A Multi-perspective Concept Mapping Study of Head and Neck Cancer Treatment Outcome Priorities

by

Waad Riyad Alolayan

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ABSTRACT

Background

Head and neck cancer treatments have been showing promising outcomes, yet they often have significant impact on patients. With an approximate 50% survival rate, individuals with a history of this type of cancer are living with long term challenges. With the increasing focus on patient-centred care, patients and caregivers are expected to be part of treatment planning and decision making. This study sought to understand what outcomes are considered by patients, caregivers, and healthcare providers during their experience with head and neck cancer, and which of these have higher priority. We also aimed to study the influence that demographic and clinical characteristics of patients' might have on their priorities.

Methods

Using purposeful and snowball sampling, patients with a history of head and neck cancer, caregivers, and healthcare providers were recruited. A mixed-method approach called Group Concept Mapping was used to collect data in two phases. In phase one (brainstorming activity), participants responded to a single focus prompt about important outcomes throughout the entire experience of head and neck cancer treatment. In phase two (sorting and rating activities), participants sorted the statements that were gathered in phase one based on their conceptual similarities. They then rated each statement based on its importance. Concept Systems Global Max™ software (www.conceptsystems.com) was used to gather data, analyze, and create visual maps based on the participants' input. All qualitative data were converted to quantitative data and went under statistical analysis to produce illustrating maps and visuals of sorting and rating.

Results

Two-hundred fifty statements were generated from the brainstorming activity. A synthesis process was completed to reduce literal and conceptual redundancies, resulting in a final list of 94 statements that were included in the second phase of the study. One sorting and two rating responses from caregivers were removed as the sample size would not be representative of this subgroup and too small for comparative purposes. A two-dimensional map with a stress value of 0.2213 was generated from multidimensional scaling analysis, suggesting a good overall fit between sort data and the map produced. Eight clusters were created to encompass all statements, namely: ‘Monetary Support’, ‘Person-Centred Care’, ‘Nutrition’, ‘Education’, ‘Psychosocial Concerns’, ‘Continuing Care’, ‘Treatment Side Effects’, and ‘Lifelong Challenges’. At a cluster level, ‘Education’ was the highest priority for patients and healthcare providers. A comparison of priority rating at statement level revealed that the highest priorities for patients and healthcare providers are prompt diagnosis and treatment, followed by ‘knowledgeable and experienced healthcare providers in head and neck cancer’, ‘survival’, and ‘clear detailed upfront information of the case and treatment plan’. Misalignment of priorities were noted in outcomes related to ‘Treatment Side Effects’ and ‘Psychosocial Concerns’. Findings shed light on how patients with history of human papillomavirus (HPV) have a higher priority for psychological concerns including anxiety, depression, fear of the unknown, and fear of recurrence than people without HPV

Conclusion

In this concept mapping study, two themes have emerged as considerations from the head and neck cancer experience: treatment-related outcomes (physical, functional, psychosocial, and financial) and healthcare related considerations (care pathway, care delivery, and education). Our findings confirm that survival is of high priority for patients and healthcare providers. Our findings further support the complexity of the treatment planning process, evident by the complex maps and highly interconnected statements related to outcomes. Implications for enhancing future treatment planning, improving the quality of care delivered and care experience for head and cancer patients and healthcare providers are discussed.

PREFACE

This thesis is an original work by Waad Riyad Alolayan. The research project, of which this thesis is a part, received research ethics approval from Health Research Ethics Board of Alberta; Cancer Committee, Project Name “A multi-perspective concept mapping study of head and neck cancer treatment outcomes priorities”, No. HREBA.CC-19-0012, March, 2019.

DEDICATION

This work is dedicated to all people experiencing head and neck cancer, you are stronger than you know.

To all caregivers dedicating their time and life in caring for their loved ones.

To all healthcare providers committed to saving lives, your efforts are much appreciated.

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To the apple of my eye and my bundle of joy Abdullah, my companion through this adventure, and the reason for its’ slowing down. Thanks for being in my life, I am proud to share this achievement with you next to me.

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LIST OF ABBREVIATIONS

HNC	Head And Neck Cancer
OPC	Oropharyngeal Cancer
HPV	Human Papilloma Virus
RT	Radiation Therapy
CRT	Concomitant Chemoradiotherapy
SNHL	Sensorineural Hearing Loss
GCM	Group Concept Mapping
ACR	Alberta Cancer Registry
AHS	Alberta Health Services
WHO	World Health Organization

GLOSSARY OF TERMS

Allodynia. Pain sensation secondary to a non-painful stimuli (International Association for the Study of Pain, 2017).

Chemotherapy. Systemic drugs that are mostly given intravenously or orally and transfer in the body to kill cancer cells or control their growth by stopping their division (Canadian Cancer Society, 2020d).

Concomitant Chemoradiotherapy (CRT). The use of chemotherapy and radiation therapy simultaneously to enhance the effect of radiation energy on cancerous cells (Canadian Cancer Society, 2020).

Dysgeusia. Alteration of taste (Maghami & Ho, 2018).

Dysphagia. Swallowing disorder, difficulty or disruption in the normal process of swallowing food and liquids. Dysphagia is not a diagnosis but a symptom that is secondary to medical conditions, and/or anatomical or physiological alterations. Interventions, such as surgery to the head and neck area, can also result in swallowing difficulty (Jones, 2003).

Group Concept Mapping (GCM). GCM is a broad term used when a concept is structurally generated by a group of individuals and represented in two and three-dimensional maps(Trochim, William M. K., 1989)

Head and Neck Cancer. Otherwise known as cancer of the mouth and throat, is a term used to describe carcinomas that arise from the mucosal lining of the upper aerodigestive tract (passage connecting the mouth, pharynx, esophagus, and stomach).

Human papillomavirus (HPV). HPV is a sexually transmitted virus that infects epithelial cells in the human body and causes their transformation into cancer cells or tumors (Vokes, Agrawal, & Seiwert, 2015).

Hyperalgesia. High sensation to pain stimulus (International Association for the Study of Pain, 2017).

Internal Acoustic Canal. is a bony canal in the temporal bone that houses nerves and vessels and is connected to the inner ear (Som & Curtin, 2011).

Laryngectomy. Surgical removal of larynx. Total laryngectomy implies the removal of the entire larynx, while partial laryngectomy is the removal of a part of the larynx.

Lymphedema. Fluid (lymph) build up due to an interruption in the lymphatic system and leading to swelling (PDQ® Supportive and Palliative Care Editorial Board, 2019).

Multidimensional Scaling. A technique that illustrates the proximity of points on a map using multivariate analysis to measure the difference/proximity between two points on a table (Cox & Cox, 2000)

Odynophagia. Painful swallowing.

Oropharyngeal Cancer. A type of head and neck cancer found in the oropharynx, which is the middle part of the pharynx. base of the tongue, tonsils, walls of the pharynx (Canadian Cancer Society, 2020f).

Osteoradionecrosis. A complication of radiation therapy leading to non-healing or death of the bone (Owosho et al., 2017)

Palliative. The decrease of symptoms without curing the disease, and providing psychological support to enhance the quality of life (World Health Organization, 2020b).

Postherpetic Neuralgia. Complication of an infection causing a burning sensation to skin and nerve fibers and a persisting pain (Mayo Foundation for Medical Education and Research, 2020).

Purulent Drainage. A fluid discharge often from wounds.

Radiation therapy or Radiotherapy (RT). The use of high energy radiation directed to local parts of the body to stop the growth of targeted cancer cells by destroying the DNA of the cell (Canadian Cancer Society, 2020a) .

Squamous cell carcinoma. Cancer that affects cells is usually found in the lining of the aerodigestive tract and respiratory tract the squamous cells lining the skin or organs, this type of (National Cancer Institute, 2015).

Transoral Robotic Surgery (TORS). A new less invasive surgical approach that uses robotic systems to access areas from the mouth and remove the tumor. This approach is used for certain types of cancer based on the location of the tumor (Mayo Clinic, 2017).

Trismus. Limitation in mouth opening and jaw range of motion due to the contraction of mastication muscles (The Oral Cancer Foundation, 2018).

Xerostomia. Is the condition of dry mouth, it presents as a symptom of certain medical conditions and/or side effects of interventions (Fox, van der Ven, P F, Sonies, Weiffenbach, & Baum, 1985).

CHAPTER 1: INTRODUCTION

Thesis Outline

This thesis will be presented in chapters. Chapter one will include background information on the significance of the problem, the purpose and incorporated objectives, and the research questions. Chapter two will include a review of the literature on cancer trends, head and neck cancer (HNC) associated with human papillomavirus (HPV), HNC treatment outcomes, patients' priorities, healthcare providers' priorities, and emphasis on the demographic and clinical factors influencing patients' priorities. In chapter three, the methodology used to conduct this research will be outlined with details on the procedures of recruitment, data collection and analysis process. knowledge around the quality of the methodology also will be shared. Chapter four will include findings obtained from the data collection, the multidimensional analysis of the data, and the resulting maps. The last chapter will include a discussion on the results of this project in relation to literature reports and previous findings of similar studies, the implications and utilization of the results, limitations, and will conclude with future directions.

Background

Head and neck tumours affect sensitive areas and functions, which often lead to long-term side-effects affecting patients' physical, psychological and social aspects of life. Shared understanding of the actual experience of HNC, and its outcomes and priorities of those affected, is valuable in improving quality of care and future planning. In an era where patient-centred care and patient-oriented research have been widely embraced worldwide by health organizations and systems, the outcomes of healthcare should be assessed from multiple perspectives (patients, caregivers, and healthcare providers).

The incidence of HPV-associated HNC has rapidly increased over the past years (You, Henry, & Zeitouni, 2019), affecting a different demographic of patients than was traditionally seen in the HNC population (Canadian Cancer Society, 2016; Elrefaey, Massaro, Chiocca, Chiesa, & Ansarin, 2014). As a result, younger and healthier patients are encountering significant alterations secondary to treatments. Previous studies found variations in cancer impacts and satisfaction levels of care depending on different demographic and clinical factors, but there is limited information on the perspective of patients with a history of HPV involvement as to what their priorities are for care (Windon, Fakhry et al., 2019).

Group concept mapping has been used to study multiple perspectives (Kane & Trochim, 2007). This method allows different groups of participants to describe their thoughts and have them visually represented through a group of related multidimensional scaling maps, which show the broad spectrum of outcomes and relationships of such outcomes across different perspectives. They can also represent the priority rating of outcomes and depict differences in priorities as influenced by different perspectives and underlying factors of participants.

Statement of The Problem

A number of studies have examined cancer patients', caregivers' and healthcare providers' experiences, needs, and priorities. In examining outcome priorities, many studies have used outcomes that were presumed by the investigators to be important to patients. This study aims to engage patients actively in identifying treatment outcomes and drawing conclusions on their priorities. Furthermore, despite the rising number of HNC cases associated with human papillomavirus (HPV) there has been very limited research in understanding how outcome priorities of patients with HPV-associated HNC compare with those who are HPV-negative.

Research Purpose

The primary purpose of the study was to explore the perspective of HNC patients on treatment outcomes and how they might compare to the perspectives of caregivers' and healthcare providers. Developing an understanding in this way of the experience of HNC and the alignment between patients' and healthcare providers' priorities will offer recommendations for treatment planning.

The specific objectives of this study were:

1. to elicit an exhaustive list of outcomes and considerations associated with HNC treatment as characterized by the patient, caregivers and healthcare providers.
2. to develop a conceptual map of prioritized outcomes to provide a comprehensive understanding of what participants prioritize as important treatment outcomes.
3. to contribute to the understanding of most appropriate and meaningful outcomes and recommendations that need to be considered when communicating with patients during the decision-making process.
4. to research and include the perception of patients with HPV, given the increasing number of these individuals.

The research questions were:

1. How do treatment outcome priorities for head and neck cancer differ between patients, caregivers and healthcare providers?
2. How do demographic and clinical factors of head and neck cancer patients influence the outcome priorities?

CHAPTER 2: LITERATURE REVIEW

Head and Neck Cancer

Cancer occurs when body cells grow or divide abnormally (Canadian Cancer Society, 2020e). It is projected that 1 in 2 Canadians will be diagnosed with cancer during their lifetime (Canadian Cancer Society, 2018). It is also projected that the number of new cancer cases will be 80% higher in 2030 compared to 2005 secondary to the increase in age and population size (Canadian Cancer Society, 2018). On the other hand, cancer deaths have decreased from 1988 to 2017 by 32% in males and 17% in females, as a result of improved treatments (Canadian Cancer Society, 2018). Currently there are more than 1.6 million Canadians living with and beyond cancer (Fitch et al., 2019).

Head and neck cancer (HNC) is a type of cancer that occurs when the lifecycle of cells from the mucosal lining of the head and neck areas are disrupted. Cancer is categorized based on the location where the tumour first occurs; HNC can be found in paranasal sinuses, nasal cavity, oral cavity, pharynx, and larynx (National Cancer Institute, 2017). A less common type of HNC is salivary gland cancer, and it occurs in different types of cells in salivary glands (National Cancer Institute, 2017).

Based on 2016 Canadian Cancer Statistics, the incidence rate of oropharyngeal cancer (OPC) which affects the back of the throat, base of tongue and tonsils, increased in both genders, but at a much faster rate among males (Canadian Cancer Society, 2016). More recent statistics reveal that 6.1% and 7.4% new cancer cases in males and females, respectively, are HNC (i.e.,oral, thyroid, and larynx) (Canadian Cancer Society, 2019). On the other hand, there was a downward trend in the incidence of laryngeal cancer in Canada, followed by a reduction in mortality rates of this type of cancer. This trend is thought to be attributed to a decrease in tobacco use (Siegel, Miller, & Jemal, 2019).

Head and Neck Cancer and Human Papillomavirus

Human papillomavirus (HPV) is a sexually transmitted virus that infects epithelial cells in the human body and causes their transformation into cancer cells or tumors. The World Health Organization reported that HPV is currently the most common sexually transmitted infection worldwide (World Health Organization, 2019). The high-risk HPV subtypes are identified as 16, 18, 31, 33, and 35 (Vokes, Agrawal, & Seiwert, 2015). Over the past 15 years, research has shown that head and neck squamous cell carcinoma can be caused by HPV infection, with HPV16 being the most frequent genotype driving this type of cancer (D'Souza & Dempsey, 2011; Vokes et al., 2015). Many HPV-associated head and neck carcinomas are oropharyngeal cancers (OPC), although it has been detected in a smaller subset of oral cavity and laryngeal cancers (D'Souza & Dempsey, 2011).

Although tobacco and alcohol intake have traditionally been the dominant risk factors, the rise of HPV-associated HNC has dramatically shifted the demographic of those affected to younger and healthier individuals (Canadian Cancer Society, 2016). Individuals with a history of HPV-associated-HNC tend to be younger, with the median age at diagnosis being 54 years (Elrefaey, Massaro, Chiocca, Chiesa, & Ansarin, 2014). Additionally, it has been observed in white males with a higher number of sexual partners and higher socio-economic status (Huang, Gullane, & O'Sullivan, 2018; Marur, D'Souza, Westra, & Forastiere, 2010). Newer studies report that there has been an increase in median age at diagnosis (Windon et al., 2018).

In 2012, the most common HPV-associated cancer in Canada was OPC with 1,335 cases, and was found to be more than 4.5 times higher in males than females (Canadian Cancer Society, 2016). From 2000 to 2012, the estimated prevalence of HPV-OPC has increased from 47% to around 74% measured in 6 cancer centres across Canada (Habbous et al., 2017). This is consistent with trends in the United States, where the incidence of HPV-associated OPC is increasing as well, making up to 90% of all new OPC cases (You, Henry, & Zeitouni, 2019). Meanwhile, tobacco-associated HNC is decreasing (D'Souza & Dempsey, 2011).

