance of closeness and love in relationship with the recipient
17	Physical Affection	Offers physical contact, including hugs, kisses, hand holding, shoulder patting
18	Confidentiality	Promises to keep the recipient's problems in confidence
19	Sympathy	Express sorrow or regret for the recipient's situation or distress
20	Listening	Attentive comments as the recipient speaks
21	Understanding/ Empathy	Express understanding of the situation or discloses a personal situation that communicates understanding
22	Encouragement	Provide the recipients with hope and confidence
23	Prayer	Prays with the recipient

**Appendix 5: A modified version of Social Support Behaviour Code
(Mo and Coulson, 2008)**

Support type	Purpose of Communication	
Informational support		
1	Advice	Offers ideas and suggest actions
2	Referral	Refers the recipient to some other source of help
3	Situation appraisal	Reassure or redefine the situation
4	Teaching	Provide detailed information, facts, or news about the situation or about skills needed to deal with the situation
5	Sharing own experience	Involves the sharing experience that served as references rather than education
Esteem support		
6	Compliments	Says positive things about the recipient or emphasize the recipient's abilities.
7	Validation	Express agreement with the recipient's perspective on the situation
8	Relief of blame	Tries to alleviate the recipient's feelings of guilt about the situation
Network support		
9	Access	Offers to provide the recipient with access to new companions
10	Presence	Offers to spend time with the person, to be there
Emotional support		
11	Expression of care	Contain expression of concern to other members
12	Relationship	Stresses the importance of closeness and love in relationship with the recipient
13	Physical Affection	Offers physical affection, including hugs, kisses, hand holding, shoulder patting
14	Confidentiality	Promises to keep the recipient's problems in confidence
15	Empathy	Express understanding of the situation or discloses a personal situation that communicates understanding
16	Sympathy	Express sorrow or regret for the recipient's situation or distress
17	Encouragement	Provide the recipients with hope and confidence
Tangible Assistance		
18	Loan	Offer to lend the recipient something (including money)
19	Perform direct task	Offers to perform a task directly related to the stress
20	Express willingness	Express willingness to help
21	Perform indirect task	Offers to take over one or more of the recipient's other responsibilities while the recipient is under stress

**Appendix 6: A modified version of Social Support Behaviour Code
(Mo and Coulson, 2008) after Pilot study**

	Support type	Purpose of Communication
	Informational support	
1	Advice	Offers ideas and suggest actions
2	Referral	Refers the recipient to some other source of help
3	Situation appraisal	Reassure or redefine the situation
4	Teaching	Provide detailed information, facts, or news about the situation or about skills needed to deal with the situation
5	Sharing own experience	Involves the sharing experience that served as references rather than education
	Esteem support	
6	Compliments	Says positive things about the recipient or emphasize the recipient's abilities.
7	Validation	Express agreement with the recipient's perspective on the situation
8	Relief of blame	Tries to alleviate the recipient's feelings of guilt about the situation
	Network support	
9	Access	Offers to provide the recipient with access to new companions
10	Presence	Offers to spend time with the person, to be there
	Emotional support	
11	Expression of care	Contain expression of concern to other members
12	Relationship	Stresses the importance of closeness and love in relationship with the recipient
13	Physical Affection	Offers physical affection, including hugs, kisses, hand holding, shoulder patting
14	Confidentiality	Promises to keep the recipient's problems in confidence
15	Empathy	Express understanding of the situation or discloses a personal situation that communicates understanding
16	Sympathy	Express sorrow or regret for the recipient's situation or distress
17	Encouragement	Provide the recipients with hope and confidence
18	prayer	Prays with and/or for the recipient
	Tangible Assistance	
19	Loan	Offer to lend the recipient something (including money)
20	Perform direct task	Offers to perform a task directly related to the stress
21	Express willingness	Express willingness to help
22	Perform indirect task	Offers to take over one or more of the recipient's other responsibilities while the recipient is under stress

Appendix 7: Coursaris and Liu (2009) coding scheme for support-seeking messages...

Sought support	Description
Seeking informational support	Included specific questions concerning the situation to obtain factual information, evaluate certain situation or to seek suggestions or advice
Seeking emotional support	Show emotional or psychological weakness and need for comfort
Seeking esteem support	Validation for perspective/relief of blame
Seeking network support	Asking for prolonged or contact with others in similar situation
Seeking tangible support	Asking for financial, material, equipment, asking to be shown an aspect of care on a one-to-one basis
Sharing personal experiences	Share personal conditions, thoughts, and feelings related to the issue with others initially and spontaneously.
Expression of gratitude	Expressed straightforward thankfulness for the recipient's previous support
Congratulations	Express joy or acknowledgment of the recipient's achievement or good fortune

Appendix 8: A modified version of Coursaris and Liu (2009) coding scheme after pilot study

Sought support	Description
Seeking informational support	Included specific questions concerning the situation to obtain factual information, evaluate certain situation or to seek suggestions or advice
Seeking wellbeing information	Specific questions about how to offer support to others
Seeking emotional support	Show emotional or psychological weakness and need for comfort
Seeking esteem support	Validation for perspective/relief of blame
Seeking network support	Asking for prolonged or contact with others in similar situation
Seeking tangible support	Asking for financial, material, equipment, asking to be shown an aspect of care on a one-to-one basis
Sharing personal experiences	Share personal conditions, thoughts, and feelings related to the issue with others initially and spontaneously.
Expression of gratitude	Expressed straightforward thankfulness for the recipient's previous support
Congratulations	Express joy or acknowledgment of the recipient's achievement or good fortune
Expressions of care	Expression of concern for others
Encouragement	Sending messages of hope and confidence

**Appendix 9: List of head and neck cancer Facebook groups
available in 2013**

	Facebook Support Groups	No of members Feb 2013	Open/Closed	Date started
1	Head and Neck Cancer Support Backus	15	Closed	Feb 2012
2	Laryngectomy Care Club (Prothsahanteam.org)	150	Closed	Nov 2012
3	Laryngectomy support	212	Open	Mar 2012
4	Lary's Speakeasy Laryngectomy throat cancer	15	Closed	Aug 2011
5	Mouth Cancer Awareness	107	Open	Dec 2012
6	Mouth Cancer Cup 'Saucer Kings'	9	Closed	Apr 2012
7	Oral Cancer Awareness	95	Open	Nov 2011
8	Oral cancer fighting club	465	Open	Jul 2012
9	Oral Cancer Foundation (OCF)	5832	Open	Nov 2012
10	PNG Mouth Cancer Awareness Program.	3486	Closed	Jan 2012
11	Prevent Mouth Cancer	411	Open	Mar 2011
12	Survivors of Head and Neck Cancer	686	Closed	Jan 2012
13	Survivors of tongue cancer	25	Open	Mar 2012
14	The Laryngectomy	59	Open	Oct 2012
15	The swallows head and neck cancer support group buy and sell	1,238	Closed	Jan 2013
16	Throat and oral cancer survivors	165	Open	Oct 2011
17	Throat Cancer Awareness	126	Open	Aug 2011
18	Thyroid Head and Neck Cancer (THANC) Foundation	290	Open	Oct 2008
19	Tonsil Cancer Support Group	25	Closed	Apr 2013

Appendix 10: Brief description of the OSGs used for sample recruitment in Study 2...

- Macmillan Head and Neck Cancer Group

An online group belong to Macmillan Cancer Support and designed for anyone affected by H&N cancers, including oral cancer, throat and larynx. Macmillan Cancer Support is one of the biggest British charities and offers specialist health care, financial and information support to individuals affected by cancer and helps them with some medical needs. Macmillan also looks at the emotional, practical and social impact of cancer, and fights for better care to people affected by cancer. The goal of this charity is to access to and improve the lives of each person living with cancer in the UK (Macmillan, 2012).

- The Oral Cancer Foundation

The Oral Cancer Foundation is an American national public service, non-profit entity intended to diminish suffering and save lives through research, education, prevention, advocacy, and patient support activities directed for people living with H&N cancer, including mouth cancer, throat cancer and tonsil cancer. An anonymous and free patient / survivor discussion forum is open to the public, enable individuals currently fighting H&N cancer and their families to achieve inspiration and insights from others have preceded them to this site. It is closely monitored for suitability of information exchanged. In spite of the main forum, the Oral Cancer Foundation has other social networking sites on Facebook, Twitter, flicker and YouTube (OCF, 2012).

- Survivors of Head and Neck Cancer

A Face Book support group aimed to act as a source of physical, emotional and spiritual encouragement for people who live/lived with any kind of H&N cancer, their families and caregivers. This group is also willing to offer a comfortable place to share common experiences and discuss ideas for all of its users (Greco, 2014).

- Throat and oral cancer survivors

A face book Group provides online support to survivors of cancers of the throat and neck, and also to their families, and caregivers (Gev, 2012).

Appendix 11: Invitation message for participation in the online questionnaire

“This posting is intended to reach people who are accessing this online support group and who have been diagnosed with head and neck cancer at some point. If you do not meet the above description, please ignore this and no need to continue”.

We are writing to ask you to take part in a research study being conducted by the School of Clinical Dentistry, University of Sheffield. The purpose of the research is to explore the role of online support groups and forums for people who live with head and neck cancer. We are interested in whether the use of such groups is related to better psychological outcomes for people living with head and neck cancer and, if so, the processes by which this may come about. In the future we hope to use the findings to identify ways to plan and develop such groups to provide maximum support for people with head and neck cancer and their families.

With this email, there is an attached file, which gives more information on the research study. If, after reading it, you would like to take part in the study, please click on the following link to access and complete our questionnaires and the consent form.

The link to our questionnaires is:

<https://docs.google.com/a/sheffield.ac.uk/spreadsheets/viewform?formkey=dEh6UUpIbXd1Q0E2bEc3RTFpQ3ZickE6M. Q>

It would be very helpful to us if you could complete the questionnaires and consent form within 7 days.

If after reading the information leaflet you would like more information then please feel free to contact, Mr Eamar Al Gtewi, Dr Sarah Baker or Dr Janine Owens, at the address given below. We would like to stress that your participation is entirely voluntary and that you can withdraw at any time All information supplied will be treated confidentially and only used for research purposes.

May we take this opportunity to thank you for your time.

Yours sincerely,

Mr Eamar Al Gtewi

Dr Sarah Baker

Dr Janine Owens

Phone
+44(0)7413691901

Phone +44(0)114
2717837

Phone: +44 (0) 114 271
7891

Email:
mdp08eea@sheffield.ac.uk

Email :
s.r.baker@sheffield.ac.uk

Email:
jan.owens@sheffield.ac.uk

Person-centred and population oral health research group
School of Clinical Dentistry
University of Sheffield
Claremont Crescent
Sheffield S10 2TA
<http://www.shef.ac.uk/dentalschool/research/papor>

Appendix 12: Information sheet for Study 2



The
University
Of
Sheffield.

School
Of
Clinical
Dentistry.