Head and Neck Cancer Treatment Outcomes

Physical and Functional Outcomes

In general, the main treatment options for this type of cancer are surgery, radiation therapy (RT), and chemotherapy or a combination thereof (Canadian Cancer Society, 2020d). Treatment plans are individualized based on the type, characteristics, location and stage of the cancer.

Radiation therapy outcomes.

Almost 80% of HNC patients undergo RT (Strojan et al., 2017), which includes the use of high energy radiation directed to stop the growth potential of targeted cancer cells by destroying the DNA of the cell (Canadian Cancer Society, 2020a; Strojan et al., 2017). However, due to its proximity to target cancer cells, surrounding normal cells might get irritated by the exposure to the high energy beams. As a result, radiation-associated toxicities or side effects are seen. Early effects develop during the course of treatment or soon afterwards and usually resolve within a period of time. Late effects occur after the RT course is complete, and are considered progressive in nature and irreversible (Langendijk et al., 2008; Llewellyn, McGurk, & Weinman, 2005; Strojan et al., 2017).

In HNC, one of the most prevalent late effects of RT is xerostomia, driven by decreased saliva secretion due to compromised functioning of salivary glands (Llewellyn et al., 2005). This condition often has a functional impact on swallowing and speech. Along with xerostomia, interruption in the complex neuromuscular process of swallowing is common in individuals with a history of RT. Local musculature damage secondary to RT, such as tissue fibrosis and lymphedema, affects the contractility of muscles needed in the swallowing activity, leading to varying degrees of dysphagia. Moreover, dysphagia can be exacerbated secondary to feeding tube placement during the RT course by disuse that might lead to muscle atrophy or weakness. Dysphagia often contributes to serious consequences such as aspiration pneumonia, extended or lasting feeding tube dependency, weight loss, and malnutrition (Strojan et al., 2017).

Trismus is a limitation in the jaw range of motion that results in a reduction in mouth opening. Trismus might present as an adverse effect of RT due to the possible fibrosis of mastication musculature and destruction of nerves supplying these structures by radiation energy. Reduced ability to open the mouth affects mastication, which in turns alters nutritional intake consistencies. It also has an effect on maintaining oral care and hygiene, increasing the risk of dental problems and infections (Strojan et al., 2017). Trismus effects may exceed physical and functional aspects of mental health: depression was reported in the literature in HNC patients secondary to trismus (Johnson, Johansson, Ryden, Houltz, & Finizia, 2015).

The high energy radiation may also cause damage to the hearing system, specifically the inner ear sensory structures: cochlea, spiral ganglion, and the 8th cranial nerve known as vestibulocochlear nerve. The damage includes progressive degeneration, fibrosis, atrophy, and might also present as edema of the internal acoustic canal that houses the vestibulocochlear nerve, leading to radiation-induced sensorineural hearing loss (SNHL) present in 43% of HNC patients with history of RT (Linskey & Johnstone, 2003; Strojan et al., 2017). Mixed hearing loss might occur as well when RT causes a conductive hearing loss through fibrosis of the middle ear or a dysfunction of the Eustachian tube, along with SNHL (Hwang et al., 2015; Strojan et al., 2017). Hearing loss may appear during RT treatment or years afterwards (Landier, 2016).

Although a small prevalence is reported in HNC patients, high dose RT may cause osteoradionecrosis, a slowly progressive condition that initially presents with pain in the bone, purulent drainage, and may further form a fistula (Strojan et al., 2017). Additional known effects of RT include: skin irritation, redness, itching, dryness, oral mucositis, and changes in the ability to taste. All of these vary in degree from mild to severe causing discomfort to patients. (Canadian Cancer Society, 2020c)

Chemotherapy outcomes.

Chemotherapy is known as systemic drugs that are mostly given intravenously or orally and transfer in the body to kill cancer cells or control their growth by stopping their division (Canadian Cancer Society, 2020b). Unfortunately, chemotherapy has the same effect on healthy cells that are quickly dividing such as hair cells, bone marrow blood cells, and cells lining the mouth and intestine, causing them to destroy or shrink (Canadian Cancer Society, 2020). Damage to hair cells can lead to hair loss, and drug effects on cells lining the mouth usually lead to oral mucositis, especially in patients receiving neutropenia-induced chemotherapy agents (National Cancer Institute, 2016), while damage to cells lining the intestines can cause diarrhea (Canadian Cancer Society, 2020) .

Platinum-based chemotherapy drugs such as Cisplatin and Carboplatin are ototoxic agents causing SNHL that is often accompanied by tinnitus and vertigo (Landier, 2016). In addition, some drugs are neurotoxic, affecting the taste buds and leading to alterations in taste ability known as dysgeusia. Patients frequently describe a bad taste in the mouth that could be driven by the chemo drugs diffusion in the oral cavity. This condition also could be related to other sequelae such as xerostomia (National Cancer Institute, 2016).

As a response to specific chemotherapy drugs or when a combination of drugs are administered, a patient might experience nausea and vomiting. As a result, individuals will most likely have less appetite which may lead to malnutrition and weight loss (Canadian Cancer Society, 2020). Fatigue and general body weakness is a known side effect of chemotherapy secondary to the damage to healthy cells by certain chemotherapy drugs, or related to loss of appetite, vomiting, and anemia. Although it may last after the treatment course, fatigue improves over time (Canadian Cancer Society, 2020; Mayo Foundation for Medical Education and Research, 2018).

Concomitant chemoradiation outcomes.

Patients with local HNC squamous cell carcinomas treated nonsurgically usually undergo concomitant chemoradiotherapy treatment (CRT) (Machtay et al., 2008) . Although the simultaneous use of chemotherapy and RT is to enhance the effect of radiation energy on cancerous cells (Canadian Cancer Society, 2020) and results in a 6.5% absolute benefit at 5 years when compared to RT alone (Pignon, le Maitre, Maillard, Bourhis, & MACH-NC

Collaborative Group, 2009), it aggravates the side effects when compared to RT alone (Machtay et al., 2008; Strojan et al., 2017). For instance, acute mucositis and dysphagia were two times higher in incidence in HNC patients undergoing CRT after surgery when compared to others who underwent only RT with surgery (Dzioba et al., 2017). Additionally, CRT led to increased severity and duration of mucositis (Epstein, Wilkie, Fischer, Kim, & Villines, 2009). Literature also reports that the risk of ototoxicity increases when RT is administered with platinum-based chemotherapy (Landier, 2016).

Surgery outcomes.

Surgery is completed to remove the tumor and might be accompanied by other treatment modalities such as RT and/or chemotherapy. These treatments can be either administered before surgery to shrink the cancer cell and is called (neoadjuvant therapy) or can be applied after surgery (adjuvant therapy) to kill the remaining cancer cells and lower recurrence risk (Canadian Cancer Society, 2020).

There are different types of total and/or partial surgical resection operations in HNC depending on the tumor site including, but not limited to, glossectomy, laryngectomy, laryngopharyngectomy, cordectomy, neck dissection, thyroidectomy, and laser surgery (National Cancer Institute, 2019a; National Cancer Institute, 2019b; National Cancer Institute, 2019c). Newer advancements of less invasive surgical intervention such as transoral robotic surgery are identified to remove cancer from hard to reach areas (National Cancer Institute, 2019d). Other types of operations are administered to restore the parts of the body affected by cancer and its treatment. For instance, options in HNC include dental implants and skin grafts (National Cancer Institute, 2019).

Surgery is like other treatment modalities, and could have side effects. For example, common side effects are disfigurement and scar formation (List & Bilir, 2004). And due to the invasive nature of surgical intervention, varying degrees of pain are also a common adverse effect (Gegechkori, Haines, & Lin, 2017). A study examined pain scores following HNC surgery and reported that oral cavity cancers showed the highest post-surgery pain, followed by laryngeal and oropharyngeal cancers (National Cancer Institute, 2016)

Mandibular surgical resection usually leads to sensory impairment if the inferior alveolar nerve is involved and hyperalgesia/allodynia is seen in more than 50% of patients (National Cancer Institute, 2016). In surgeries targeting the laryngeal area, voice loss and/or impairment might result secondary to the impacted anatomical structures responsible for voice production (List & Bilir, 2004). When speech-related structures and mechanisms are interrupted by surgery, a speech disorder is noted (List & Bilir, 2004), and dysphagia is seen when the neuromuscular process of swallowing is affected.

Nerve palsy in the 11th cranial nerve is common post radical neck dissection, leading to impaired innervation and limited shoulder movement, also known as upper limb dysfunction (Gegechkori et al., 2017). One study reported that upper limb dysfunction is present in 77% of patients (Carr, Bowyer, & Cox, 2009). Moreover, one of the late adverse effects of surgery is lymphedema. Lymphedema leads to reduced movement of the neck, which in turn was found to affect an individual’s social interaction and mental health, in that depression is correlated with lymphedema (Gegechkori et al., 2017)

Psychosocial and Financial Burden

Daily life activities and physical functions commonly include social tasks such as eating and speaking, and are a reflection of a person's identity such as voice and physical appearance. Alterations in these functions secondary to cancer treatment can lead to deterioration in psychological wellbeing and mental health of individuals (Nguyen et al., 2005). Literature reports found that HNC patients present the highest levels of distress compared to other cancers (You et al., 2019) and it was argued that high levels of distress are due to the sensitivity of the areas and functions affected by this type of cancer, given the impact this illness and its treatment has on a person's identity, visible disfigurement and changes in daily life functions essential for living (List & Bilir, 2004). Consequently, individuals with a history of HNC may present with anxiety, depression, fear of relapse, low self-esteem, and embarrassment (Nguyen et al., 2005; Ward, Bishop, Frisby, & Stevens, 2002). All of that can result in decreased social engagement, or sometimes, in severe cases, withdrawal from all social interactions, and building a social barrier (List & Bilir, 2004; Nguyen et al., 2005; Stringer, 1999; Ward et al., 2002). The newer demographic of young patients with HPV-associated HNC also have shown signs of distress due to the negative impact of treatment on their daily life functions, namely swallowing and speaking (Fitzpatrick & Zizzi, 2014; You et al., 2019).

Treatment has an impact on employment and financial aspects of life that become challenges for people experiencing cancer. It was found that some patients do not return to work post-treatment because they are unable to fulfill their job requirements, or choose to retire early as they cannot function in their old job (Taylor et al., 2004). A recent study compelled in Australia found that fatigue and functional outcomes including xerostomia, dysphagia, and speech were the highest barriers to returning to work after treatment for people with HPV-OPC (Morales, McDowell, Lisy, Piper, & Jefford, 2020). Patients facing financial struggles related to their time off work may be inclined to return to work before they are fully physically able (Morales et al., 2020). In this regard, it was found that support from employers was a key factor to helping individuals transition back to work (Morales et al., 2020). This support was described as providing adequate sick-leave, job assurance, providing payments during time off work, and flexible working hours or responsibilities upon return to work.

Demographic and Clinical Variables

The substantial impacts of cancer treatments and satisfaction levels vary depending on various demographic and clinical factors. Older patients with a history of HNC, lung, prostate, and breast cancers tend to report higher levels of satisfaction of care experience in terms of professionalism of healthcare providers, education and interpersonal trusting between patients and healthcare providers than middle-aged patients (Charalambous, 2013). Moreover, level of education was found to influence the expressed satisfaction levels of care experience; patients with bachelor degrees were less satisfied than those with lower education (Charalambous, 2013). Patients' satisfaction is discussed as it may alter how patients perceive treatment outcomes and their priorities. HNC patients who have partners show better psychological improvement after treatment when compared to single patients, which suggests that social support is an essential factor in the psychological recovery and wellness of patients (Harding & Moss, 2018) .

In the context of clinical factors, people diagnosed at an advanced stage (IV) HNC had the least psychological improvement up to one year post treatment. Those who had stage II and III tumors at time of diagnosis, showed better psychological improvement after treatment compared to the earlier group, but were less so when compared to people diagnosed at an early stage (I). The significant negative impact of intensive treatment on people diagnosed at late stage was interpreted as the possible underlying factor for the reported low psychological improvement after treatment (Harding & Moss, 2018). Home visits after discharge were found to be related to better psychological outcomes (de Boer et al., 1995) and it was found that the more time after treatment passes, the less psychosocial challenges are reported in HNC (de Boer et al., 1995). Moreover, psychological status was reported to be more positive after treatment in HNC patients who underwent surgery alone than people who had surgery with adjuvant RT, or those who had non-surgical intervention (i.e., chemotherapy and/or RT). Multiple hospital visits required for non-surgical treatment sessions may have a negative impact on the psychological status after treatment (Harding & Moss, 2018). Due to severely affected functional outcomes, negative psychosocial symptoms were found to be highly prevalent in patients who have undergone total laryngectomy (Ward et al., 2002).

Treatment regimen also was found to have influence on HNC patients' functional abilities and were noted to be significantly worse in patients who had surgery and CRT compared to patients who underwent surgery and adjuvant RT only. This suggests multiple adjuvant treatments may impact patients' functional abilities more negatively (Dzioba et al., 2017).

HPV-associated HNC has a better prognosis and survival rate when compared to non-HPV associated HNC of a similar stage (Bhatia & Burtness, 2015; Vokes et al., 2015). The increase in the number of survivors is secondary to the increase in incidence rate and the younger age at diagnosis (Patel et al., 2016; Windon, D'Souza, & Fakhry, 2018). As a result, younger patients are encountering significant physical and functional alterations secondary to treatments, which is impacting their quality of life in terms of social, psychological, and financial aspects (Bhatia & Burtness, 2015; List & Bilir, 2004). Although no official health guidelines yet exists for providing those patients with a treatment approach that is less-toxic than traditional intensive treatment planned for HNC patients without HPV (Bhatia & Burtness, 2015), clinical trials have been exploring alternations in treatment plans based on the tumor pathogenesis, HPV status, and patient's history by assessing less intensive treatment regimens (Ang et al., 2010; Bhatia & Burtness, 2015; Pai, 2012; Vokes et al., 2015; Windon et al., 2018). Less intensive treatment is an approach designed to focus on cure and survival while enhancing the quality of life through minimizing negative treatment impacts (Windon et al., 2018). This is achieved by either performing transoral surgery, changing chemotherapy dose or agents, changing radiation dose, or reducing the total of treatment regimens used (Kelly, Husain, & Burtness, 2016; Windon et al., 2018). HNC patients with HPV showed higher concern of cancer recurrence and death (Windon, D'Souza et al., 2019); literature has highlighted the negative impact that fear of recurrence has on quality of life of patients and their caregivers (Hodges & Humphris, 2009; Mellon, Northouse, & Weiss, 2006).

One study explored the relationship between information received and the development of expectations and suggested that adverse effects can be traumatizing if unexpected, and it can be less traumatizing with efficient education (Llewellyn et al., 2005). This justifies the variations between patients' expectations of treatment outcomes and their actual experiences and why some patients described their whole cancer experience as being worse than anticipated (Llewellyn et al., 2005). Expectations appeared to be influenced by the information received pre-treatment. Moreover, not knowing the full facts when treatment side effects arose was a major source of anxiety post-treatment for patients and relatives (Bisschop et al., 2017; Llewellyn et al., 2005). Receiving adequate information from specialists was a predictor of positive rehabilitation outcomes in laryngectomy patients (de Boer et al., 1995). It has been recommended by patients that healthcare professionals share and talk about overall information as early as possible (Dodd, Forster, Marlow, & Waller, 2019). This fact points out the need for meaningful and understandable medical clarification about the expected functional outcomes, and it has been suggested to provide a full-detailed written information source for the patients and families that can be accessed when they are ready (Llewellyn et al., 2005), as not all patients wanted detailed information at all stages of the illness (Leydon et al., 2000; Llewellyn et al., 2005). A study that investigated facilitators and barriers to return to work in patients with HPV-associated HNC suggested that people would have been able to return to work earlier if they had received sufficient information on rehabilitation (Morales et al., 2020).

Treatment Outcomes Priorities

Patients' Perspective

Previous studies found that survival from cancer was the top priority for patients (Badr et al., 2010; Gill et al., 2011; Sharp et al., 1999; Tschiesner et al., 2013b) and that patients were inclined to accept treatment negative impacts for survival (Windon et al., 2018). One recent study reported that patients prioritized being cured from cancer over survival, living as long as possible. Swallowing was ranked as the third highest priority following cure and survival (Windon, D'Souza et al., 2019). Preservation of function in daily activities such as swallowing safely or speaking clearly among others were deemed more important than mere preservation of anatomical structures responsible for those functions (Badr et al., 2010; Gill et al., 2011; Sharp et al., 1999; Tschiesner et al., 2013; Wilson, Carding, & Patterson, 2011). Although literature reports similar priorities of HNC patients with and without HPV, one study found that change in appearance and ability to chew were less important for patients with history of HPV-associated HNC compared to HNC patients without HPV-association (Windon et al., 2019). HNC patients' perceptions and functional outcomes were noted to be different at different stages of the recovery and to change over time; before the initiation of treatment, 1-month, 3-month, 6-month, and 1-year post treatment (Badr et al., 2010; Kucuk, Kurnaz, & Kutlar, 2015; Sharp et al., 1999; Tschiesner et al., 2013; Wilson et al., 2011). However, a recent study found that cure and survival remained patients' top priority even after treatment for those with history of HPV-associated HNC (Windon et al., 2019).

The majority of patients in three studies (Bisschop et al., 2017; Charalambous, 2013; Llewellyn et al., 2005) reported being satisfied with the information received from their medical team regarding the expected treatment outcomes and side-effects. More recent study meanwhile reported insufficient information delivery to HNC patients with HPV (Dodd et al., 2019), and reported that patients were mostly using other means such as the internet to look for answers and more information regarding HPV, symptoms, etiology, and treatment options available. It was found that patients also looked for information on the clinical team providing care to them, and educating themselves in reading test results (Dodd et al., 2019). These reports on patients seeking more information reflect the importance of education for patients, and the previously highlighted reports on how information is correlated with treatment outcomes and patients' wellbeing after intervention further underscores its importance and significance.

In terms of decision making, earlier literature found that although a number of patients were given the option to choose, they reported not having sufficient information on the treatment options to make a choice. Hence, the majority of HNC patients wanted to be involved in the decision making process by considering their opinion along with healthcare providers expertise to make a joint decision (Edwards, 1998). Another study reported that patients also considered it highly important to include their families and friends in the decision-making process and to consider their opinions and worries throughout the treatment process (Bisschop et al., 2017).

The greatest dissatisfaction for cancer patients was related to discomfort and pain management (Charalambous, 2013; Sharp et al., 1999). This dissatisfaction persisted even in long-time survivors (Tschiesner et al., 2013a). Given that pain is a common side effect and a high frustration reported in the HNC population, pain might be one of the priorities to consider in treatment outcomes.

Healthcare Providers' Perspective

Findings around healthcare providers' perspectives were conflicting. Although the majority reported quality of life assurance as a priority during treatment planning (Demez & Moreau, 2009; Edwards, 1998; Gill et al., 2011), others prioritized cure and survival above preservation of function (Gill et al., 2011). Younger and less experienced otorhinolaryngologists were more likely to withhold curative treatments for the purpose of preserving function and quality of life compared to older experienced physicians. This finding was interpreted as that the consideration of quality of life assurance developed more recently, while survival has been formerly the ultimate goal. Moreover, it was thought that with time, experience, and higher exposure to HNC cases, treatment adverse effects become less overwhelming for providers (Demez & Moreau, 2009). With respect to treatment related quality of life outcomes, pain was the most important for ENT physicians. Breathing, feeding, voice, and physical appearance followed (Demez & Moreau, 2009).

In terms of patients' education, literature found that less than 50% of oncologists in the United States talk about HPV with patients they are seeing (Dodd et al., 2019; Milbury, Rosenthal, El-Naggar, & Badr, 2013). It was reported that most healthcare providers believed that due to time limitations, it was difficult for them to share all the necessary information (Edwards, 1998; Tschiesner et al., 2013). Another barrier to delivering sufficient information was the assumption that patients already had the information (Edwards, 1998).

There were different opinions among healthcare providers about involving patients actively in the decision-making. One study reported that the majority preferred that the choice of primary treatment be done by the primary physician/surgeon given their expertise and knowledge while patients can be involved in rehabilitation planning and palliative care (Edwards, 1998). This might be hypothesized as physicians are inclined to reduce and limit the confusion that decision-making responsibility might have on patients, especially during the time of uncertainty that patients are going through with their diagnosis of cancer.

Conclusion

A number of studies have examined cancer patients', caregivers' and healthcare providers' experiences, needs, and priorities. In examining outcome priorities, many studies have used outcomes that were presumed by the investigators to be important to patients. This study aims to engage patients actively in identifying treatment outcomes and drawing conclusions on their priorities. Furthermore, despite the rising number of HNC cases associated with human papillomavirus (HPV) there has been very limited research in understanding how outcome priorities of patients with HPV-associated HNC compare with those who are HPV-negative.

CHAPTER 3: METHODS

The study was conducted using a mixed-method approach called Group Concept Mapping (GCM). Group concept mapping is a broad term used when a concept is structurally generated by a group of individuals and represented in two and three-dimensional maps (Trochim, William M. K., 1989). The study consisted of three tasks: (a) brainstorming (gathering ideas and statements on the topic of interest); (b) sorting (defining the conceptual interrelationships across statements); and (c) rating (giving a value for each statement) (Kane & Trochim, 2007).

Participants

Eligibility Criteria

Individuals were eligible for inclusion if they met the following criteria;

- Patients: eligible for participation were adults of age 18 years or more, who were diagnosed with Head and Neck Cancer (HNC) and were treated in Alberta, Canada, patients can be either currently receiving treatment or were post-treatment at the time of study enrollment.
    - Patients with thyroid or salivary gland cancer (adenocarcinoma), and/or who did not start treatment, and /or patients with conditions that could compromise their ability to perform the required task in the study (e.g., dementia), were excluded from the study.

- Caregivers of patients: adults of age more than 18 years and were either living with the patient who met the inclusion criteria or provided care and support to him or her during the experience of HNC. Caregivers of deceased patients with HNC that met the criteria also were eligible to participate.
- Healthcare providers: who regularly work with HNC patients in Alberta were asked to participate in the study.

Recruitment

Data of potential and eligible HNC patients were extracted from the Alberta Cancer Registry (ACR), who mailed out study information packages by post. Packages included the study information letter, ACR cover letter, and ACR information pamphlet. Patients and caregivers also were recruited through various snowball recruitment methods including electronic communication via emails. Posters were displayed in public spaces of offices or facilities in Edmonton and Calgary where the target patient population may attend to receive consultations and treatments.

Healthcare providers were recruited through various snowball recruitment methods including word of mouth and electronic communication via emails by clinicians within their network. Posters were displayed in locations where the target clinical population may attend in Edmonton and Calgary. There were also broadcast email notifications distributed by clinical administrative staff to relevant clinicians and trainees within their list.

Sample Size

A convenience sample of 305 was targeted based on previously reported GCM study sample sizes required for data saturation. Fifteen participants were targeted for pilot testing the prompt (five key individuals from each group). Two hundred participants were targeted for data collection in phase one (brainstorming) to develop a varied but exhaustive list of outcomes, covering domains of treatment outcomes and considerations. Ninety participants, 30 from each participant group, were targeted for data collection in phase two (sorting and rating). Based on the literature, 20-30 participants will reflect the diversity and variation of priorities and is the optimum number of sorters needed to reduce the stress value, which leads to a higher fit of the visual maps on GCM (Rosas & Kane, 2012). Stress (a goodness of fit statistic) is the essential statistical diagnostic in multidimensional scaling analysis, it shows the amount of inconsistency between the statements representation on the point-map and the input statements sorting (Kane & Trochim, 2007).

Procedures

Briefly, a GCM study consists of:

- Preparation stage: the research team identifies the desired outcome of the study and target population, and develops and pilots test the prompts used in the study.
- Idea generation: this step includes ideas brainstorming statements, and the statement synthesis procedure.
- Idea structuring: this step includes a sorting activity where statements are organized into groups, and the rating activity where values are assigned to each statement.
- Concept mapping analysis: this step includes multidimensional scaling, hierarchical cluster analysis and a bridging analysis to compute maps
- Interpretation of maps.

- Utilization: using the maps, findings are related to planning, measurement or evaluation.

In the following sections I will address details of each stage.

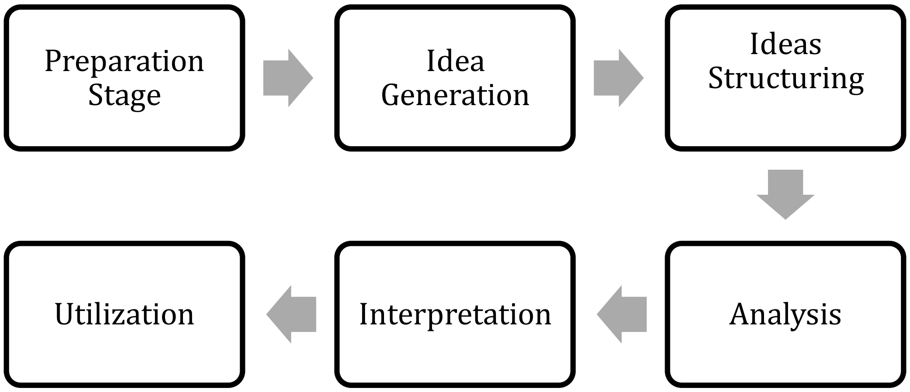


Figure 3.1. Group Concept Mapping Process.

1. Preparation Stage

The preparation stage consisted of two main steps: prompt development and prompt testing. The prompts were the questions asked, or the instructions given during data collection to evoke a response from participants.

Developing the prompt is an essential step in group concept mapping as it affects the outcome of the study (Sjodahl Hammarlund, Nilsson, & Hagell, 2012). The more accurate the prompts and the more specific the wording of the prompts, the more targeted and accurate the elicited responses will be. This can be determined by pilot testing the prompt. In this study, the process of developing the focus prompt examined sentence structure and specific word choice.

In terms of sentence structure, the prompt can be developed in either a prompt form which uses an open-ended sentence (i.e., "a common outcome of cancer treatment would be…") or a statement form that uses an instruction (i.e., "generate a common outcome of cancer treatment"). In this study, the prompt was developed in an open-ended sentence form, as it was found that this form helps to obtain grammatically similar statements across participants that are easy to work with in phase two (Kane & Trochim, 2007). This form of prompt also elicits a higher number of statements and responses compared to the statement form, due to the ease of completing a sentence (Kane & Trochim, 2007).

In terms of prompt lexicon, keywords that drive target responses (i.e., treatment outcomes) were identified from previous literature. We searched for words that described outcomes through the experience of HNC and not limited to a certain period of time (i.e., diagnosis, treatment, recovery or rehab). We avoided using the terms (e.g., treatment outcome, side-effects) so as to not limit generated ideas on functional or structural outcomes. We also avoided the use of the term 'priority' to not limit thoughts only on outcomes of highest priorities to participants. 'Consideration' was selected because it was felt it was a neutral word that may elicit important outcomes and impacts of the experience of HNC.

An initial prompt was developed and refined through an iterative feedback process amongst the research team. The final crafted prompt was: ***"Important considerations throughout the entire experience of head and neck cancer are.."***

The developed prompt was then tested on a group of representative target participants to ensure that it resulted in exhaustive and relevant statements.

2. Idea Generation

Group Concept Mapping (GCM) was used through Concept Systems (CS) Global Max™software as a web-based platform to arrive at the various perspectives of treatment outcomes. In this study, data was collected in two phases; phase one (brainstorming activity) and phase two (sorting and rating activities) at separate time periods to reduce the potential for participants' fatigue.

A GCM study can be conducted either on-site or remotely. An on-site or physical approach allows engagement of participants, which enriches the data through participants' interaction during data collection sessions. A remote approach meanwhile facilitates reaching participants at various geographical locations, and allows participants to respond at their convenience and gives them more time to think and generate thoughts. As the purpose of the study was to include different groups' perspectives, and to reach participants across the province of Alberta, collecting responses using a remote approach was selected. Although this approach allows reaching a higher number of participants, it has a lower-response rate and is more susceptible to obtaining duplicate thoughts and statements (Kane & Trochim, 2007).

Phase one.

The first screen that participants saw when logging into the study was a 'project introduction page' with the title of the study and general instruction for participating and responding to the activities (Appendix A). Demographic questions were asked to capture the demographic and clinical characteristics of participants, including: role, age, gender, education level, marital status, tumor site, stage at diagnosis, time since treatment, treatment type, healthcare providers specialty (Appendix B).

The brainstorming task was open between September 16, 2019 and October 20, 2019. Participants were instructed to list as many statements as they could to the focused prompt (stated above). Additionally, they were instructed to keep each statement brief and to a single thought (Appendix C). This phase was estimated to take about 20 - 40 minutes to complete. Once responses were submitted, participants received a “thank you” message and a reminder of phase two opening dates. A preview of the “thank you” screen is illustrated in (Appendix D(

Synthesis.

Synthesis is a structured process that is applied when a large number of statements of more than 100 are generated from the brainstorming activity, to create a manageable number of concise and easily comprehended statements that would be carried forward to the sorting and rating tasks. Although there is no fixed number of statements theoretically, literature supports that a set of 100 statements or less is sufficient to cover the variety of thoughts while being attainable for sorters and raters in phase two (Kane & Trochim, 2007; Trochim, 1989). In the pooled analysis of 69 concept mapping studies that Rosas and Kane published, they reported an average of 96 statements with a range of 45-132 statements (Rosas & Kane, 2012). To ensure that the list of statements contained statements relevant to the purpose of the study, the synthesis process followed the sequence (Kane & Trochim, 2007):

1. Grouping general concept statements that reflected a certain concept were grouped together and concepts were identified.
2. Highlighting keywords (ideas) in each statement. Since some statements might include more than one idea, keywords were highlighted in each statement.
3. Breaking ideas in a single statement to multiple statements. Based on the highlighted keywords, statements that contained more than one idea were divided.

4. Grouping similar keywords (ideas). The divided statements were grouped under their reflective concept.
5. Merging and editing the sentence structure to be easily comprehended by participants in phase two. If number of statements identified the same keywords and concepts, statements will be merged to a single statement for each keyword.

As stressed in the literature (Kane & Trochim, 2007; Trochim, 1989), we kept the edits at minimum, maintained the original meaning of the statement, and ensured that no ideas or thoughts have been removed during this process.

3. Idea Structuring

Phase two.