Academic Unit of Dental Public Health

Head of Unit

Professor Peter G Robinson
BDS, MSc, PhD, FRACDS, FDSRCS, FFPH, FHEA

Claremont Crescent
Sheffield
S10 2TA

Telephone: +44 (0) 114 271 7885 (office)

Fax: +44 (0) 114 271 7843

Email: ohd@sheffield.ac.uk

INFORMATION SHEET

You are being invited to take part in a research project. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

Please remember that all details will be kept anonymous, confidential and used solely for research purposes.

Thank you for taking the time to complete this survey.

The Research Project

Title: "The role of online support groups for individuals with head and neck cancer"

Purpose: Social support is increasingly recognised as playing an important role in individual's health; particularly helping people cope with the diagnosis, progression, and outcomes of cancer. There has been an increase in the number of people using the internet for advice, information, and support related to various health conditions, including cancer. To date, many online groups have been established for individuals and their carers to discuss issues relating to their head and neck cancer. This research project aims to investigate whether the frequency of using such groups is related to better psychological outcomes for people who live with head and neck cancer and, if so, the processes by which this may come about.

To do this, we are asking patients with head and neck cancer who use such online groups or groups to complete a questionnaire. There is no funding for this project; it is part of a doctoral dissertation being conducted in the School of Clinical Dentistry at the University of Sheffield.

Why have I been chosen?

You have been chosen because you have experienced head and neck cancer and you are currently using online forums. Your participation will enable us, in the future, to plan and develop such forums to provide maximum support for people who live with head and neck cancer and their families.

The project aims to recruit around 239 individuals with head and neck cancer.

Do I have to take part?

It is up to you to decide whether or not to take part, and you are free to withdraw at any time. If you do decide to take part, you should keep this information sheet. You will also be asked to fill in a consent form. You should keep one copy of the consent form until the end of the study.

If you decide to take part you are still free to withdraw at any time and without giving a reason by simply closing the web browser.

What will happen to me if I take part?

If you decide to take part you are asked to complete a series of short questionnaires. In the questionnaires, you will first be asked to confirm some demographic information such as, gender and age followed by, some questions about your cancer such as the site and stage of treatment. Then you will be asked to complete some questions related to how you cope, your support and social networks, anxiety, depression and quality of life. Many of the questions may seem similar in what they are asking; even if this is the case, we would ask you to complete all of the questions. There are no right or wrong answers; we simply want your opinion. For all questions, you will be asked to indicate your preferences by either choosing between a few options or rating the scenario presented.

What do I have to do?

If you would like to take part, simply fill in the consent form and complete the questionnaires, then just click on the submit button at the end.

If you would be willing, we are asking a small group of individuals to take part in a short online interview to explore the issues raised and the role of online support groups in more detail. If you would be willing to take part, please indicate so at the end of the questionnaires.

What are the possible disadvantages and risks of taking part?

There are no known risks for individuals who take part.

What are the possible benefits of taking part?

Whilst there might be no immediate or direct benefits for those people participating in the project, the information you provide us with will help us gain a better understanding of how online support groups may have an impact on the quality of life of individuals with head and neck cancer in relation to improving support, coping strategies and reducing anxiety and depression. It is hoped that this study will help advance awareness of the importance of online head and neck cancer groups in potentially improving psychological outcomes.

Do I have to participate in the interview?

We are asking a small group of individuals (approximately 30) to take part in a further online interview to explore in more detail the role of online support groups in head and neck cancer. You do not have to take part in the interview. Even if you decide to take part, again you are free to withdraw at any time and without giving a reason.

What should I do if I want to take part in the interview?

If you would like to take part in the interview, simply respond 'yes' to the question at the end of the questionnaires and then indicate a suitable means by which we can contact you. We will contact you about arranging a suitable time.

Do I have to answer all the questions during the interview?

No, the interview will be flexible and you have the right to answer or refuse any question and you can stop the interview at any time according to your situation and convenience.

Will my taking part in this study be kept confidential?

All information that you provide us for this study will be kept strictly confidential. The whole study will be conducted according to guidance on ethics from the University of Sheffield / UK (www.shef.ac.uk). To protect your privacy the following measures will be taken to ensure that no-one, apart from the principal researcher, has access to your identity:

- All the information and responses that you give will be completely anonymous. Your name is not required.
- All information supplied will be kept confidential.

What will happen to the results of the research study?

The results from the information you provide will be used to help us gain a fuller picture of the role of online support forums for people with head and neck cancer in terms of support, coping and quality of life.

No-one will be able to recognise your identity in any report or related publication based on the results of the study. Following completion of the study a completed report will be placed on the forum or sent to you by email giving a summary of our findings and recommendations.

Who is organising and funding the research?

There is no funding for this project; it is part of a PhD programme in the School of Clinical Dentistry at the University of Sheffield. The principal researcher is a PhD student and the co-researchers are academic members of staff at the University of Sheffield.

Who has reviewed the study?

The study's protocol has been reviewed and ethically approved by School of Clinical Dentistry, The University of Sheffield, in accordance with the University Research Ethics policy.

What if I have questions?

This project is being supervised by Dr Sarah Baker and Dr Janine Owens, School of Clinical Dentistry, The University of Sheffield. For further information please contact: Researcher: Eamar Al Gtewi, mdp08eea@sheffield.ac.uk , +44(0)7413691901, Supervisors: Dr Sarah Baker, s.r.baker@sheffield.ac.uk, +44 (0) 114 271 7837 or Dr Janine Owens jan.owens@sheffield.ac.uk +44 (0) 114 271 7891.

Thank you for reading this and I hope you wish to participate.

A copy of this information sheet and the consent form should be kept by you during the research study either in your email, computer or hard printed copy if you are able to print.

Appendix 13: Consent form for Study 2



The
University
Of
Sheffield.

School
Of
Clinical
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Academic Unit of Dental Public Health

Head of Unit

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Email: ohd@sheffield.ac.uk

CONSENT FORM

Title of Project: The role of online support groups for individuals with head and neck cancer'

Name of Researchers: Mr Eamar Algtewi, Dr Sarah Baker and Dr Janine Owens

Please check box

1. I confirm that I have read and understand the information sheet dated 05 December 2012 (version: 1) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without there being any negative consequences
3. I understand that my responses will be kept strictly confidential and give permission for the researcher to have access to my anonymised responses.
4. I agree to take part in the above study.

Date: __/__/20__

By clicking the "Agree" button below, you agree that you have read, understand, and agree to take part in above study.

Please tick this box to proceed.

Appendix 14: Instruction leaflet for the online questionnaire and interview



The
University
Of
Sheffield.

School
Of
Clinical
Dentistry.

Academic Unit of Dental Public Health

Head of Unit

Professor Peter G Robinson
BDS, MSc, PhD, FRACDS, FDSRCS, FFPH, FHEA

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Email: ohd@sheffield.ac.uk

INSTRUCTION LEAFLET

Thank you for agreeing to participate. As explained in the information leaflet, you are being asked to complete a series of questions that explore the use of online support groups, support, coping and quality of life relating to head and neck cancer. Everybody is different; you may find that some of the statements do not apply to you, that is OK, please give the response that best fits how you feel. Remember, there are no right or wrong answers.

Instructions:

We would like you to read and accept the consent form. Its purpose is to safeguard that you have understood the aim of the study and your involvement in it. Please print and keep one copy of the consent form until the end of the study. Even after accepting the consent form you can withdraw from the study at any time if you wish to do so.

Please complete the questionnaires at a time when you are on your own, in their order. Try not to spend too much time on each statement, give your first response. Most responses need you to click the appropriate response. However, in some cases if you are asked to write a brief explanation to a question, please do this in the space indicated.

Once completed would you kindly click on the submit button at the end of the questionnaire.

Regarding the interview:

- If you would like to participate in the interview just answer (yes) to the relevant question and indicate a suitable chatting mean of contact and you will be will be contacted later for suitable appointment.
- The appointments will be flexible according to your suitable time and you will have the right to cancel or amend the appointment according to your situations.
- The interview will last between 20-30 minutes
- The interviewer will start this online interview by typing the first question in a small text box of the chat software and will send it to you. You will read the question in a text box and then can send an answer to the interviewer the same way.
- You have the right to withdraw at any time during the interview.

We would like to stress that all information is anonymous and will be treated in the strictest confidence and only used for the purpose of this research

May we take this opportunity to thank you for your participation and remind you that if you wish to discuss any aspect of the research do not hesitate to contact us at the address given above.

With regards

Mr Eamar Al Gtewi
(PhD student)

Dr Sarah Baker
(Health Psychologist)

Dr Janine Owens
(Heath Promotion Expert)

Appendix 15: Questionnaires for study 2, Part 1

QUESTIONNAIRES

(Questionnaires was formatted for use on Google Drive)



School of Clinical Dentistry
University of Sheffield

The role of online support groups for head and neck cancer

Questionnaire

A. About you

1. What is your age?

_____ years

2. Which of the following describes you?

Male

Female

3. What country do you live in?

4. What is your religion?

No religion

Christian (all denominations)

Muslim

Buddhist

Hindu

Jewish

Sikh

Any other religion (Please specify) _____

Prefer not to say

5. What is your marital status?

Married / Living with a partner

Widowed

Single

Other,..... Please specify: _____

- Prefer not to say

6. Who else lives in your household?

Please click all of the boxes that apply

- No-one, I live alone
- Children
- Siblings
- Other relatives (e.g. parents, grandparents)
- Non-family members
- Anyone else,..... Please specify: _____

7. How satisfied are you with your income?

- Totally insufficient,
- Somewhat insufficient
- Sufficient for essential needs
- More than sufficient

B. About your cancer

1. Where is/was your cancer located?

- Lip and mouth***
(Lips, tongue, under my tongue, gum, jaw bones, roof of my mouth, cheeks, salivary gland)
- Throat***
- Vocal cords***
- I am not sure***

2. Which of the following describes your cancer stage?

- Stage I
- Stage II
- Stage III
- Stage IV
- I am not sure

3. Has the cancer spread into other organs (metastatic)?

- Yes
- No
- I am not sure

4. What treatment(s) or therapies have you undergone so far?

(Please click all of the boxes that apply)

- | | |
|--|---|
| <input type="checkbox"/> Chemotherapy | <input type="checkbox"/> Colour, Art or Music Therapy |
| <input type="checkbox"/> Radiation | <input type="checkbox"/> Spiritual Healing |
| <input type="checkbox"/> Surgery | <input type="checkbox"/> Prayer |
| <input type="checkbox"/> Acupuncture/Oriental Medicine | <input type="checkbox"/> Meditation or Self-Healing |
| <input type="checkbox"/> Naturopathy | <input type="checkbox"/> Psychological Counselling |
| <input type="checkbox"/> Herbology or Nutritional Consulting | <input type="checkbox"/> Face-to Face Support Groups |
| <input type="checkbox"/> Online Support Groups | <input type="checkbox"/> Massage or other Bodywork |
| <input type="checkbox"/> Others_____ | <input type="checkbox"/> I am not sure |

5. In which treatment stage are you now?

- Pre-diagnosis
- Pre-treatment
- Under-treatment
- Post-treatment
- I am not sure

6. How long approximately have you been diagnosed with this cancer?

_____ years _____ months

- I am not sure

C. About using online support groups

1. Approximately **how many days in the past month** have you spent accessing head and neck cancer-related online support groups (i.e. forums, chat rooms, bulletin boards)?]