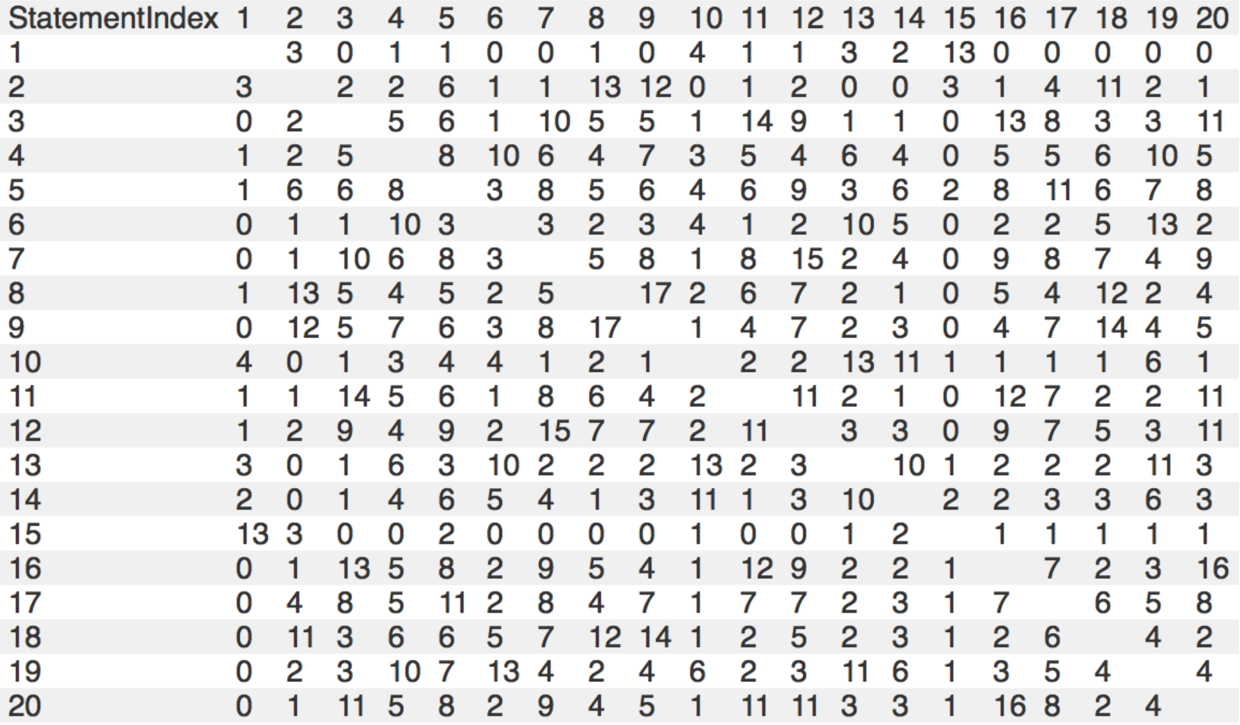
Demographic questions were asked to capture the demographic and clinical characteristics of participants, including: role, age, gender, education level, marital status, tumour site, stage at diagnosis, time since treatment, treatment type, HPV status (Appendix B). In this phase, participants were expected to sort the statements based on their conceptual similarities, and then to rate each statement based on its importance. The online forum was open for three weeks, from November 9-30, 2019. Participants were provided with a link and login information. They were able to log in anytime within those three weeks.

The electronic sorting activity can be done either in a tabletop manner or drop down sorting as represented in (Appendix E). A tabletop approach was chosen because it has less complexity for participants. In this phase, instructions were given on how to sort the data (Appendix F) and each participant grouped the statements into different groups according to the similarity of theme based on their own perspective. Participants received a “thank you" message upon submitting their final response in the sorting activity and a reminder to proceed and respond to the rating activity, with a reminder of the last day to submit the response for phase two.

Next, participants rated each statement separately on a Likert-scale 1 to 5, in terms of priority (Appendix G). This phase of sorting and rating was estimated to take between 60 and 90 minutes, participants could pause at any time and return to complete their response to the activity during the three week period. Participants who submitted their responses for the rating activity received a "thank you" message and a note to contact the research team via email if they were interested in receiving a report of the study's findings.

4. Data Analysis

Data were analyzed using the Concept Systems (CS) Global Max™ software (www.conceptsystems.com). All statements from the brainstorming activity was converted to quantitative data by core mapping analysis. In this analysis, each statement is numbered and entered into a cross-correlational matrix. From there, a tally of the number of times two statements occur together is created (Figure 3.2). A series of analyses take place within the software subsequent to the creation of this matrix. The reader is referred to (Appendix H) for a detailed description of these analyses.



StatementIndex	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1		3	0	1	1	0	0	1	0	4	1	1	3	2	13	0	0	0	0	0
2	3		2	2	6	1	1	13	12	0	1	2	0	0	3	1	4	11	2	1
3	0	2		5	6	1	10	5	5	1	14	9	1	1	0	13	8	3	3	11
4	1	2	5		8	10	6	4	7	3	5	4	6	4	0	5	5	6	10	5
5	1	6	6	8		3	8	5	6	4	6	9	3	6	2	8	11	6	7	8
6	0	1	1	10	3		3	2	3	4	1	2	10	5	0	2	2	5	13	2
7	0	1	10	6	8	3		5	8	1	8	15	2	4	0	9	8	7	4	9
8	1	13	5	4	5	2	5		17	2	6	7	2	1	0	5	4	12	2	4
9	0	12	5	7	6	3	8	17		1	4	7	2	3	0	4	7	14	4	5
10	4	0	1	3	4	4	1	2	1		2	2	13	11	1	1	1	1	6	1
11	1	1	14	5	6	1	8	6	4	2		11	2	1	0	12	7	2	2	11
12	1	2	9	4	9	2	15	7	7	2	11		3	3	0	9	7	5	3	11
13	3	0	1	6	3	10	2	2	2	13	2	3		10	1	2	2	2	11	3
14	2	0	1	4	6	5	4	1	3	11	1	3	10		2	2	3	3	6	3
15	13	3	0	0	2	0	0	0	0	1	0	0	1	2		1	1	1	1	1
16	0	1	13	5	8	2	9	5	4	1	12	9	2	2	1		7	2	3	16
17	0	4	8	5	11	2	8	4	7	1	7	7	2	3	1	7		6	5	8
18	0	11	3	6	6	5	7	12	14	1	2	5	2	3	1	2	6		4	2
19	0	2	3	10	7	13	4	2	4	6	2	3	11	6	1	3	5	4		4
20	0	1	11	5	8	2	9	4	5	1	11	11	3	3	1	16	8	2	4	

Figure 3.2. Similarity Matrix. This is an example of the similarity matrix of 20 statements in our study, it shows the number of participants grouped the statements together.

5. Interpretation of the Maps

The multidimensional maps generated by the software are the visual representation of the project's data and finding. They depict how the participants perceive the statements in terms of similarity, and how they rated those statements as well (Kane & Trochim, 2007). A number of maps were selected based on the study purpose, including point maps, cluster maps, cluster rating maps, pattern matches and go-zones. The reader is referred to (Appendix I) for a thorough description of these maps.

Variables.

The independent variable in this project was participant group, which had four levels: head and neck cancer patients with HPV, head and neck cancer patients without

HPV, caregivers, and healthcare providers. Dependent variables included: treatment outcome, statement sorting results, statement inter-relationships, and the value attached to each statement. Covariates included: age, sex, marital status, education level, tumor site, stage of cancer at diagnosis, time since treatment, and treatment method.

Reliability and Validity

Reliability

Traditional means of assessing reliability does not fully apply to concept mapping as there are no right and wrong sorting scores (Trochim, William, 1993). The GCM has been found to be a reliable method itself for establishing maps (Rosas & Kane, 2012; Trochim, 1993).

Reliability estimate of the rating data were calculated using Cronbach's alpha to determine internal consistency (Rosas & Kane, 2012) and was found to be a=0.97563, suggesting the statements on the rating scale are highly inter-correlated and internally consistent. The alpha value found also supports previous literature reports on higher internal consistency estimates expected when there are larger statements sets, as in the present study (Rosas & Kane, 2012).

Validity

Since concepts are based on social input, it is difficult to standardize a degree of error of that concept (Jackson & Trochim, 2002). The validity of GCM result was assessed by external and internal representational validity indicators identified in the literature (Rosas & Kane, 2012). The external representational validity according to Rosas and Kane (2012) is "the extent to which a conceptualized model mirrors the reality it is purported to represent" (p.237). Cacy (1996) enumerated strategies to measure the external representational validity including; the degree to which the set of statements reflect the topic of interest and to include independent participants with different perspectives (Cacy, 1996). In the present study, the pilot testing of the focus prompt ensured external representational validity, as it verified that the brainstormed statements represented the topic studied. Furthermore, participants in this study were from different groups (i.e., patients, caregivers, and healthcare providers), genders, ages, marital statuses, and education levels, ensuring their independency and variation of perspectives.

Internal representational validity is the matching of input sorting data to the output map or as defined by Rosas and Kane (2012) "the degree to which the conceptualized model reflects the judgements made by participants in organizing information to produce the model" (p.237). The stress value (goodness-of-fit) was used as an indicator of the internal representational validity (Kruskal & Wish, 1978) and compared against values reported in the literature. A low stress value indicates a low discrepancy and a better statistical fit of maps. An average stress value of 0.28 was suggested in the literature with a range of 0.17-0.34 in a pooled analysis study with a standard deviation of 0.04 and a 95% CI(Rosas & Kane, 2012). A well-structured concept that is more agreed upon, with higher number of sorters and a higher number of statements generated, will eventually lower stress value (Kane & Trochim, 2007).

Ethical Consideration

Ethical approval was obtained from the Health Research Ethics Board of Alberta: Cancer Committee (HREBA-CC). All data collection was completed using Concept Systems (CS) Global Max™, a secure web-based platform for group concept mapping. Prior to each task of the study, study information and consent were outlined (Appendix J). Consent was indicated by overt action when participants submitted their responses online. Participants were able to withdraw responses up to the point of clicking the button “save and submit”. All responses were anonymous and therefore irretrievable once submitted.

CHAPTER 4: RESULTS

Participants

Recruitment

Nine-hundred-and-eighty-five envelopes were mailed out to potential study participants through the Alberta Cancer Registry to patients with head and neck cancer (HNC) that met the inclusion criteria. Additionally, recruitment posters were placed at the Tom Baker Cancer Centre in Calgary, University of Alberta Hospital, Cross Cancer Institute and the Institute of Reconstructive Sciences in Medicine (iRSM) in Edmonton. Recruitment took place between September and November 2019.

Demographic and Clinical Characteristics

A total of 66 participants completed Phase one (brainstorming) and 46 participants completed Phase two (sorting and rating). A number of participants logged in to the website, but did not respond to the questions or activities in phase one (n=12) and phase two (n=8). Another group answered the questions, but did not respond to the activities in phase two. Table 4.1 shows the numbers in terms of responses to the demographic and clinical questions.

Table 4.1

Number of Responses to the Participant Questions

Phase	Patients	Caregivers	Healthcare Providers	Total	Logged in but did not respond
Brainstorming (phase one)	59	3	4	66	12
Sorting and rating (phase two)	29	3	14	46	8

Phase one.

The majority of participants in brainstorming activity were patients and all healthcare providers were allied health practitioners. For the clinical-related questions, caregivers were instructed to answer these questions based on their loved one's clinical situation. Detailed participant demographic and clinical characteristics are reported in Table 4.2.

Phase two.

Sixty-three percent of the total pool of participants who responded to demographic questions were patients; only three caregivers answered demographic questions. Detailed participant demographic and clinical characteristics are presented in Table 4.2.

Table 4.2

Demographic and Clinical Characteristics of Participants

Characteristics	Responses in Phase one	Responses in Phase two
	All (n= 66)	All (n=46)
Role N(%)		
Patient	59 (89.39)	29 (63.04)
Caregiver	11 (4.55)	3 (6.52)
Healthcare provider	4 (6.06)	14 (30.43)
Age range	30-71	24-74
Gender N(%)		
Male	42 (63.64)	28 (60.87)
Female	24 (36.36)	18 (39.13)
Marital status N(%)		
Single	3 (4.55)	4 (8.70)
Married or in a domestic partnership	55 (83.33)	37 (80.43)
Widowed	1 (1.52)	1 (2.17)
Divorced or separated	7 (10.61)	4 (8.70)
Education level N(%)		
Less than high school degree	1 (1.52)	1 (2.17)
High school degree or equivalent	21 (31.82)	12 (26.09)
Associate degree	17 (25.76)	9 (19.57)
Bachelor degree	16 (24.24)	12 (26.09)
Graduate degree	11 (16.67)	12 (26.09)

Tumour site (multiple options apply) N(%)		
Nasal cavity and paranasal sinus*	0 (0.00)	1 (2.50)
Oral cavity (mouth, lips, gum, tongue)*	40 (56.56)	20 (50)
Pharynx (throat)*	6 (8.33)	10 (25)
Larynx (voice box)*	3 (4.17)	3 (7.50)
Other*	23 (31.94)	6 (15)
Stage at diagnosis N(%)		
Early stage	26 (42.62)	10 (30.30)
Advanced stage	30 (49.18)	19 (57.58)
Not known	5 (8.20)	4 (12.12)
Time since treatment N(%)		
Currently undergoing treatment	2 (3.28)	1 (3.03)
Less than 6 months post-treatment	0 (0.00)	1 (3.03)
6-12 months post-treatment	1 (1.64)	0 (0)
1-2 years post-treatment	8 (13.11)	1 (3.03)
2-5 years post treatment	15 (24.59)	7 (21.21)
More than 5 years post treatment	35 (57.38)	23 (69.70)
Treatment type (multiple options apply) N(%)		

Surgery*	40 (30.30)	26 (32.91)
Chemotherapy*	33 (25.00)	19 (24.05)
Radiation therapy*	51 (38.64)	30 (37.97)
Immunotherapy*	2 (1.52)	1 (1.27)
Targeted therapy *	1 (0.76)	0 (0)
Other *	5 (3.79)	3 (3.80)
Healthcare provider specialty N(%)		
Physician	0 (0%)	
Allied health clinician	4 (100%)	
Clinical support	0 (0%)	
HPV N(%)**		
HPV+		13 (35.14)
HPV-		11 (29.73)
Not known		2 (5.41)
Not applicable		11 (29.73)

*Multiple options apply. Participants were able to choose more than one tumour site and/or treatment type as it applies to their case.
**Identified subjectively by participants.

Brainstorming Activity

Two hundred fifty statements were generated in phase one (Appendix K) by 66 participants. Data variety was ensured by the number of statements generated and a wide range of perspectives captured. For a successful synthesized set of statements, the number of statements was reduced to 94 statements (Appendix L) without compromising any ideas generated. This number falls under the average reported number of statements found in the literature of 96 statements (Rosas & Kane, 2012). The majority of statements were semantically and syntactically preserved from the original responses gathered. To ensure relevance to the question, statements that did not fall under treatment outcomes were excluded and categorized under the following general groups: ‘personal experiences’, ‘advice’, ‘recommendations to enhance healthcare services and quality of services delivered’, ‘unclear meaning of the statements’, ‘not outcomes’. The synthesis process is summarized in (Appendix M).

Core Analysis of Sorting Data

Twenty-three participants completed their sorting response. Of the participants, only one was a caregiver so his/her response was removed, as a single response would not be representative of this subgroup. Another participant’s sorting responses were also removed because the responses were sorted based on what the outcome meant to the individual (e.g., not an issue for me, not a serious issue for me, major concerns) rather than categorizing statements into groups based on their conceptual similarities. Thus, twenty-one sorters’ responses were identified and eligible for core analysis.

The Point Map

A final multidimensional scaling (MDS) stress value of 0.2213 was obtained, which falls in the range (0.205-0.365) and is lower (i.e., better) than the average stress value of 0.285 reported in the literature (Kane & Trochim, 2007). The MDS analysis generated a point map, which represented the distances between the 94 statements in points to illustrate the relationship among statements (Figure 4.1).

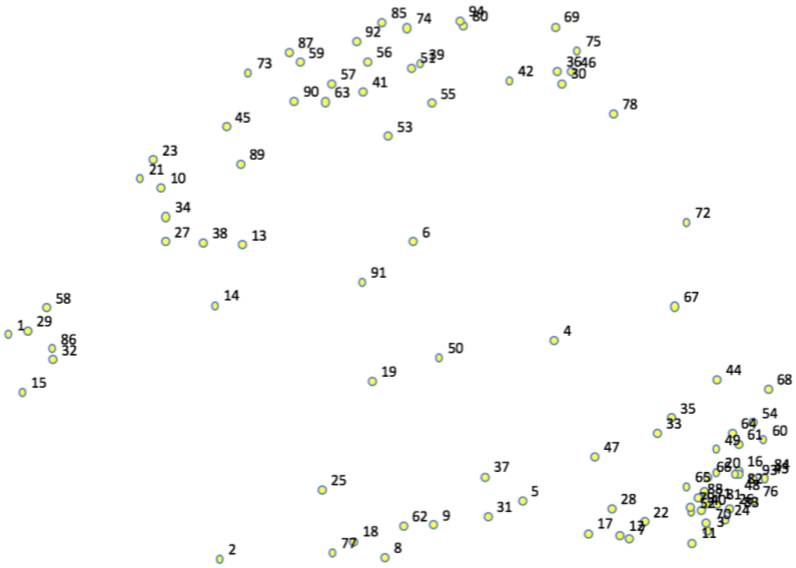


Figure 4.1. The Point Map. This figure illustrates the 94 statements in (x,y) points. Distance between points indicate the frequency which participants sorted them together.

The Cluster Map

The 94 (x,y) points representing statements in the point map went under a hierarchical cluster analysis. This analysis examined the bridging value which represents the possible solutions to indicate accurate statistical and interpretation. The cluster bridging values along with the research team's judgement were used to identify the final number of clusters (eight clusters). A cluster replay map also was used in deciding the number of clusters. This active map showed the process of merging clusters after defining clusters and the list of statements included in each one. Eight clusters were determined to be optimal and are represented in the cluster map (Figure 4.2). When the cluster number was reduced to seven, a higher bridging value resulted in most clusters. In examining the cluster map, two main themes emerged; treatment-related outcomes ('Nutrition', 'Treatment Side Effects', 'Lifelong Challenges', 'Psychosocial Concerns', and 'Monetary Support') and healthcare related considerations (‘Education’, ‘Continuing Care’, And ‘Person-Centred Care’).

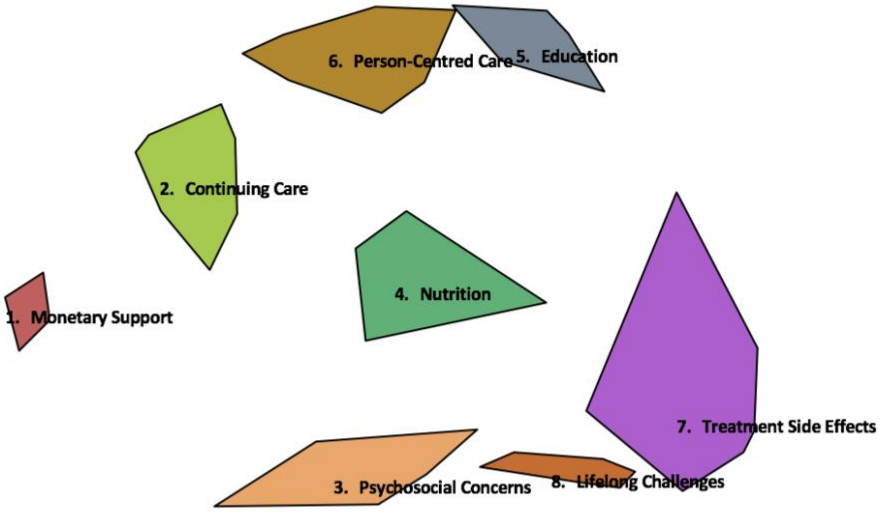


Figure 4.2. The Cluster Map. This figure depicts the eight clusters of statements. Smaller clusters are more focused in concept while larger clusters are relatively heterogeneous.

Table 4.3

Cluster Descriptions

Cluster label	Number of statements	General focus of cluster
1 ‘Monetary Support’	6	This small cluster focused on accessibility of treatment and health-related sources especially for out of town patients. It also covered the financial aspect/burden of treatment.
2 ‘Continuing Care’	10	Statements within this cluster reflected continuing care after initial treatment including long-term follow ups, routine checkup

		appointments, and allied health services.
3 'Psychosocial Concerns'	8	This cluster represented the psychological outcomes of treatment and the influence the treatment has on social life and interaction including within the work environment.
4 'Nutrition'	5	Statements included factors related to nutrition: the quality of feeding tube food, proper fit of dentures and maintaining a healthy diet. Survival was also included in this cluster.
5 'Education'	8	This cluster focused on all types of information patients need throughout the experience of head and neck cancer, information around diagnosis, disease, treatment plan and treatment options, expected outcomes, and possible impacts of treatment.
6 'Person-Centred Care'	16	The content of this cluster covered all aspects of support to patients and family before, during, and after treatment, it also contained statements around the quality of healthcare provided in terms of the healthcare team's engagement, communication and tracking patients' progress.
7 'Treatment Side Effects'	34	These statements reflected mainly the physical and functional impacts of treatment.
8 'Lifelong Challenges'	7	Statements in this cluster reflected physical and functional impacts of treatment that are of a persistent nature or with uncertain interventions available for them.

The central location of cluster 4 ‘Nutrition’ reflects the relationship of the statements in this cluster with different aspects and statements from other clusters. Survival might be located at this area of the map, not because of how much it is connected to nearby statements of ‘Nutrition’ but rather because it might be related to several other areas and clusters on the map.

Statements within cluster 8 ‘Lifelong Challenges’ seem to be related to cluster number 7 ‘Treatment Side Effects’, and the adjacent location of the two clusters explains it as well. However, these statements were found to have more persistent nature than statements in cluster 7, and some of these statements cover challenges with uncertain intervention available.

The Cluster Bridging Map

The lowest cluster bridging value was for cluster ‘Treatment Side Effects’, with an average bridging value of (0.16). ‘Lifelong Challenges’ had an average bridging value of (0.29), and ‘Person-Centred Care’ had an average bridging value of (0.49). The lower a bridging value, the higher internal-consistency of statements and homogeneity within. While the clusters with the highest cluster bridging value were cluster 1 ‘Monetary Support’ with an average bridging value of (0.80), ‘Psychosocial Concerns’ had an average bridging value of (0.71), ‘Nutrition’ had an average bridging value of (0.66), ‘Patient Education’ had an average bridging value of (0.65), and ‘Continuing Care’ had an average bridging value of (0.60). These results suggest that statements within these clusters have a higher tendency of being related together with statements in other clusters. The cluster bridging values are represented in cluster bridging map (Figure 4.3) and details on clusters and statements average bridging values is reported in (Appendix N).

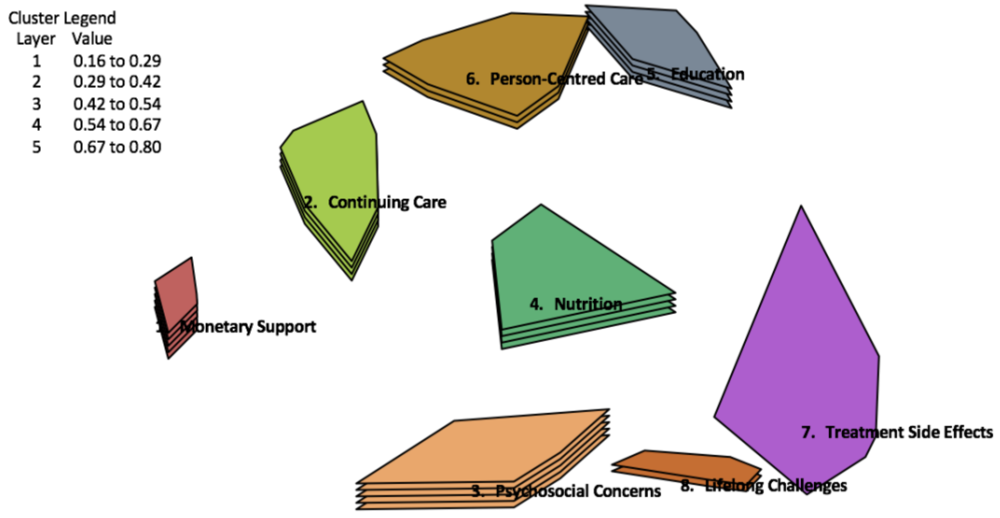


Figure 4.3. The Cluster Bridging Map. This figure shows the clusters in layers referring to the bridging value of each cluster. The more layers, the higher the bridging value of the cluster, indicating higher tendency of heterogeneity of statements within these clusters.

Rating Analysis

The average rating for each statement and cluster of statements was computed. Twenty-five participants submitted a completed rating for all 94 statements, but 2 participant responses, from caregivers, were removed as the sample size for this participant group was too small for comparative purposes.

Across all groups, the top 5 priorities identified at a statement level were ‘promptness of treatment’ (4.91), ‘promptness of diagnosis’ (4.86), ‘knowledgeable and experienced healthcare providers in head and neck cancer’ (4.82), ‘survival’ (4.68), and ‘clear detailed upfront information of the case and treatment plan’ (4.64). Appendix O provides a detailed report on the average rating for all statements and clusters.

The Cluster Rating Map

The highest rated clusters in terms of priority were 'Education', with an average rating of (4.28), 'Person-Centred Care' with an average rating of (4.20), 'Nutrition' with an average rating of (4.15), and 'Continuing Care' with an average rating of (4.08).The average rating values of the clusters are plotted in the cluster rating map (Figure 4.4**).**

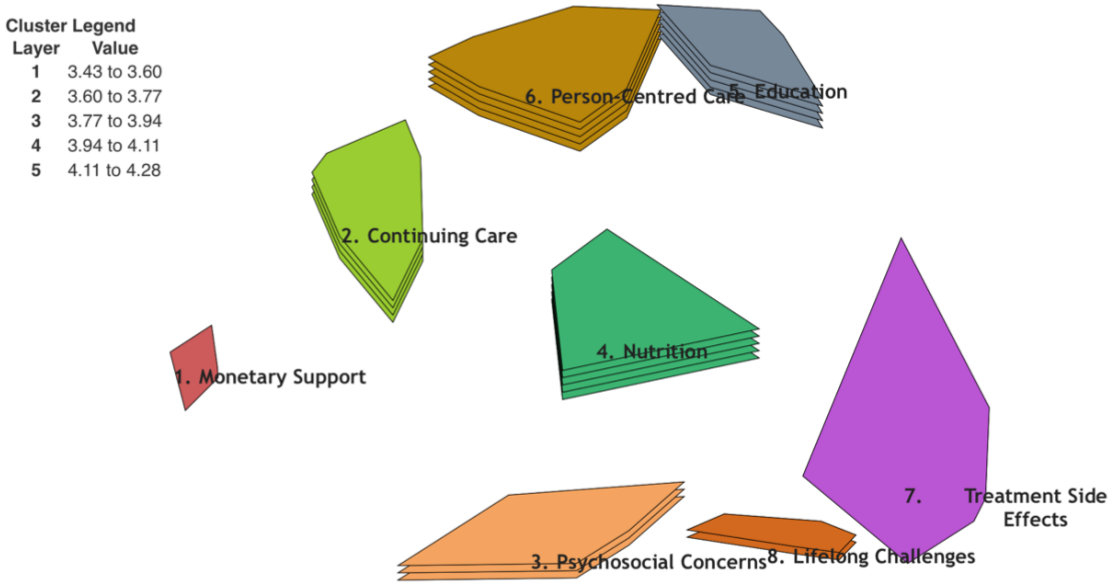


Figure 4.4. The Cluster Rating Map. This figure illustrates the clusters in layers reflecting average rating. The more layers, the higher the average rating is given to the cluster in terms of priority.

Pattern Match

The first pattern match (Figure 4.5) represents the level of agreement on the importance of outcomes (clusters) between patients and healthcare providers. The range of average importance rating in patients and healthcare providers was relatively narrow (3.32 - 4.26, 3.58 - 4.34), respectively. Overall, there was a strong correlation between patient and healthcare providers ratings (r=0.80). 'Education' was the highest priority for both groups.

Although ‘Psychosocial Concerns’ was the third highest-ranked priority for healthcare providers, it was the fifth most important consideration for patients. This difference was found to be statistically significant t (14) =2.76, p <0.02.

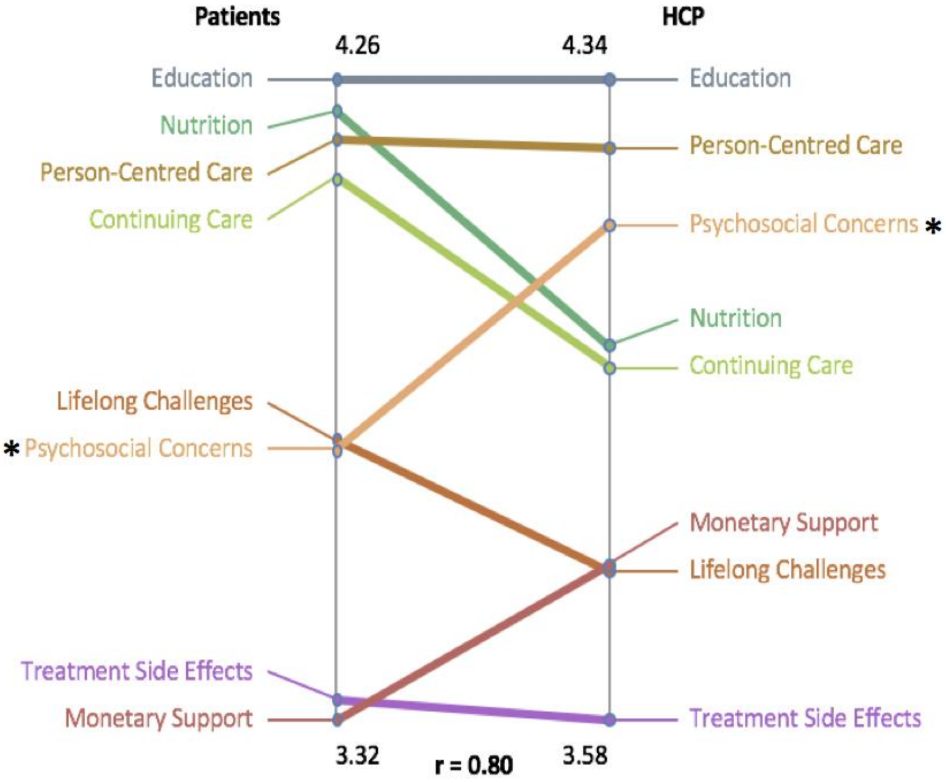


Figure 4.5. Pattern Match: Patients and Healthcare Providers (HCP). This figure illustrates the average rating agreement between patients and healthcare providers (HCP) in terms of importance. *statistically significant difference

Demographic variables in patients.

Age. was found to be a factor influencing patient priority ratings as seen in pattern match (Figure 4.6). While ‘Person-Centred Care’ was the highest priority for patients who were older than 60 years (n=11), it was the third highest priority for younger patients (n=4). This difference was found to be statistically significant (t (30) = 2.81, p<0.01).