_____ days

2. Approximately, **how many hours per day in the past month** have you spent accessing head and neck cancer-related online support groups (i.e. forums, chat rooms, bulletin boards)?

_____ hours

3. Approximately, how **long have you been accessing** these online groups (head and neck cancer -related online support groups)?

_____ years _____ months _____ days

4. Are you a member of an online support group for head and neck cancer?

Yes (if yes go to question 5)

No (if no go to question 8)

5. How long have you been member of an online support group for head and neck cancer?

_____ years _____ months

6. Approximately, how many messages have you posted requesting advice or support to that online group?

7. How many messages have you sent as a response to other people's messages in that online group?

8. Could you tell us why you decided to participate in an online support group?

Because I was curious how other members were doing

It was part of my daily routine

When I had a question about my health condition

To enjoy myself

When I heard new information about my health condition

When I had a lot of symptoms

Before visiting a doctor

After visiting a doctor

When I had new symptoms

Because I felt lonely

Because other members expected me to be here

- To stay in touch with other members
 - To help other members in their health condition
 - Other reason (please specify)
-
-

9. In your view, has being a member of an online support group made any difference to how you cope with your cancer?

- No
- Yes

10. What do you consider to be the main advantages of participating in an online support group?

11. Are there any problems you have experienced in participating in an online support group?

- No
- Yes

D. About support you receive from others

The following questions ask about your social support. Please read each question and click the response that most closely describes your current situation.

1. How many close friends do you have, people that you feel at ease with, can talk to about private matters?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

2. How many of these close friends do you see at least once a month?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

3. How many relatives do you have, people that you feel at ease with, can talk to about private matters?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

4. How many of these relatives do you see at least once a month?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

5. Do you participate in any groups other than online groups, such as a senior centre, social or work group, religious-connected group, self-help group, or charity, public service, or community group?

- No

- Yes
- Unknown

6. About how often do you go to religious meetings or services?

- Never or almost never
- Once or twice a year
- Every few months
- Once or twice a month
- Once a week
- More than once a week
- Unknown

7. Is there someone available to you whom you can count on to listen to you when you need to talk?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

8. Is there someone available to give you good advice about a problem?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

9. Is there someone available to you who shows you love and affection?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more
- Unknown

10. Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more

Unknown

11. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?

None

1 or 2

3 to 5

6 to 9

10 or more

Unknown

E. About confidence in doing things related to your cancer.

This questionnaire contains many things that a person might do when receiving treatment for cancer. *We are interested in your judgment of how confident you are that you can accomplish those things.* Make sure your ratings accurately reflect your confidence whether or not you have done it in the past. So, your ratings reflect your confidence that you can do these things now (or in the near future). Please read each numbered item. Then rate that item on how confident you are that you can accomplish that behaviour. Check a number on the scale. If you check a "1" you would be stating that you are not at all confident that you can accomplish that behaviour. If you check a "9" you would be stating that you are totally confident that you can accomplish that behaviour. Numbers in the middle of the scale indicate that you are moderately confident that you can accomplish that behaviour. Please rate all items. If you are not sure about an item, please rate it as best you can.

How confident are you in:

1. Maintaining independence

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

2. Maintaining a positive attitude

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

3. Maintaining a sense of humour

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

4. Expressing negative feelings about cancer

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

5. Maintaining work activity

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

6. Remaining relaxed throughout treatments and not allowing scary thoughts to upset me

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

7. Actively participating in treatment decisions

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

8. Asking doctors questions

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

9. Seeking consolation

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

10. Sharing feelings of concern

Not at all confident					Moderately confident				Totally confident
1	2	3	4	5	6	7	8	9	

11. Managing nausea and vomiting

Not at all					Moderately				Totally
------------	--	--	--	--	------------	--	--	--	---------

confident 1 2 3 4 confident 5 6 7 8 confident 9

12. Coping with physical changes

Not at all confident 1 2 3 4 Moderately confident 5 6 7 8 Totally confident 9

F. About feelings of anxiety and depression

Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

G. How do you cope with your illness?

		Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
1	At the moment I take one day at a time				
2	I see my illness as a Challenge				
3	I've put myself in the hands of God				
4	I feel like giving up				
5	I feel very angry about what has happened to me				
6	I feel completely at a loss about what to do				
7	It is a devastating feeling				
8	I count my blessings				
9	I worry about the cancer returning or getting worse				
10	I try to fight the illness				
11	I distract myself when thoughts about my illness come into my head				
12	I can't handle it				
13	I am apprehensive				
14	I am not very hopeful about the future				
15	I feel there is nothing I can do to help myself				
16	I think this is the end of the world				
17	Not thinking about it helps me cope				
18	I am very optimistic				
19	I've had a good life what's left is a bonus				
20	I feel that life is hopeless				
21	I can't cope				
22	I am upset about having Cancer				
23	I am determined to beat this disease				
24	Since my cancer diagnosis I now realise how precious life is and I'm making the most of it				
25	I have difficulty in believing that this happened to me				
26	I make a positive effort not to think about my illness				
27	I deliberately push all thoughts of cancer out of myMind				
28	I suffer great anxiety about it				
29	I am a little frightened				

H. Your experience of online support groups

We are interested in the role online support groups play in people's lives. Could you tell us how often the following events have taken place throughout your experience using online support groups?

		Never	Rarely	Sometimes	Often	Very often
1	Someone in the group pays you a compliment?					
2	Someone in the group confides in you?					
3	Someone in the group asks you for your help or advice?					
4	Someone in the group points out your strengths?					
5	Someone in the group is interested in you?					
6	Someone in the group consoles you?					
7	Someone in the group offers you sound advice?					
8	Someone in the group reassures you?					
9	Someone in the group invites you to have (personal) contact outside this online support group?					
10	Someone in the group starts a private conversation with you?					
11	Someone in the group pays particular attention to you in special cases, such as during illness or moving house?					
12	Someone in the group gives you encouragement?					
13	You share your worries and fears with other members?					
14	Someone in the group is empathic?					
15	Someone/message in the group shows you the positive side of living with the disease					
16	Someone/message in the group helps you take a more positive attitude towards life					
17	Someone/message in the group shows you how to value life					
18	Someone/message in the group helps you understand more the meaning of life					
19	Someone/message in the group helps you find new and worthwhile goals					
20	Someone/message in the group helps you find the direction in which life is headed					
21	Someone/message in the group offers you hope towards the disease					
22	Someone/message in the group helps you					

	know more about yourself					
23	Someone/message in the group helps you reinterpret the meaning of a situation in a more positive manner					
24	Someone/message in the group shows optimism about the situation you have gone through					
25	Someone/message in the group shows you that there are people worse off than you					
26	Someone/messages in the group helps you realize you are not so bad off after all					
27	Others are an example to you?					
28	You recognize yourself in the stories of other online support group members?					
29	Information exchanged is valuable					
30	Information exchanged is in line with the information I receive from my care providers					
31	Information exchanged is correct					
32	Information exchanged is reliable					
33	Information exchanged is understandable					
34	Information exchanged is usable					
35	Information exchanged is new					
36	Information exchanged is of added value to the information I receive from my care providers					
37	Information exchanged is applicable to my present situation					
38	You can share your everyday experiences with others					
39	You can offer advice and support to others?					

I. About quality of life related to your cancer

This questionnaire asks about your health and quality of life **over the past seven days**. Please answer all of the questions by checking one box for each question.

1. **Pain.** (Check one box:)

- I have no pain.
- There is mild pain not needing medication.
- I have moderate pain - requires regular medication (codeine or nonnarcotic).
- I have severe pain controlled only by narcotics.
- I have severe pain, not controlled by medication.

2. **Appearance.** (Check one box:)

- There is no change in my appearance.
- The change in my appearance is minor.
- My appearance bothers me but I remain active.
- I feel significantly disfigured and limit my activities due to my appearance.
- I cannot be with people due to my appearance.

3. **Activity.** (Check one box:)

- I am as active as I have ever been.
- There are times when I can't keep up my old pace, but not often.
- I am often tired and have slowed down my activities although I still get out.
- I don't go out because I don't have the strength.
- I am usually in bed or chair and don't leave home.

4. **Recreation.** (Check one box:)

- There are no limitations to recreation at home or away from home.
- There are a few things I can't do but I still get out and enjoy life.
- There are many times when I wish I could get out more, but I'm not up to it.
- There are severe limitations to what I can do, mostly I stay at home and watch TV.
- I can't do anything enjoyable.

5. **Swallowing.** (Check one box:)

- I can swallow as well as ever.
- I cannot swallow certain solid foods.

- I can only swallow liquid food.
- I cannot swallow because it "goes down the wrong way" and chokes me.

6. **Chewing.** (Check one box:)

- I can chew as well as ever.
- I can eat soft solids but cannot chew some foods.
- I cannot even chew soft solids.

7. **Speech.** (Check one box:)

- My speech is the same as always.
- I have difficulty saying some words but I can be understood over the phone.
- Only my family and friends can understand me.
- I cannot be understood.

8. **Shoulder.** (Check one box:)

- I have no problem with my shoulder.
- My shoulder is stiff but it has not affected my activity or strength.
- Pain or weakness in my shoulder has caused me to change my work.
- I cannot work due to problems with my shoulder.

9. **Taste.** (Check one box:)

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

10. **Saliva.** (Check one box:)

- My saliva is of normal consistency.
- I have less saliva than normal, but it is enough.
- I have too little saliva.
- I have no saliva.

11. **Mood.** (Check one box:)

- My mood is excellent and unaffected by my cancer.

- My mood is generally good and only occasionally affected by my cancer.
- I am neither in a good mood nor depressed about my cancer.
- I am somewhat depressed about my cancer.
- I am extremely depressed about my cancer.

12. **Anxiety.** (Check one box:)

- I am not anxious about my cancer.
- I am a little anxious about my cancer.
- I am anxious about my cancer.
- I am very anxious about my cancer.

Which issues have been the most important to you <u>during the past 7 days?</u>		
Check <input type="checkbox"/> up to 3 boxes.		
<input type="checkbox"/> Pain	<input type="checkbox"/> Swallowing	<input type="checkbox"/> Taste
<input type="checkbox"/> Appearance	<input type="checkbox"/> Chewing	<input type="checkbox"/> Saliva
<input type="checkbox"/> Activity	<input type="checkbox"/> Speech	<input type="checkbox"/> Mood
<input type="checkbox"/> Recreation	<input type="checkbox"/> Shoulder	<input type="checkbox"/> Anxiety

GENERAL QUESTIONS

I. Compared to the month before you developed cancer, how would you rate your health-related quality of life? (check one box:)

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

II. In general, would you say your **health-related quality of life** during the past 7 days has been: (check one box:)

- Outstanding
- Very good
- Good
- Fair
- Poor
- Very poor

III. Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being, rate your **overall quality of life** during the past 7 days. (check one box:)

- Outstanding
- Very good
- Good
- Fair
- Poor
- Very poor

IV. Please describe any other issues (medical or nonmedical) that are important to your quality of life and have not been adequately addressed by our questions (you may attach additional files if needed and send them by email to the emails provided in the information sheet).