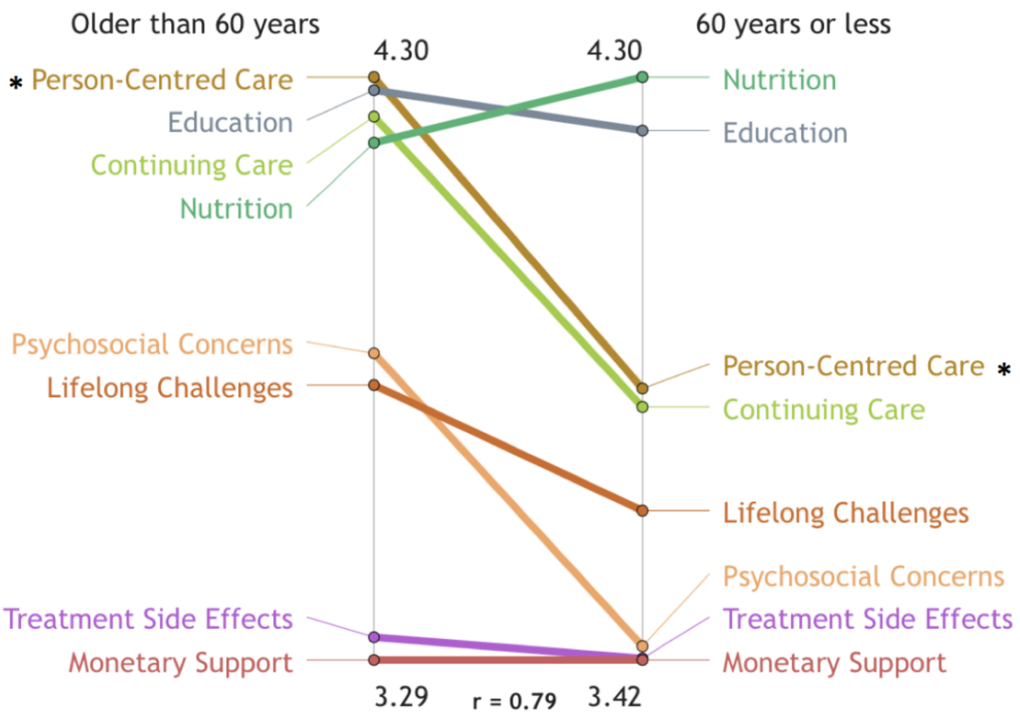


Figure 4.6. Pattern Match: Age Variable in Patients. This figure illustrates the average rating agreement between patients older than 60 years and patients 60 years of age or less. *statistically significant difference

Gender. A pattern match used to compare how male patients (n=12) and female patients (n=3) rated the clusters. Both genders relatively agree in the low rating average given for 'Treatment Side Effects' and 'Monetary Support'. Almost a perfect correlation of ratings was found (r=0.94), and there were no statistically significant differences between the two groups in clusters rating (p>0.05).

Education level. The possible influence that education level might have on patients' priorities is explored in a pattern match. with strong correlation in rating between the two groups (r =0.83) noted. No statistically significant difference between ratings of people with a bachelor degree or higher (n=7) and people with less than a bachelor degree (n=8) (p>0.05) was found.

Marital status. Pattern match (Figure 4.7) looked at the marital status of patients and its role in rating priorities. Single patients (n=4) rated 'Person-Centred Care' as the highest consideration while patients in a domestic relationship (n=11) ranked it as the third priority. This difference was found to be statistically significant (t (30) =4.1926, p<0.001). In general a strong correlation was demonstrated r (13) =0.80.

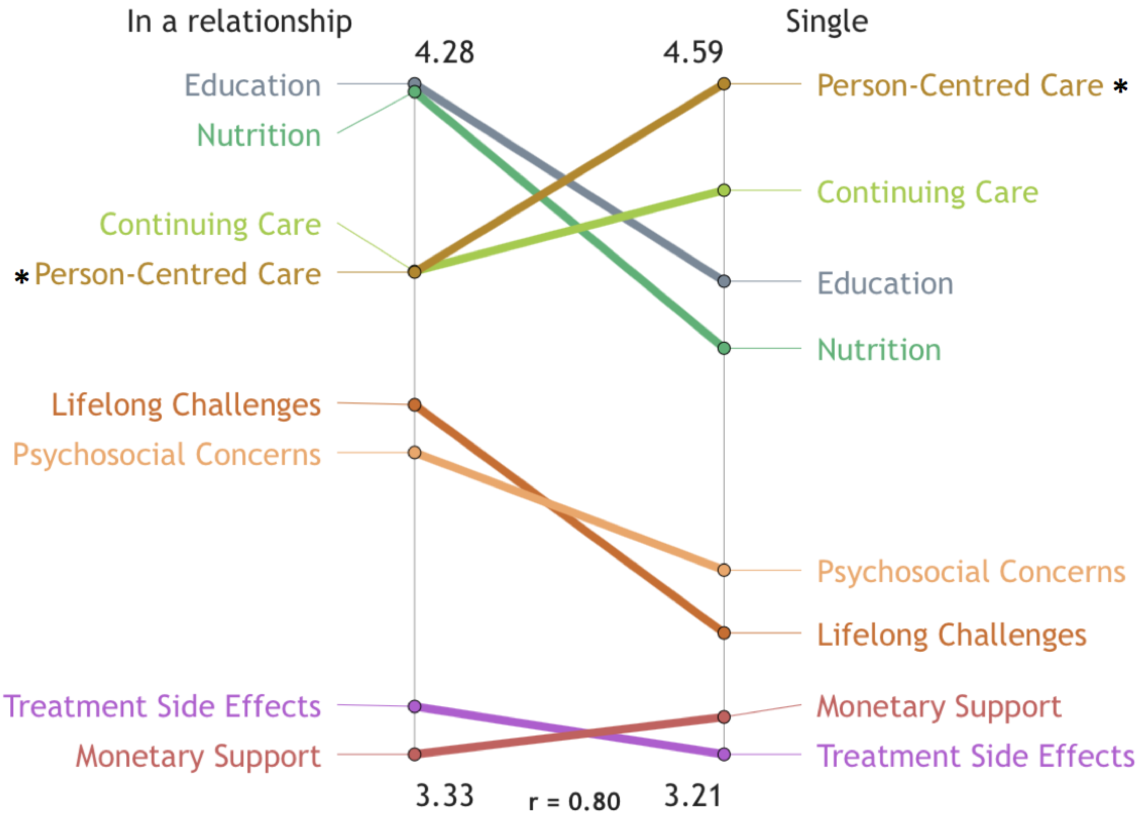


Figure 4.7. Pattern Match: Marital Status Variable in Patients. This figure illustrates the average rating agreement between patients in a relationship and single patients.

*statistically significant difference

Clinical variables in patients.

HPV status. The role of HPV was explored in terms of its impact on patients' priority ranking in pattern match (Figure 4.8). Five out of the 15 patients did not know if they had HPV involvement or not. A statistically significant difference was found for rating 'Psychosocial Concerns'; it was of a higher priority to patients with HPV (n=6) compared to patients without HPV (n=4), t (14) = 2.6535, p<0.02). A moderate correlation of rating was found (r=0.47)

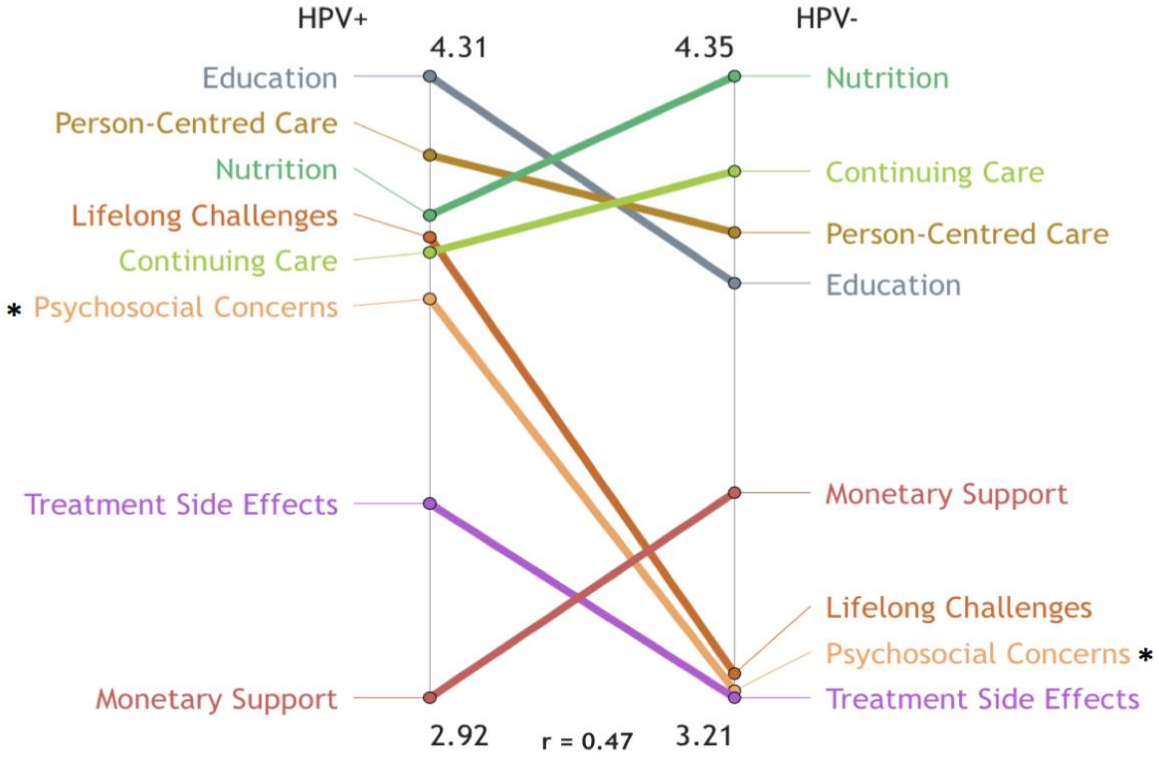


Figure 4.8. Pattern Match: The Role of HPV in Patients. This figure illustrates the average rating agreement between patients with and without HPV. *statistically significant difference

Tumour site. The pattern match (Figure 4.9) shows the tumour site as a possible factor for changing the perspectives of patients in terms of their priorities. It is clear that patients who had oral cavity tumors (n=11) ranked ‘Psychosocial Concerns’ and ‘Treatment Side Effects’ higher in terms of priority than patients with the experience of pharyngeal/oropharyngeal cancer (n=6). These findings were statistically significant (t (14) = 2.4107, $p<0.05$) and (t (66) = 2.3203, $p<0.05$), respectively. ‘Education’ was of high importance for the two groups, a strong correlation is found with r=0.74.

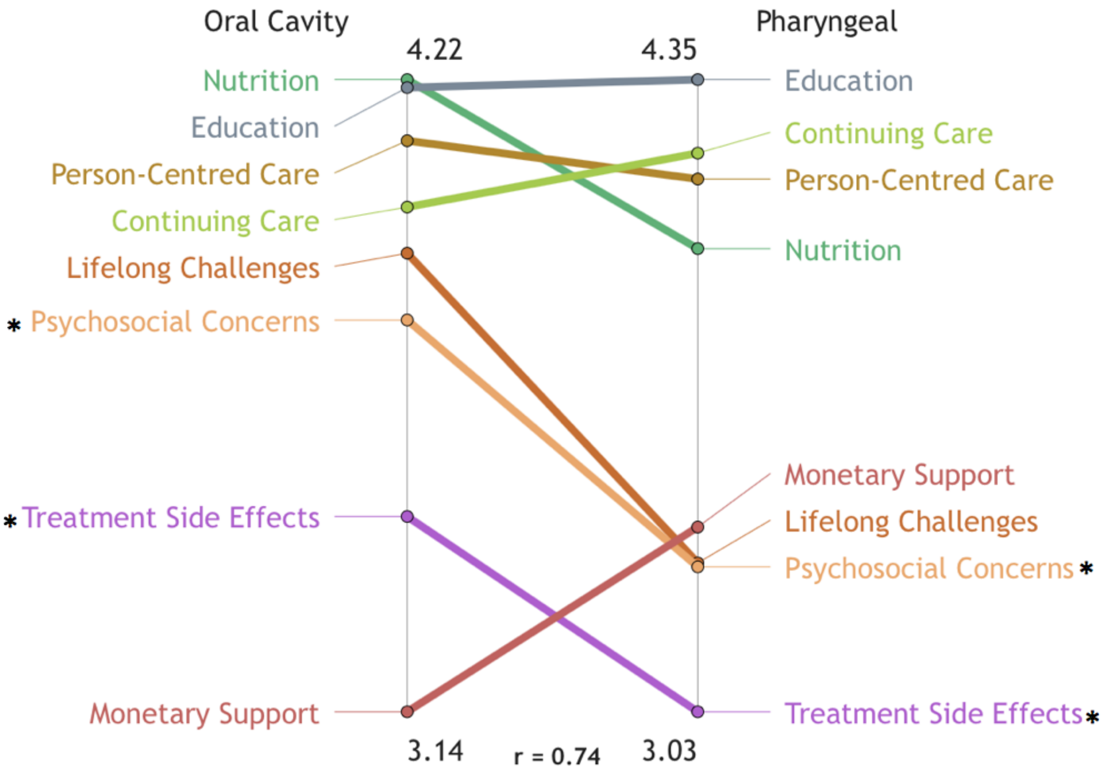


Figure 4.9. Pattern Match: Tumour Site. This figure illustrates the average rating agreement between patients with oral cavity cancers and pharyngeal/oropharyngeal cancer.

*statistically significant difference

Stage at diagnosis. A comparison between the priorities rating of patients who were diagnosed with cancer at an early stage (n=6) and patients who were diagnosed at an advanced stage (n=7) is depicted in pattern match (Figure 4.10). The stage at diagnosis did not have an influence on the highest rated priority, as both groups rated ‘Education’ as their top priority. Although ‘Treatment Side Effects’ and ‘Monetary Support’ were the lowest ranked consideration in terms of importance among both groups, the two clusters were of a higher priority rating for patients diagnosed at an advanced stage, statistically significant (t (66) = 4.9386, $p<0.001$), (t (10) = 2.9964, $p<0.02$) respectively. ‘Person-Centred Care’ was the second highest priority for patients who were at an advanced stage of cancer at the time of diagnosis but was ranked as the fourth high priority for the other group. The difference in rating was statistically significant (t (30) = 4.1683, $p<0.001$). Additionally, patients diagnosed at an advanced stage reported significantly higher importance of ‘Psychosocial Concerns’ than the other group, (t (14) = 4.4879, $p<0.001$). ‘Continuing Care’ was of higher priority to patients diagnosed at an advanced stage of cancer. A statistically significant difference in rating was noted (t (18) = 2.1125, $p<0.05$).