Many thanks for completing this questionnaire. It will be a valuable contribution to our study.

One last question:

In the course of the next few weeks, it may be that we would like to contact you by any of the following ways that you feel it is convenient to you (phone, Skype, yahoo messenger, MSN or Paltalk) at any time suitable for you to organise a short interview regarding your experiences of using online support groups. Would you be willing to help us by participating in this interview? Please check.....

YES

NO

If you have further comments, please feel free to write them in the space provided below (or by email to the addresses provided on the information sheet).

Thank you for your help

Appendix 16: Ethical approval for Study 2



The
University
Of
Sheffield.

School Of Clinical Dentistry.

Mr Eamar Al Gtewi
The School of Clinical Dentistry
University of Sheffield
19 Claremont Crescent
Sheffield
S10 2TA

University Research Ethics Committee (School of Clinical Dentistry)

Research Ethics Lead - Dr Lynne Bingle
Claremont Crescent
Sheffield S10 2TA
Telephone: +44 (0)114 271 7951
Fax: +44 (0)114 271 7894
Email: l.bingle@sheffield.ac.uk

5th December 2012

Full title of study: The role of online support groups for head and neck cancer
Reference number: 56

On behalf of the committee, I am pleased to confirm a favourable ethical opinion for the above research based on the revised supporting documentation. If any further changes are made to these documents the Ethics Committee should be informed and their opinion requested.

With the Committee's best wishes for the success of this project

Yours sincerely

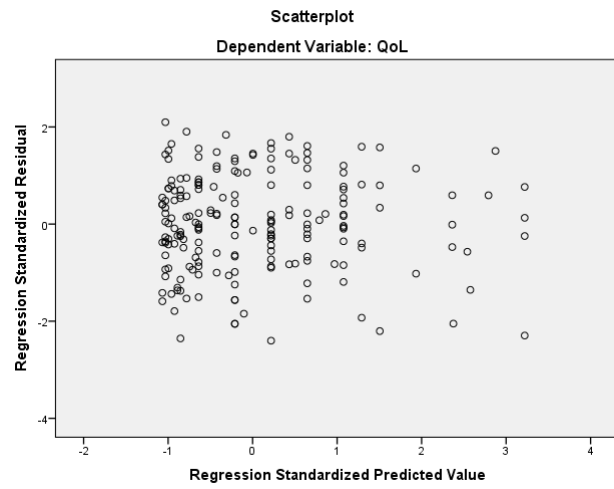
Lynne Bingle
Research Ethics Lead



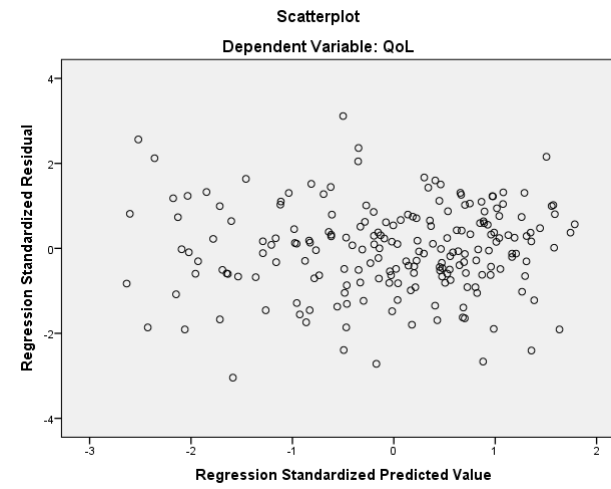
THE QUEEN'S

**Appendix 17: Scatterplot of Regression Standardised Residuals
against Regression Standardised Predicted of each model**

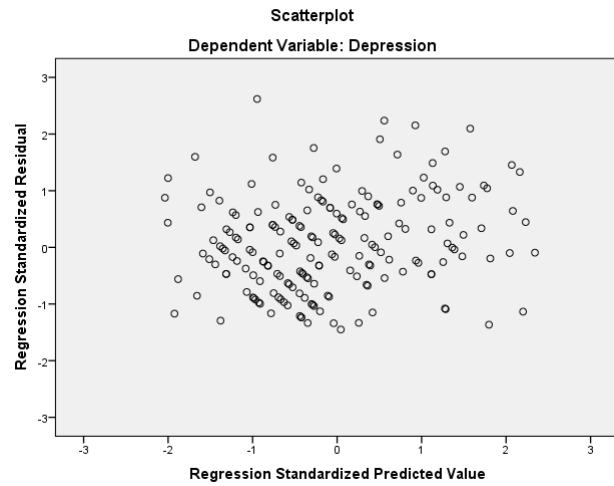
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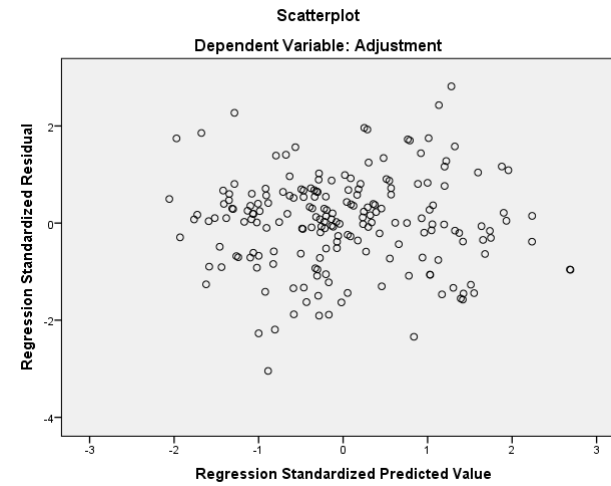
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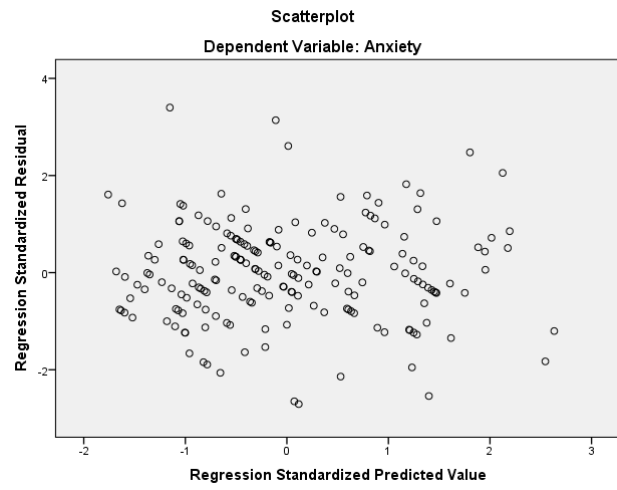
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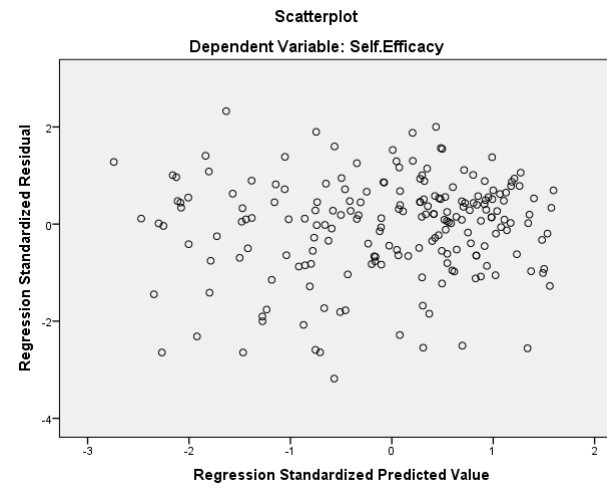
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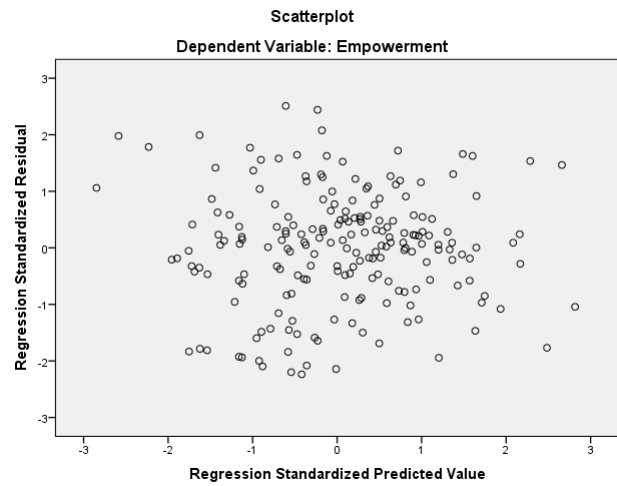
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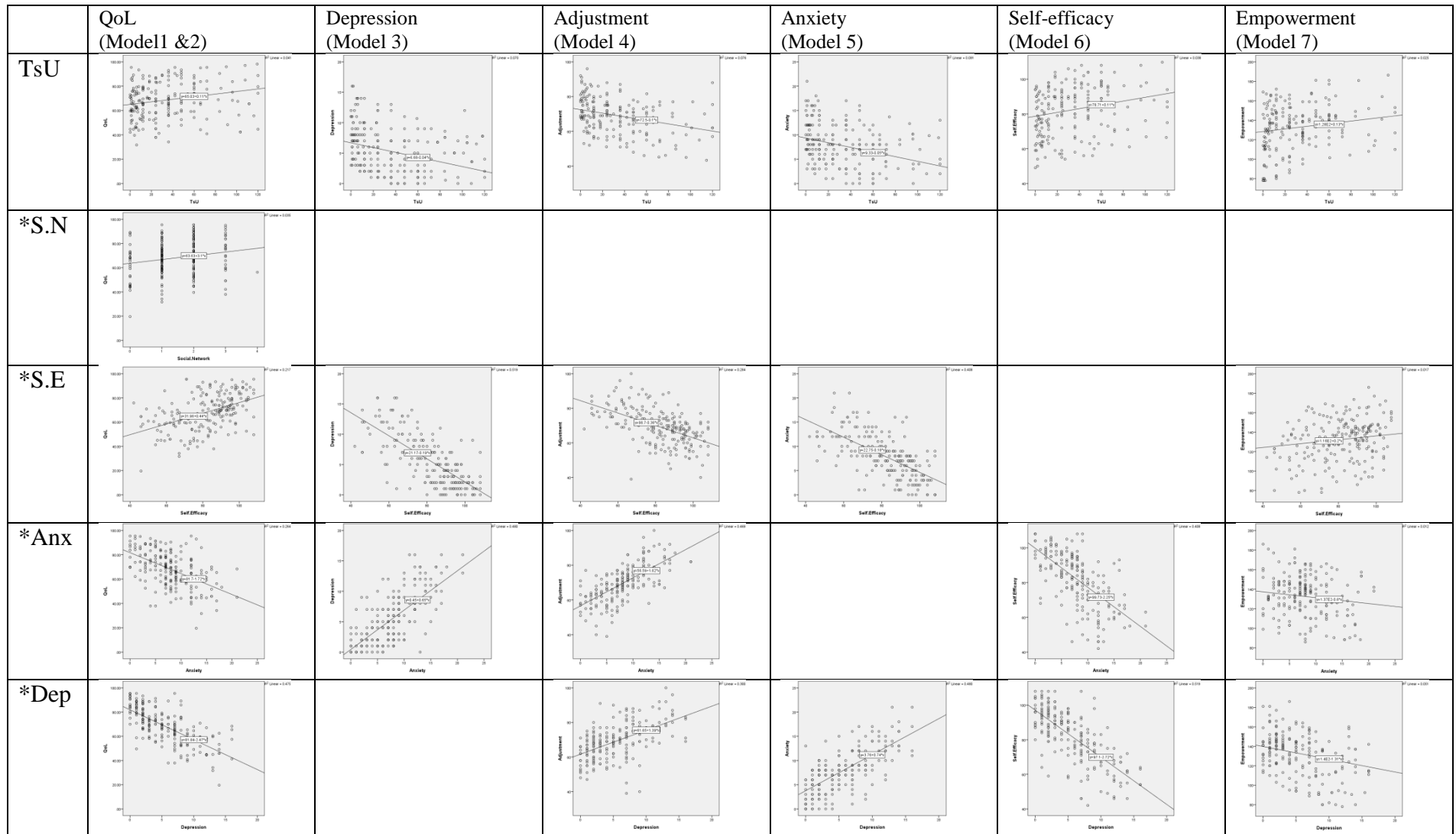
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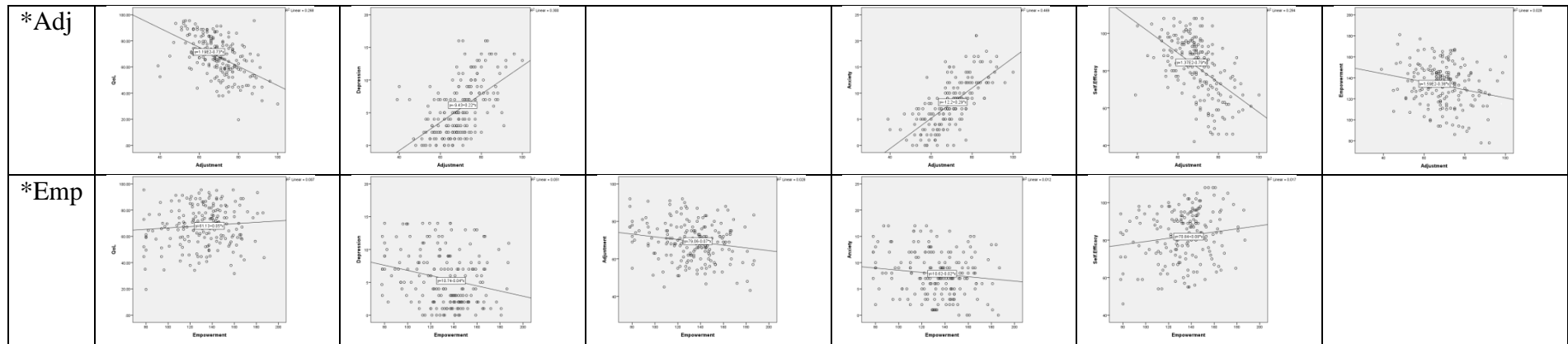


Model (7)



Appendix 18: Regression plots between the variables in the models.

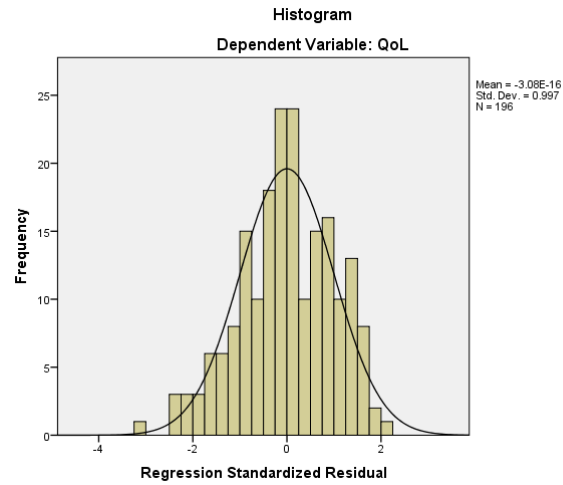




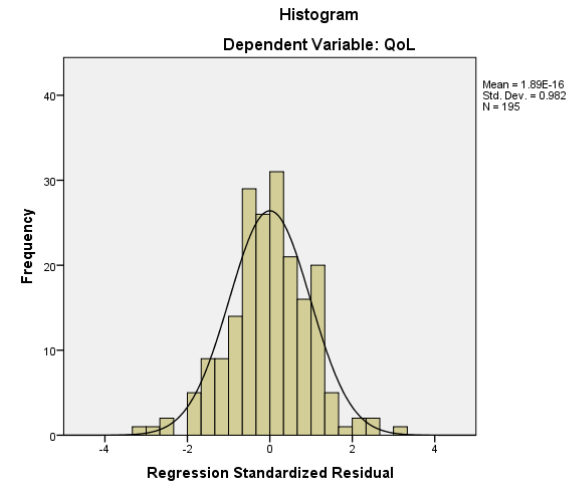
* S.N= Social Network, S.E= Self-efficacy, Anx= Anxiety, Dep =Depression, Adj= Adjustment, Emp= Empowerment

Appendix 19: Histogram for the residuals of each regression model

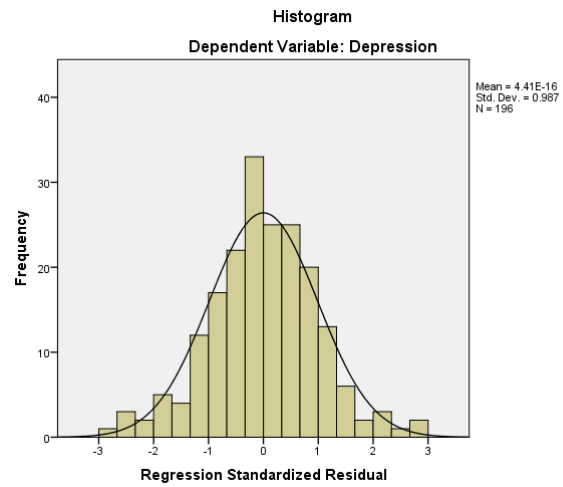
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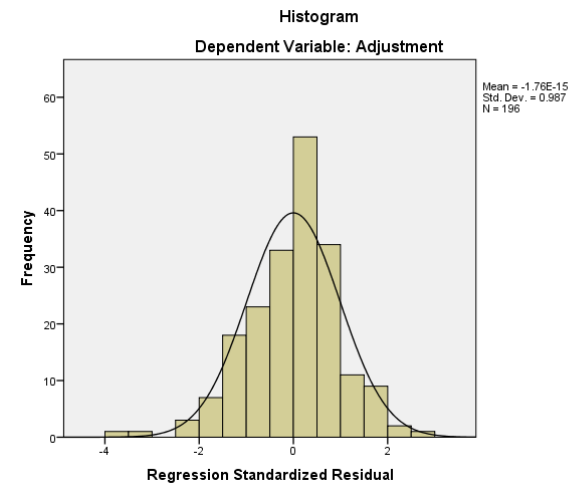
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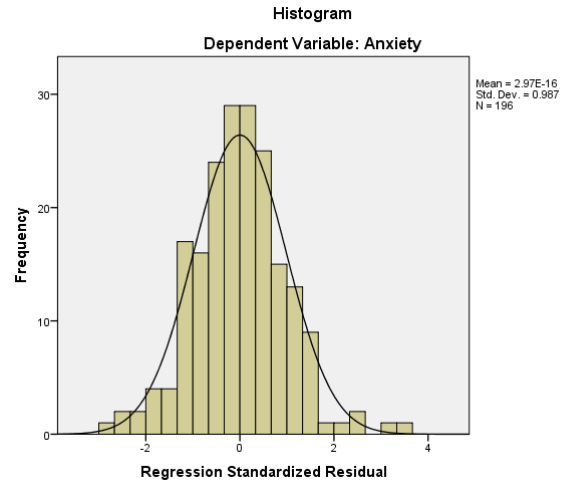
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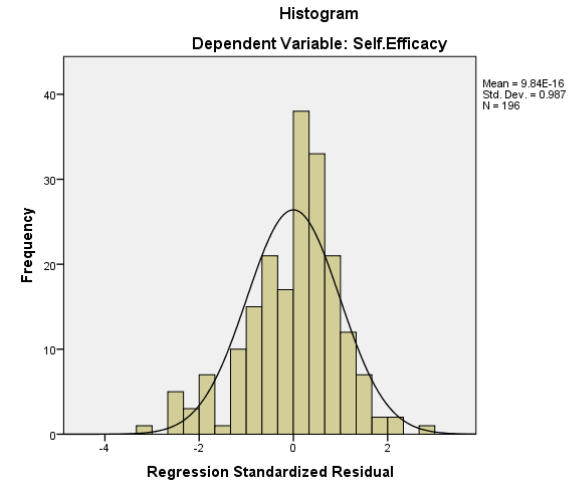
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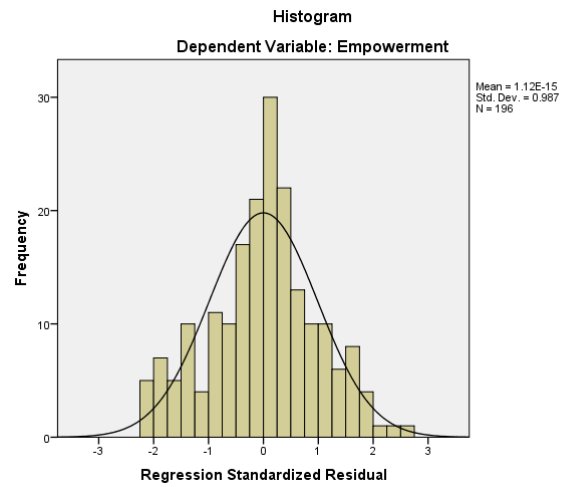
Model (5)



Model (6)

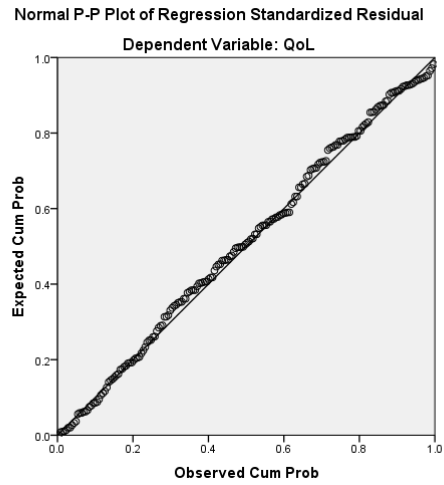


Model (7)