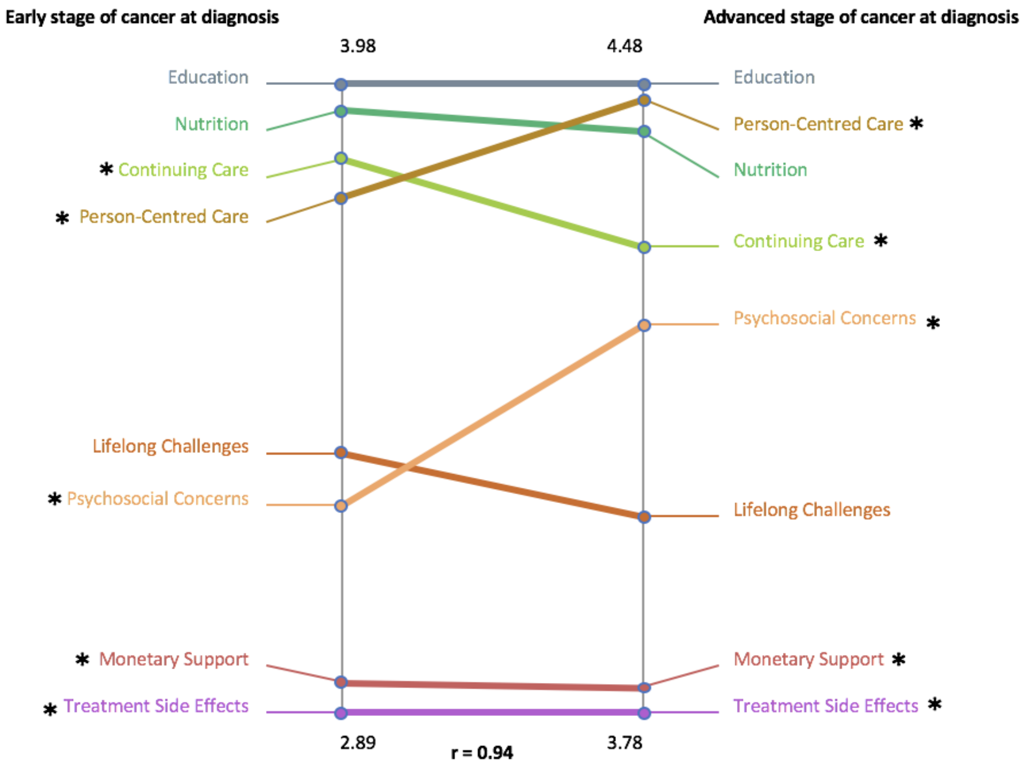


Figure 4.10. Pattern Match: Stage of Cancer at Diagnosis. This figure illustrates the average rating agreement between patients diagnosed at early stage and patients diagnosed at a later stage. *statistically significant difference

Time since treatment. There was no statistically significant influence of time since treatment on patients' priorities as plotted on pattern match. Patients who were 5 years post-treatment (n=10), patients who are less than 5 years post-treatment (n=5).

Treatment modalities. Pattern match (Figure 4.11) illustrates the impact that different treatment modalities can have as a variable for priorities in patients. Surgical (n=2) vs. non-surgical intervention (n=3) impact was explored in pattern match (a). Although 'Psychosocial Concerns' was of a higher priority for patients undergoing non-surgical intervention, it was the least important consideration for patients who had surgical intervention. This difference was statistically significant (t (14) = 3.5290, p<0.005). ‘Education’ was also found to be statistically more important for people with history of non-surgical intervention (t (14) = 2.8934, p<0.02). Surgery + RT was compared to surgery + CRT in pattern match (b) (Figure 4.14) to study the influence of including chemotherapy in a treatment plan on patients' priorities. ‘Continuing Care’ was the top priority for the latter group and the fifth priority for the former group. This difference was statistically significant (t (18) = 4.4846, p<0.005).

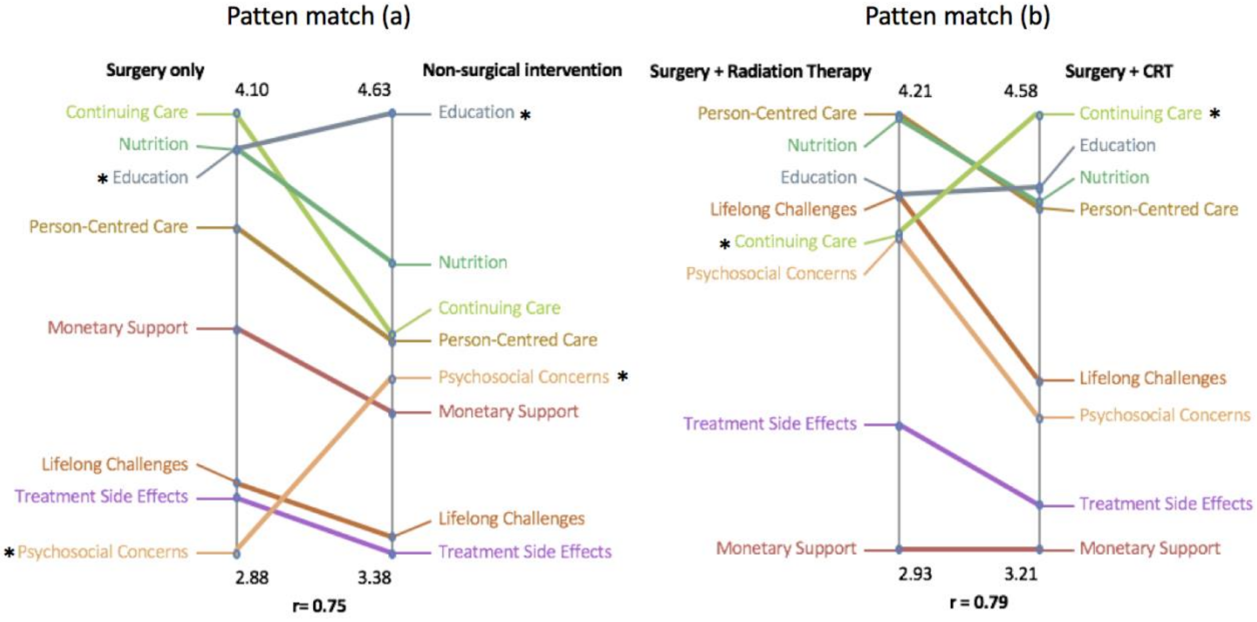


Figure 4.11. Pattern Match: Treatment modalities. *statistically significant difference

Go-Zone

Go-Zone: patients and healthcare providers.

A relatively high correlation was found between patients’ and healthcare providers’ ratings (r=0.71) at a statement level (Figure 4.12). Forty statements found in the go-zone quadrant (depicted as the green quadrant in Figure 4.12) were associated with ‘promptness of treatment’ and ‘promptness of diagnosis’. A full list of statements in all zones is found in (Appendix P).

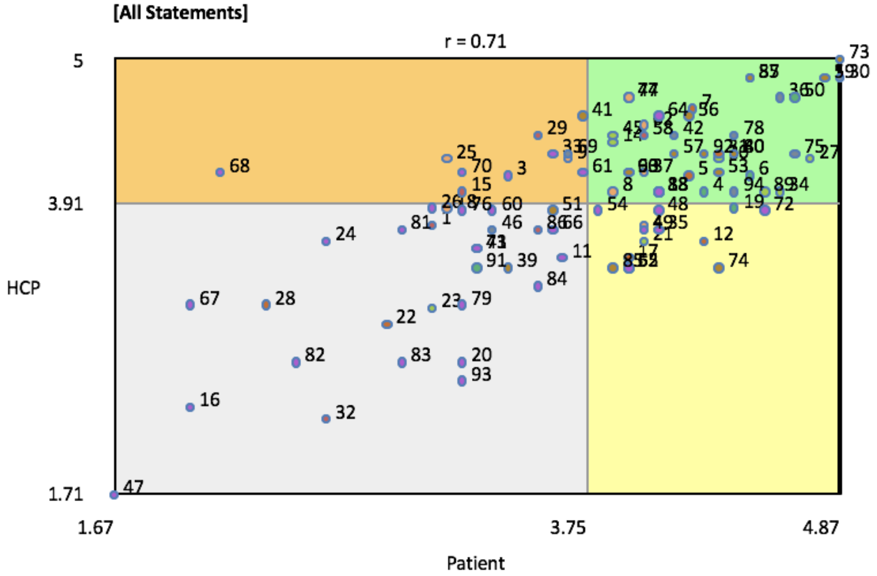


Figure 4.12. Go-Zone: Patients and Healthcare Providers (HCP). This figure represents statements ratings across patients and healthcare providers.

Go-Zone: the role of HPV.

A medium to large correlation was found between the statements made by patients with HPV and those without HPV (r= 0.61) (Figure 4.13). Of all statements, ‘promptness of treatment’ and ‘promptness of diagnosis’ were found at the top of the go-zone quadrant, suggesting a high level of agreement on these statements by patients in both groups. In contrast, patients with HPV gave four statements from ‘Psychosocial Concerns’ an above-average ranking of importance, whereas patients with HPV gave them a below-average rating. A full list of statements in all zones is found in (Appendix Q).

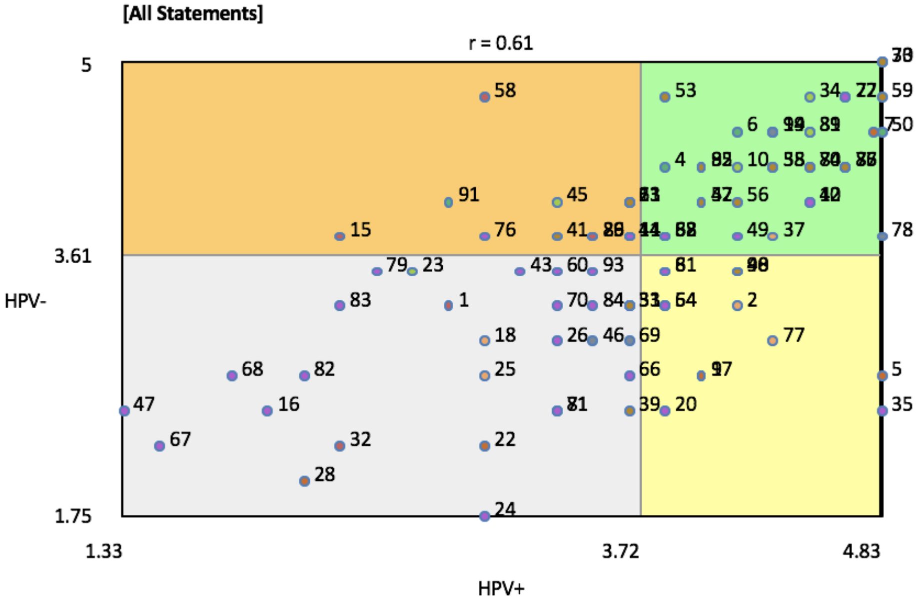


Figure 4.13. Go-Zone: The Role of HPV. This figure represents the HPV role in changing the statements ratings in terms of importance.

CHAPTER 5: DISCUSSION

In this study, we explored the experience of head and neck cancer (HNC) in terms of outcomes priorities from different perspectives. We set out to determine the relationship between patients' and healthcare providers' priorities to help influence future treatment planning and enhance care experience. Results revealed general alignment of priorities between patients and healthcare providers, with only one significant difference of priority rating in the 'Psychosocial Concerns' context. We also set out to understand how demographic and clinical factors of head and neck cancer patients influenced outcome priorities. Three factors, human papillomavirus (HPV), age, and marital status were found to be influential.

In answering the first research question, several priorities were revealed that reflect the complexity of treatment outcomes. These will be discussed in terms of their subsequent impact on treatment planning for the HNC population. We will examine how the highest priorities identified by participants – timely care and education – can influence treatment outcomes and overall care experience. Additionally, the importance of support, proper communication and compassionate care as part of 'person-centred' approach to care will be discussed as part of common priorities. Finally, differences in priorities of patients based on HPV, age, and marital status and how they must be considered in treatment planning will be addressed.

Complexity of Treatment Outcomes

Our first objective was to provide an exhaustive list of outcomes reflecting the HNC care experience. A holistic set of 94 outcomes were refined from the brainstorming activity. These included statements not only related to treatment outcomes but also to healthcare-related outcomes, reflecting the global and complicated impact of this illness. Healthcare-related statements were centred around accessibility to health services for those in rural communities, care services after primary intervention, psychological and social support before, during, and after treatment, healthcare providers' knowledge, and patient and family education. Other outcomes reported in the literature also were identified in the present study including: survival (Badr et al., 2010; Gill et al., 2011; Sharp et al., 1999; Tschiesner et al., 2013b); pain and functional outcomes (Badr et al., 2010; Gill et al., 2011; Sharp et al., 1999; Tschiesner et al., 2013; Wilson, Carding, & Patterson, 2011); physical alterations and psychological outcomes (Jackson & Trochim, 2002; List & Bilir, 2004; You, Henry, & Zeitouni, 2019); social impact of treatment (List & Bilir, 2004; Nguyen et al., 2005; Stringer, 1999; Ward, Bishop, Frisby, & Stevens, 2002); financial challenges (Morales et al., 2020; Taylor et al., 2004); support and involvement in decision-making (Bisschop et al., 2017; Edwards, 1998).

The priorities extracted in brainstorming were not distinct but rather interconnected at multiple levels, supporting the complexity of the cancer treatment process and the multifactorial nature of treatment decisions that have already been reported in the literature (Windon et al., 2018). For example, the 'Nutrition' cluster identified in the present study is an example of this interconnection of treatment outcomes. Although this particular cluster mainly included considerations related to feeding and nutrition, it also included a statement on *'survival'*. The location of '*survival'* in the centre of the map and within the 'Nutrition' cluster was primarily driven by *'survival'* being related to many different clusters and statements around the map. This is reflected by the relatively high bridging value of this statement. Furthermore, '*survival*' was sorted by 10 participants with '*fear of recurrence*' and ‘*fear of the unknown*’, which highlights the relationship between psychological outcomes and survival and how the desire to survive might co-exist with the fear of recurrence and uncertainty.

Importance Ranking of Treatment Outcomes

The second and third objectives in this study included developing a conceptual map of prioritized outcomes, and then using that map to determine the most meaningful outcomes to be considered during future decision-making process in order to improve the care experience for future patients. Outcomes were examined at both a priority level and a cluster level. At a priority level, timeliness and promptness of care were ranked the highest. At a cluster level, education and person-centred care were ranked highly in terms of importance for patients and healthcare providers.

Timeliness of Care

At a *priority* level, timely care was ranked the highest for both HNC patients and healthcare providers. Despite recognizing the need for prompt HNC intervention in ensuring optimal outcomes, delays in delivering care for HNC is frequently reported (Graboyes, Garrett-• Mayer, Sharma, Lentsch, & Day, 2017; Graboyes et al., 2019). These delays ultimately affect functional outcomes (Graboyes et al., 2019; Xiao et al., 2018) and mortality (Graboyes et al., 2019; Guttmann et al., 2018). A recent systematic review looked at the effect of treatment delay on outcomes and survival (Graboyes et al., 2019). There was no clear association between delay in initiation of treatment and survival or its effects on outcomes (Graboyes et al., 2019; Ho et al., 2018)however, delay in initiation of surgery has been found to enhance tumor progression (Jensen, Nellemann, & Overgaard, 2007). Shorter intervals between surgery and initiation of adjuvant radiation therapy (RT) was found to be correlated with better survival outcomes (Graboyes et al., 2019). As a result, timeliness in initiating RT after surgery has been presented as a quality measure for HNC (Cramer et al., 2017; Graboyes et al., 2019) and standardized guidelines have been suggested by the National Comprehensive Cancer Network to initiate RT within six weeks or less of surgery (Graboyes et al., 2019). Despite such recommendations, barriers to timely treatments still exist, such as travel-related limitations, treatment complications, prolonged surgical recovery, tumor board meetings and decision processes, need for patient transfers to different care facilities and waiting for second opinions (Ho et al., 2018). Successful strategies to facilitate the promptness of HNC treatment remains undetermined (Graboyes et al., 2019)

Prompt diagnosis was the second highest priority in our findings, and one that both HNC patients and healthcare providers agreed upon. One measure of promptness of diagnosis is the time between symptom presentation to the primary care/family physician and referral to a specialist. One study found that among 175 HNC patients, time to specialist referral ranged between 0-27 days with a median of 6 days (Lyratzopoulos, Abel, McPhail, Neal, & Rubin, 2013). The HNC clinical practice guideline in Alberta states that HNC patients will start initial diagnostics within two weeks of referral to the experienced surgeon. When a patient presents with severe symptoms that suggest HNC, urgent assessments are conducted instantly (Alberta Provincial Head and Neck Tumour Team, 2015).