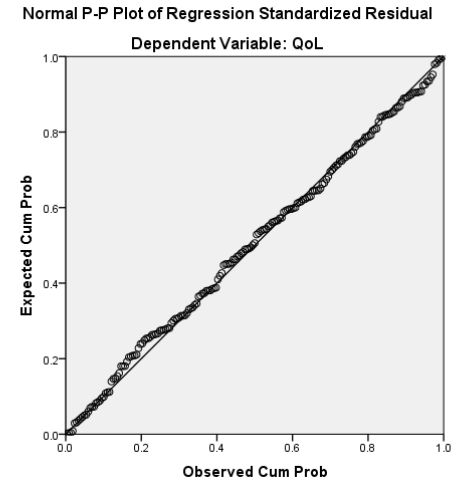


**Appendix 20: Normal Propability Plot P-P Plot) of Regression
Standardised Residuals of each regression model**

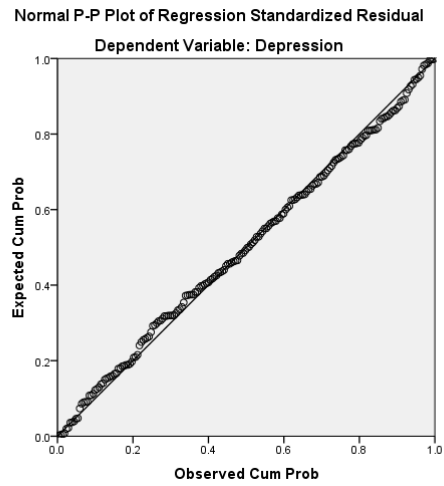
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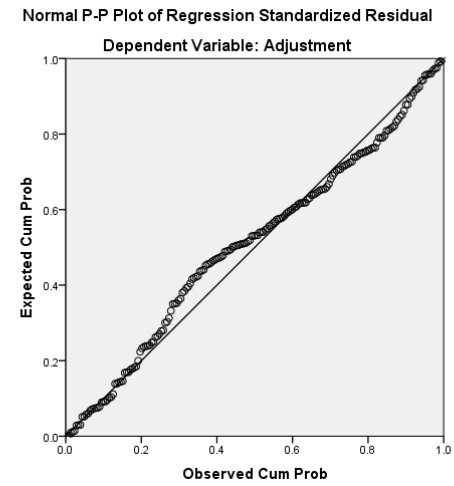
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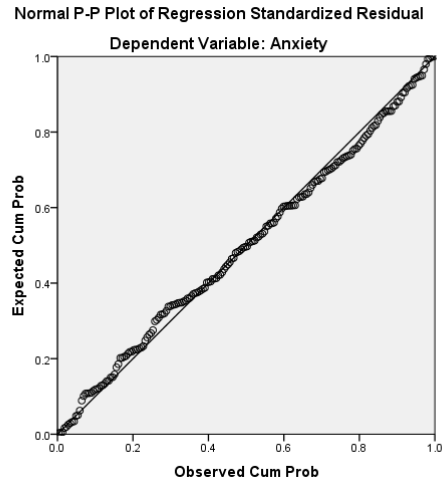
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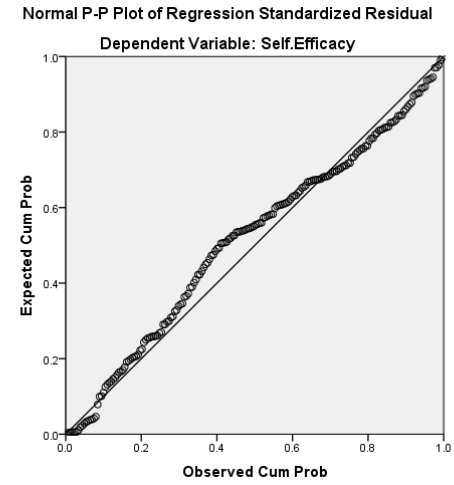
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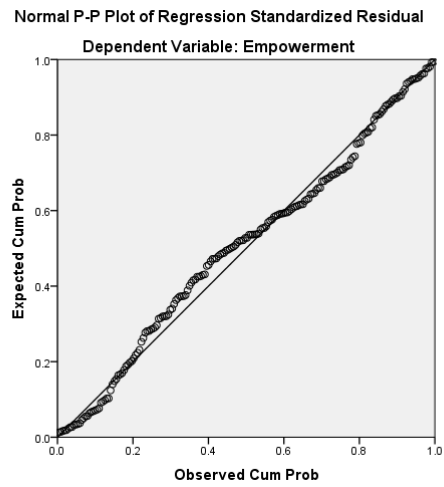
Model (5)



Model (6)

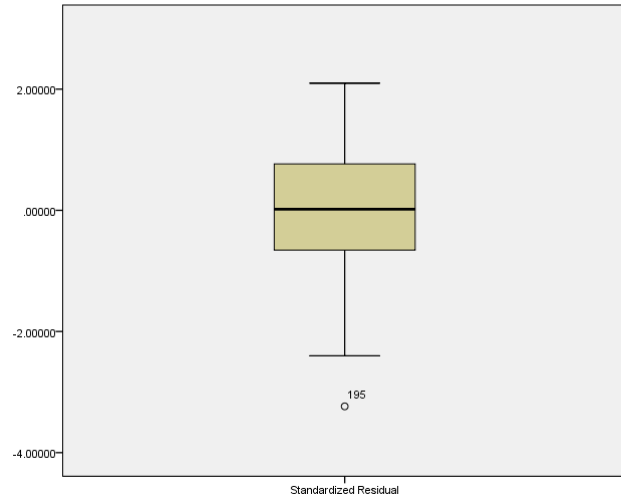


Model (7)



Appendix 21: Box Plot of Regression standardised residuals of each regression model

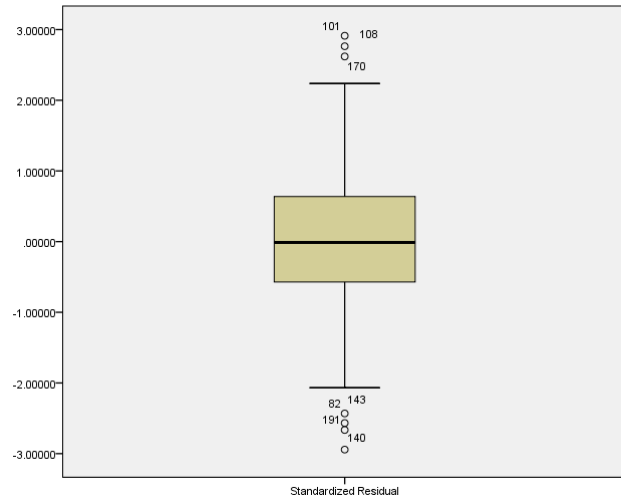
Model (1)



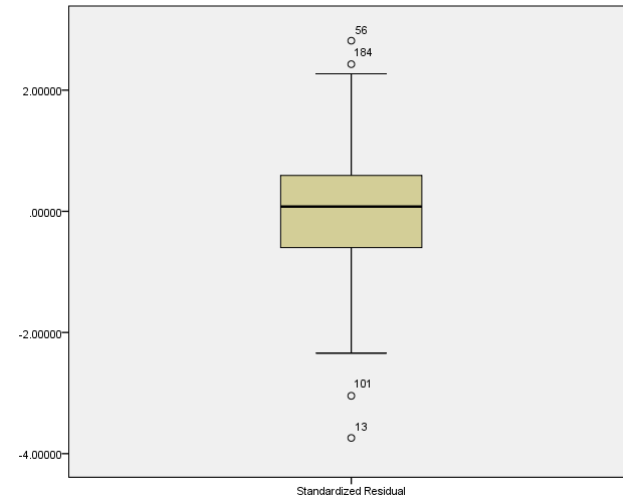
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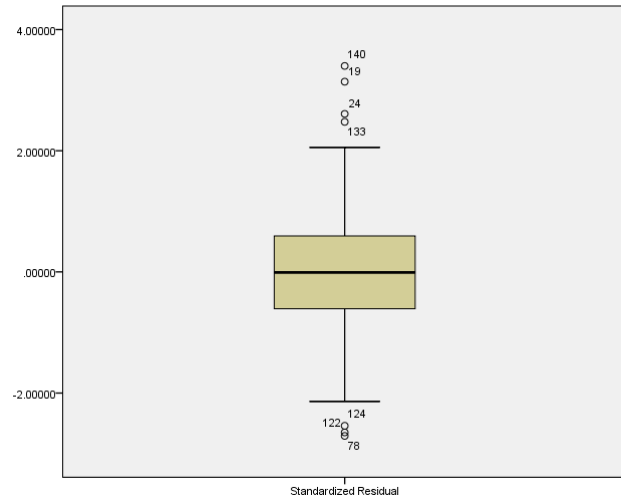
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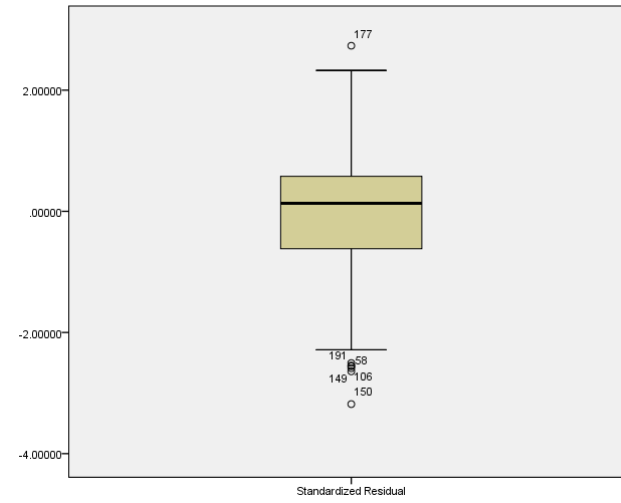
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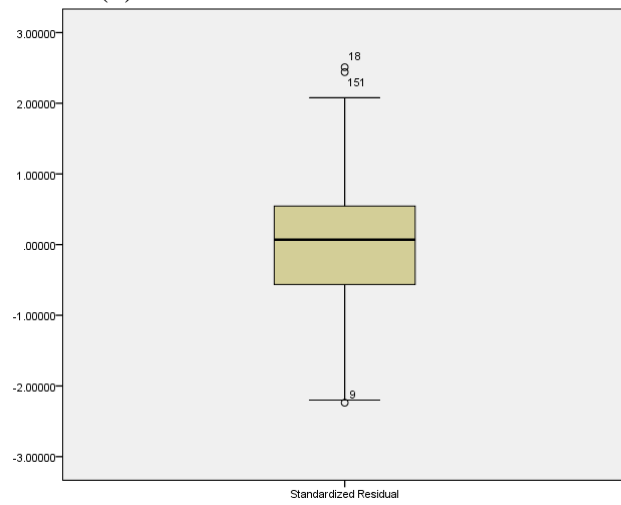
Model (5)



Model (6)

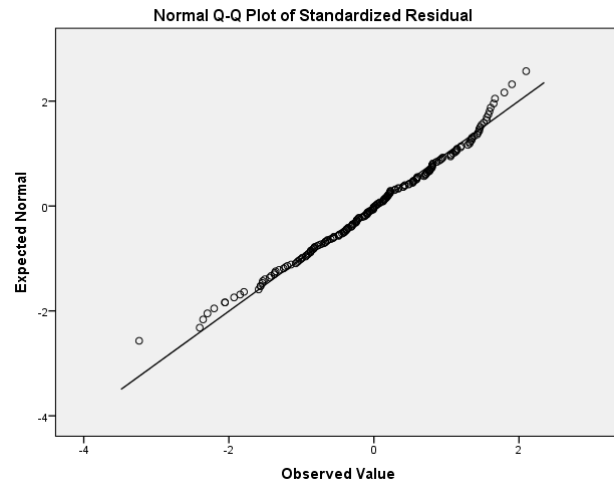


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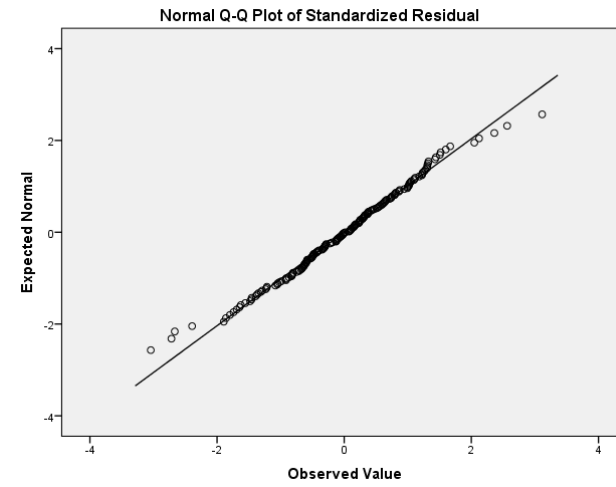


Appendix 22: Normal Q-Q Plot of Standardised Residual for each regression model...

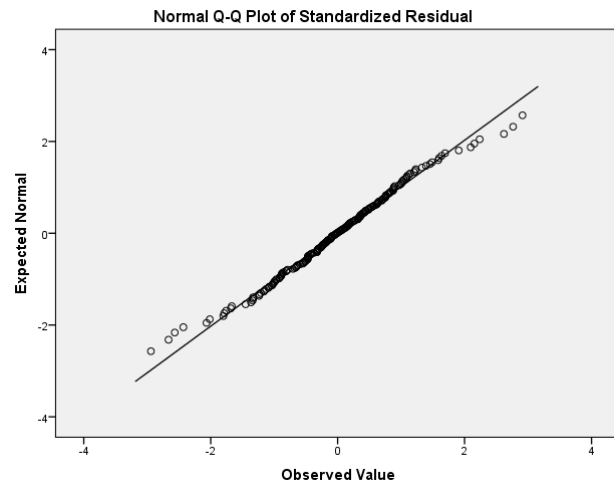
Model (1)



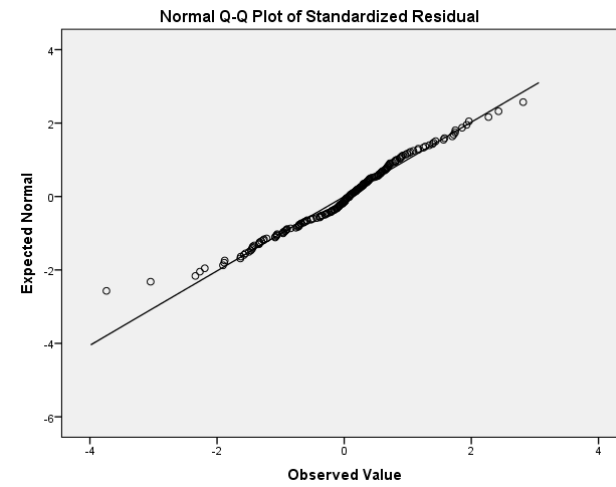
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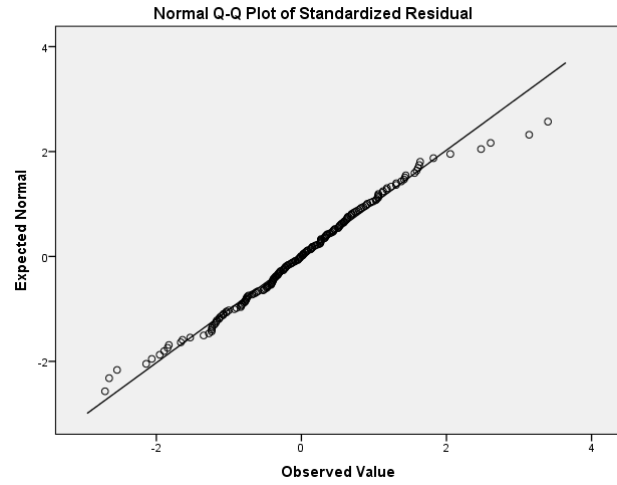
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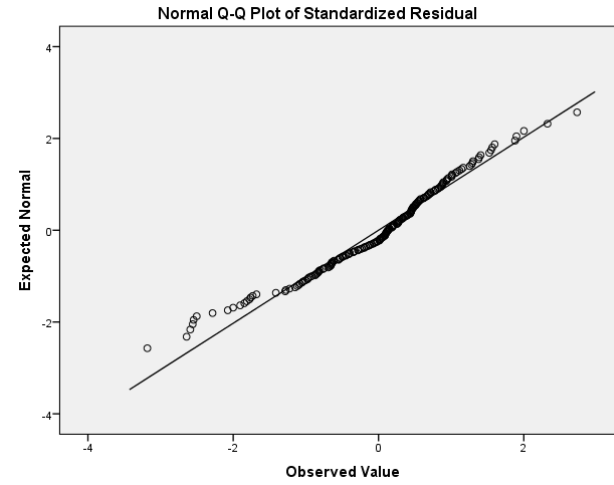
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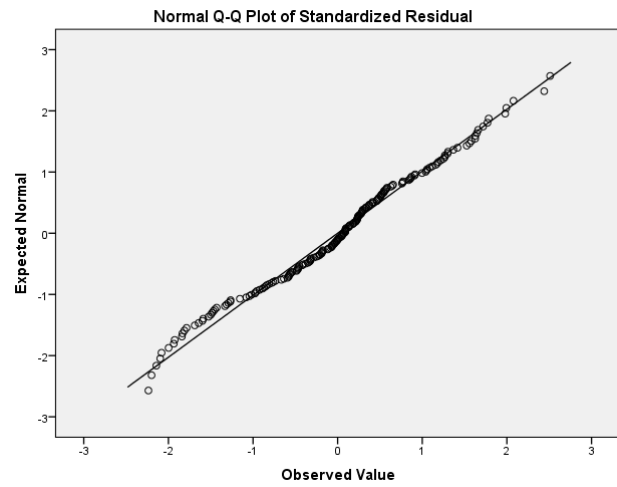
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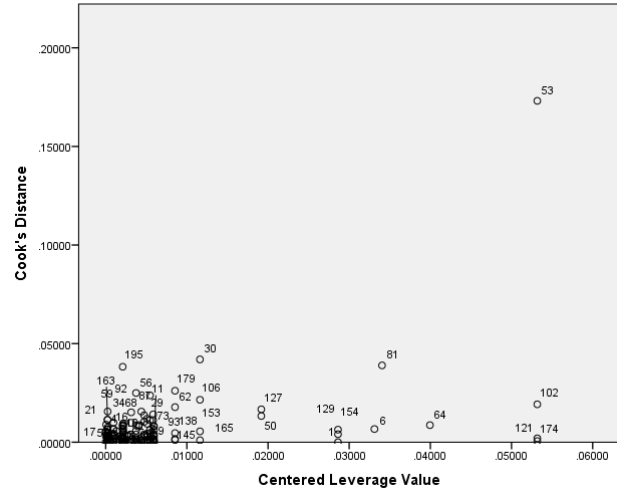


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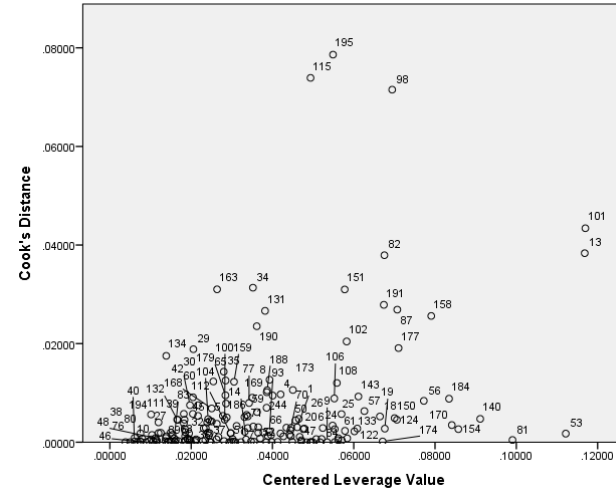


Appendix 23: Leverage Value and Cook's Distance labelled by the ID of candidates.

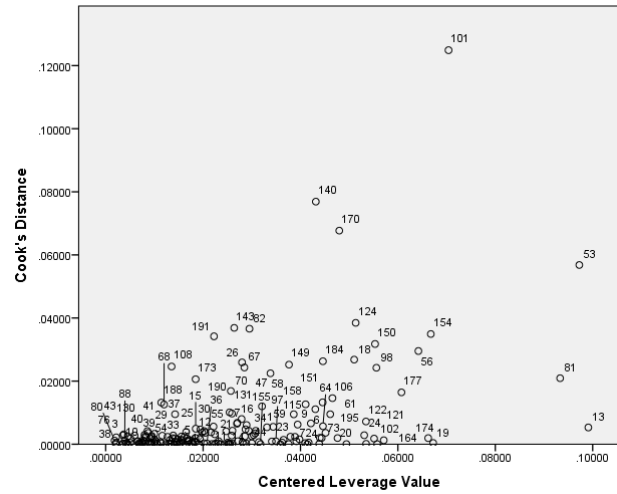
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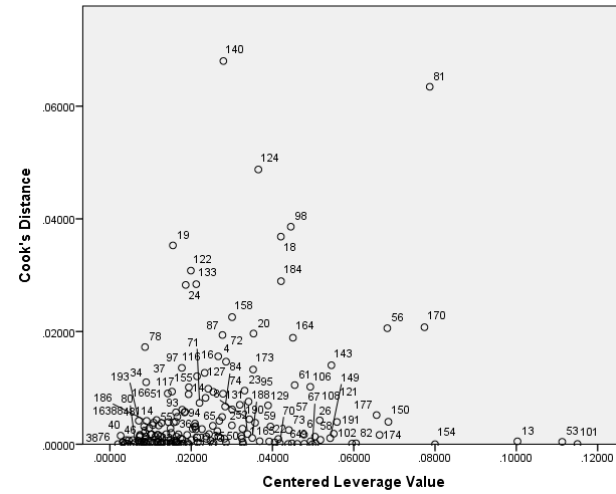
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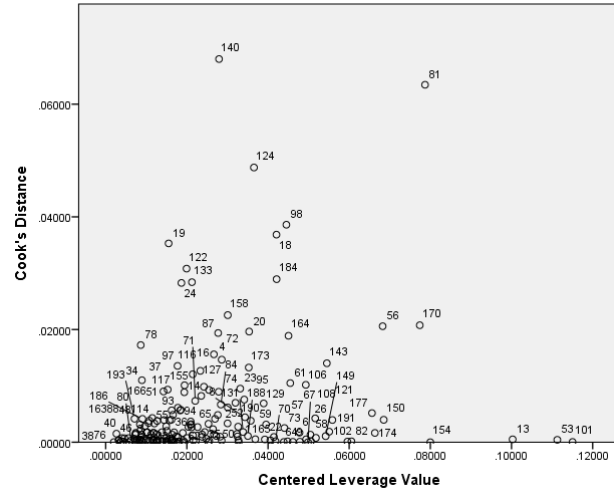
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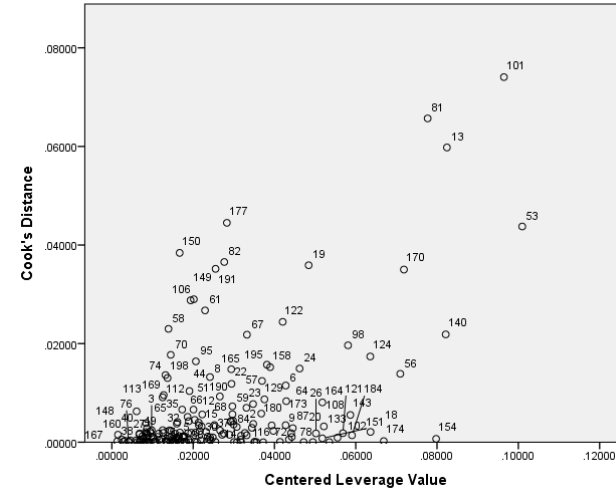
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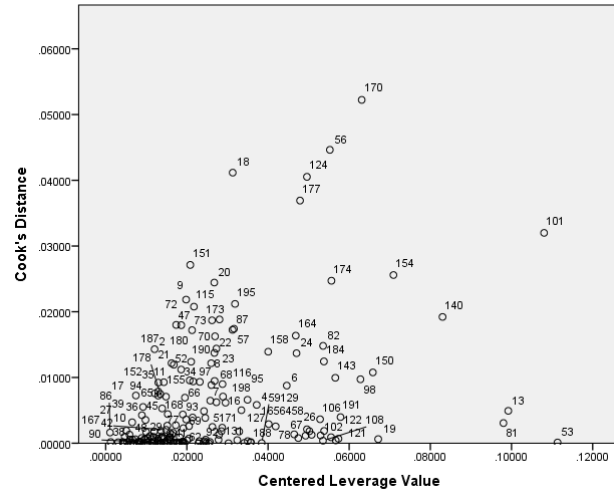
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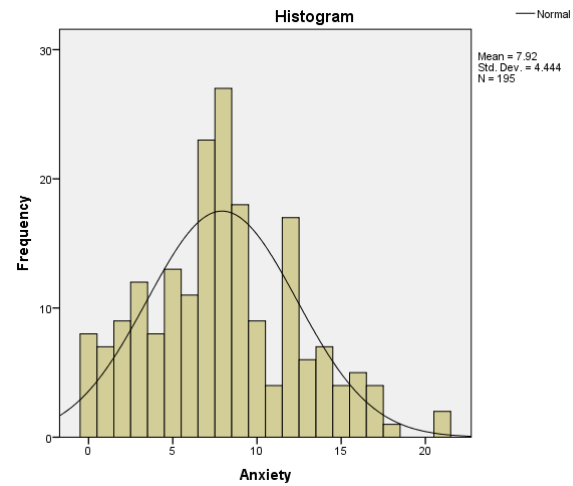
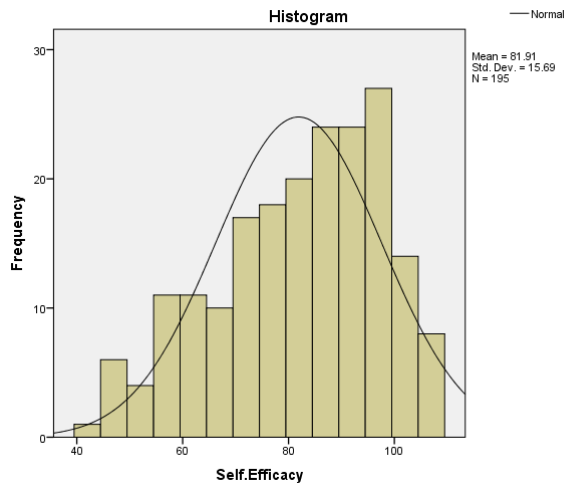
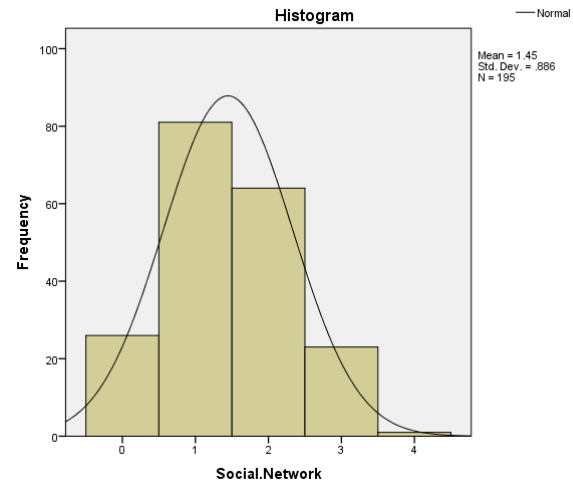
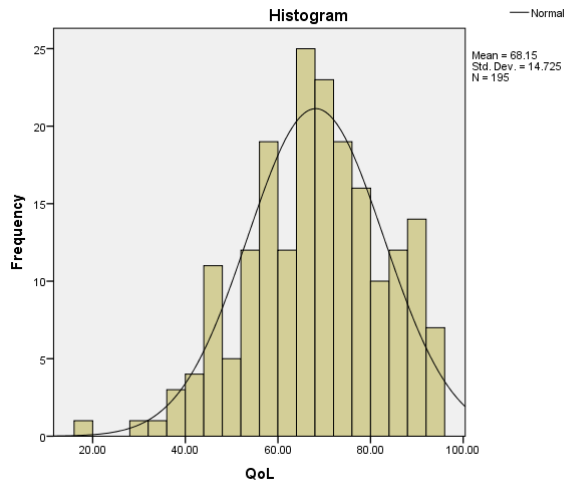
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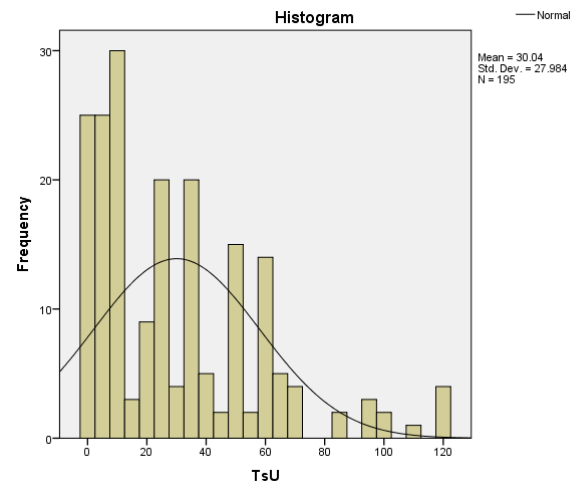
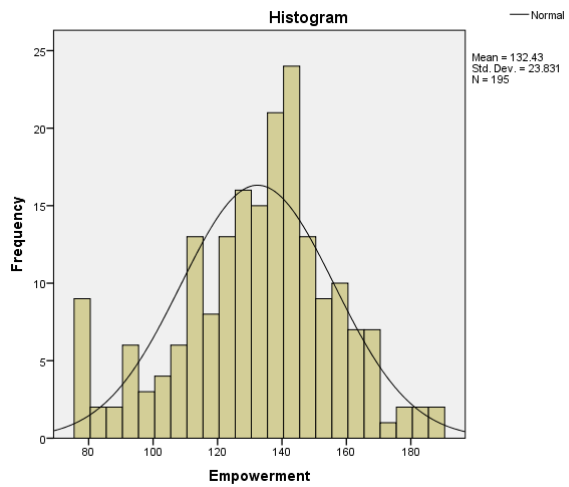
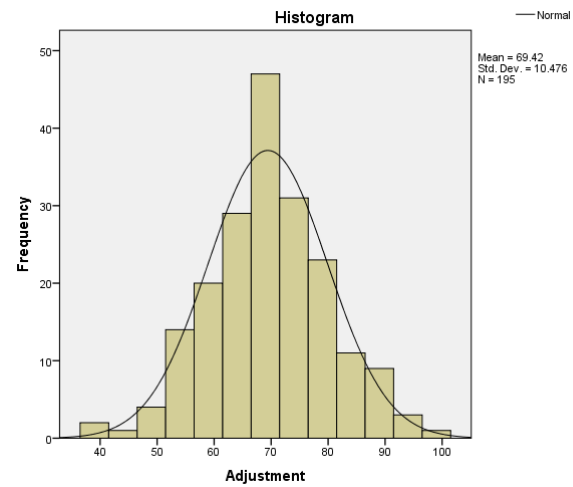
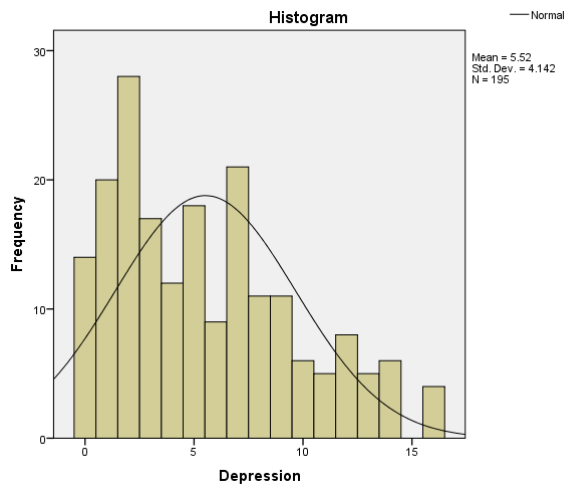


Model (7)



Appendix 24: Histograms of shape of the distribution for each variable





**6.12 Appendix 25: Aide memoir used for the interviews for study 2,
Part 2**

1. How did you find out about the online support group?
2. Do you use computers frequently?
3. What was your initial feeling about this type of group?
4. What influenced you to join the online group?
5. What level of participation do you have with the group?
6. What do you feel when you contribute to this type of group?
7. What does this type of group offer you?
8. In what ways do you feel your life has improved as a result of the group?
9. What do you think may have happened if you had no contact with the group?
10. What do you feel that online support groups offer?