Education

To further address our objectives on determining the most important HNC related outcomes, our findings showed that at a cluster level, ‘Education’ was the highest ranked cluster in terms of importance for patients and healthcare providers. While patients are looking for timely diagnosis, they also require clear information on the disease, treatment plan, treatment options, long-term side effects, clarity on the possible experience of side-effects and how to manage them, and having an accessible tool to find this information and answer common questions. Healthcare providers similarly stressed the importance of these aspects of education.

In our findings, patients and healthcare providers valued '*clear detailed upfront information of the case and treatment plan*', and '*information on the available treatment options and new advancements*' as high educational priorities. This finding has been substantiated in the literature in several studies. It has been found that clear information on the treatment plan prior to the initiation of treatment can impact overall outcomes (Checklin, Bain, Bath, & Lethbridge, 2019). For instance, comprehensive information delivered on the rehabilitation process and stages of therapy facilitated the ability to return to work earlier in HNC patients (Morales et al., 2020). Nevertheless, the patients' ability to comprehend information considering their emotional readiness is critical, as some patients with HNC reported difficulty remembering the information given before treatment sessions regarding their treatment plan (Brockbank, Miller, Owen, & Patterson, 2015). It is also valuable to scaffold education throughout all stages of care as this is shown to have a positive effect on recovery (Morales et al., 2020). Health organizations have established patient-centred care strategies (Alberta Health Services, 2015; Covenant Health, 2016) that have recognized the importance of having timely clear discussions around the goals of care and expectations of such care.

'Information on long-term side effects and the possible traumatic experience' and *'Education on how to manage and cope with long-term side effects*' were also priorities that

are agreed upon between patients and healthcare providers. In this regard, HNC patients stress the importance of receiving thorough information covering all expected outcomes before initiating treatment to better anticipate and prepare for possible side effects (Brockbank et al., 2015; Checklin et al., 2019). It should be noted that studies have shown different preferences for how this information is delivered. For example, while some patients preferred to know everything at the time of diagnosis, others felt it was difficult to comprehend information on side effects when provided right after diagnosis (Brockbank et al., 2015). In addition to their need for some time to realize the diagnosis first, detailed information about all possible side effects can be overwhelming, which in turn affects patients' motivation to request further clarifications or ask questions (Brockbank et al., 2015). On the other hand, inadequate information delivered on side effects can have a negative impact on patients' psychological wellbeing. Patients who did not receive sufficient information on treatment-related side effects were found to develop anxiety and depression (Llewellyn et al., 2005)

In the age of the internet, patients seek health information related to symptoms, etiologies and treatment options online and even try to educate themselves in interpreting test results (Dodd et al., 2019). Such health behaviours pose a risk that patients might rely on nonmedical sources to ease their concerns and highlights the need for trustworthy and informed sources to provide appropriate information to patients and their families, in a timely manner (Bisschop et al., 2017; Checklin et al., 2019; Llewellyn et al., 2005). This aligns with the priority found in our study *'providing an accessible resource/tool for information and common questions*'. The method of information delivery can be an important factor in what information is being used and how information is comprehended. Some patients may prefer receiving verbal information as it allows them to declare concerns, ask questions and clarifications. Others may find written educational materials more appealing because it is accessible when needed. The downside to written resources is that they are typically designed to convey general rather than tailored information for individuals (Brockbank et al., 2015; Checklin et al., 2019). Clear and tailored information on outcomes specific to a patient's case and situation throughout the care journey is valued by patients and it helps them in having a better care experience (Checklin et al., 2019).

Patients in our study reported '*fear of the unknown*' as a priority to consider when delivering care. Literature has proposed that fear is the first and most powerful feeling in humanity, and the unknown is the earliest and most powerful fear, as originally dictated by Howard Phillips Lovecraft in 1927 (Carleton, 2016). To define the unknowns, Carleton (2016) suggested that "an unknown is the perceived absence of information at any level of consciousness". One study suggested that sharing experiences and emotional support through support groups can lift this fear of uncertainty (Weis, 2003). Thus, providing comprehensive information to individuals and families may contribute to reducing fear.

Person-Centred Care

Participants in our study value the 'Person-Centred Care' model as a high priority. The 'Person-Centred Care' cluster in the present study covered statements on support, knowledge, and involving the patient and their families in care decisions. This cluster was given a high average rating value reflecting the importance of the person-centred care model. People/person-centred care is a trending approach in global health systems and organizations. The World Health Organization (WHO) defined this type of care as a system that is oriented around the patients' needs rather than centred on the disease. It is applied by providing care *with* patients rather than *to* them and it considers patient and family perspectives on the care plan (World Health Organization, 2020). Patients and healthcare providers in our study reported that *'being involved in decision-making*' and '*keeping the family informed'* are important to planning treatment for HNC. Patients generally consider it highly important to include their families and friends in the decision-making process and to consider their opinions and worries throughout the treatment process (Bisschop et al., 2017). Yet, not having sufficient information on the treatment options makes it difficult to be actively involved in decision-making (Edwards, 1998). Thus, in order to be able to discuss and share thoughts around decisions related to care, patients need to be educated on their care options, nature of illness, prognosis and expected outcomes. They also need to be supported throughout the decision-making process and afterwards.

HNC patients appreciate healthcare providers showing empathy and care, as well as communicating actively with them (Checklin et al., 2019). *'Communication with healthcare providers*' and *'Engaged healthcare providers with compassionate care*' were also high priorities in the 'person-centred care' domain in the present study. Patients need to communicate effectively with healthcare providers to be able to make decisions. They also need to be provided with opportunities for feedback on treatment outcomes. AHS stated that its strategy in patient-centred care includes training opportunities to further improve the communication between care providers, patients and families to help ensure that patient priorities are being met. This communication skill development is expanded to include communication within the healthcare team (Alberta Health Services, 2015). It is also crucial that health authorities ensure training and resources for healthcare providers on how to manage compassion fatigue (Checklin et al., 2019) Previous literature has suggested that with time, experience, and higher exposure to HNC cases, treatment adverse effects become less overwhelming for providers (Demez & Moreau, 2009). This might raise a question of what factors other than experience and exposure exacerbate compassion fatigue.

Influential Patient Variables

The second research question in the present study intended to determine the influence that demographic and clinical factors might have on outcomes priorities. Highlighted by their priorities rating, the results showed that there were specific groups of patients who may need special consideration. These included patients with HPV, the elderly, and people who are single.

People with HPV in our study considered psychological concerns including *'anxiety', 'depression', 'fear of the unknown',* and '*fear of recurrence*' as more important than people without HPV. Due to its nature of transmission (i.e., sexual contact), HPV involvement has shown an impact on individuals' psychosocial wellbeing and patients with HPV-associated HNC have been shown to have a higher fear of recurrence compared to HNC patients without HPV-association (Windon et al., 2019). Signs of anxiety, distress, and concerns regarding intimacy or transmission also have been reported in the literature for this population (Windon et al., 2018; Windon et al., 2019). Considerations in the patient care pathway should account for the psychosocial impacts HPV involvement can have when planning treatment for this subset of patients.

With respect to age, older individuals in our study found it important to consider *'psychological support and recommendations before treatment', 'support and guidance after treatment', 'family/ caregiver/ loved one/ social support',* and to *'keeping the family informed'*. The family of older cancer patients are often highly involved in the cancer experience. It has been shown that elderly patients associate pleasantness and comfort when they had strong social supports (Haley, Ehrbar, & Schonwetter, 1998; Weitzner, Haley, & Chen, 2000). These reports appear to reflect our findings where patients who were older than 60 years identified different means of support as a priority when compared to younger patients. Obtaining social support has been found to be the most indicated coping strategy for elderly cancer survivors (Kahana, Kahana, Langendoerfer, Kahana, & Smith-Tran, 2016). Seeking social support varied in types including emotional support, medical assurance, and being dependent on a caregiver or a family member (Kahana et al., 2016).

Greater psychological distress has been noted in single individuals diagnosed with HNC compared to those that have partners (Karnell, Christensen, Rosenthal, Magnuson, & Funk, 2007; Kugaya, Akechi, Okamura, Mikami, & Uchitomi, 1999). In the present study, individuals who were single, widowed, or divorced gave more importance to *'having mentors who share the same experience', 'identification of support groups and resources specific to head and neck cancer', 'social support/ counseling services (individual or group)', 'Accessibility of counseling services in cancer treatment centres', and 'psychological support and recommendations before treatment'* than patients in a relationship. In other studies, significant positive correlation has been found between the level of social support and the level of adjustment to treatment outcomes, namely disfigurement (Katz, Irish, Devins, Rodin, & Gullane, 2003). Support groups allow peers to share advice and tips from their experience, especially in managing treatment outcomes, providing psychological support and improving quality of life for HNC patients (Checklin et al., 2019; Vakharia, Ali, & Wang, 2007).

Study Implications

This study aimed to explore the experiences in HNC and identify priorities of both patients and care providers in order to enhance future treatment planning for this population. The priorities captured in this study align with the vision and care delivery plan of AHS (Alberta Health Services, 2015), which identifies education and person-centred care as top priorities while ensuring timely diagnosis and intervention.

A significant priority identified in our study was the need for effective information delivery considering mode of delivery, timing of information and patients' readiness to receive information. Clear and tailored information should be communicated to enable patients to better understand their care pathway. Another consideration is the continuity of information delivery, including education on management of side-effects and the availability of educators and resources along the entire pathway of the patient's cancer journey. It is encouraging that patients and healthcare providers in Alberta have a desire to enhance education and information delivery as reported in the AHS patient-first strategy (Alberta Health Services, 2015).

Person-centred care as a model is known for its impact on quality of care, and the importance of this model has been reflected by our participants. Both education and support are key factors to help patients and families be actively involved in the decision-making processes. We need to confirm that patients are supported and have the appropriate and adequate information needed to make a decision with their healthcare team.

Psychosocial support before treatment is essential to assess and maintain patients' wellbeing after the diagnosis of HNC and to provide professional psychological support in preparing them for the treatment phase. It is also vital to have support sources available after treatment. Due to the value of social support, information on support groups and mentors with clear pathways for accessibility should be available for patients and families. Given that certain patients groups have been correlated with a higher need and a higher value for support, care providers should identify patients who are either older, single, or with etiologic subset related to HPV to ensure the adequate support sources obtainable. Because healthcare providers' communication and engagement with patients is perceived as a priority and a means of support for patients, continuous professional training on communication for healthcare providers and engaged communication and compassion with patients and their families is necessary.

Study Limitations and Future Research Directions

There are several limitations to the study that may limit the generalizability of the findings. Although the sample was sufficient to produce valid and reliable data in concept mapping, it was small to be generalizable for all HNC patients and healthcare providers. The HNC patients and healthcare providers were only from the province of Alberta and because the healthcare is provincial in Canada, our findings from Albertans may not be representative of patients in other geographical regions. In Alberta, there are three main cancer centres, along with one prime institution responsible for reconstructive medicine and rehabilitation services. Patients from different provinces and/or regions might have different access of care and care experiences, which could shift their priorities and considerations. A larger study can look into the priorities of Canadian HNC patients and healthcare providers, and compare priorities across provinces. This would allow for further investigation of underlying factors causing the differences in priorities.

Although it was intended to include the perspective of caregivers on priorities, the very low sample size in sorting (n=1) and in rating (n=2) activities did not allow us to include any of their responses in the analysis process. Understanding caregiver considerations and priorities is an area of research that requires further investigation, given that this may impact the patient's well-being (Longacre, Ridge, Burtness, Galloway, & Fang, 2012)and may play a vital role in the care experience and outcomes of patients.

Despite the fact that group concept mapping (GCM) facilitated the active identification of treatment outcomes from participants and allowed the capture of multiple perspectives, we are missing a deeper understanding of why some outcomes are of a higher priority than others. Future studies might consider conducting qualitative interviews or focus groups to further understand the participants' priorities. Of particular importance would be to understand why education and person-centred care are higher priorities than side-effects. Are these priorities unmet? Or otherwise met and believed to be factors for a successful experience? Further research may investigate details of priorities in each phase: diagnosis, treatment, and transitioning to rehabilitation.

Another study limitation was the low response rate in the online method used. Although online methods of GCM have certain benefits, including access to a large number of participants across the province, a low response rate was addressed in the literature and noted in our study (Kane & Trochim, 2007). Feedback was received by email on technical confusions in following the link provided and logging into the study page. However, we followed up with that feedback and ensured a successful login and participation. On the other hand, positive feedback was received in this regard where participants found it "fun" to participate in these activities. Although the on-site method is more time challenging and financially demanding as it requires traveling, providing meeting site, printing and providing tools for data collection, it is suggested that when feasible, an on-site method of GCM might be used in future studies to overcome the limitations seen in this study.

Another limitation secondary to the study design was that a number of participants logged in and initiated a non-complete response in the sorting and rating activities. In this situation, participants required frequent prompts to be reminded of participating or completing their response. However, since the responses were anonymous, researchers were unable to contact participants prompting them for completion. In future online GCM studies, a registered participant approach might be applied to overcome this limitation. We also received feedback that the instructions and process of the sorting activity were unclear. This was reflected in the number of participants who completed the sorting activity but grouped the statements in relation to their own experience rather than the meaning of statements. A tutorial of how the responses can be obtained and how to navigate through the website is suggested for future GCM studies. Furthermore, because the statements in sorting and rating activities were subject to the participants' interpretation, differences in interpreting the meaning of some statements might have occurred across participants. Other limitations related to study design are noted in participants' questions; it is probable that differences in tumor site naming e.g., larynx/voice box, pharynx/throat affected participants' answers to demographic and clinical questions. Additionally, since the stage of cancer at diagnosis was plotted in the demographic questions with no clear definition of each stage, possible differences in interpreting early and advanced cancer stages perhaps occurred. This might possibly cause questionable results in priorities comparing stage of cancer as a variable in patients. Another issue arose due to a software malfunction. One of the outcomes extracted from brainstorming activity (i.e., ”tongue pain”) was accidently duplicated in the synthesized set, and participants had to sort and rate this statement twice. When the software experts were consulted, the duplication issue was found to be somehow frequent, and since the duplicated statement was found together in the same cluster after analysis, no negative effect is estimated.

Conclusion

Being diagnosed with HNC is devastating and the treatment and recovery experience can be traumatizing. In an era focused on survivorship, putting survivors first starts by understanding their needs and priorities to better understand and serve future patients and families. In this study we discussed approaches to improve care experience for HNC patients, determined by our findings on outcomes priorities. The perspective of healthcare providers was explored to compare their priorities with patients'. General agreement and high correlation was noted. Some demographic and clinical characteristics in patients influenced their priorities and highlighted their special needs. These include elderly patients, single patients, or with etiologic subset related to HPV.

Future research is warranted to identify standardized time limits for treatment and develop strategies to enhance timely care and reduce delays in treatment. Future research can look into patients' perspective on receiving general written educational sources with contact information to answer specific concerns, or an online accessible tailored information tool. Future studies also can investigate if HNC patients feel they are receiving adequate education and support to be comfortable in active engagement in decision-making.

In conclusion, throughout the care experience of HNC, timely care, education, and person-centred care were identified as the most meaningful considerations for future treatment planning.

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APPENDICES

Appendix A

Introduction to Project

Welcome to this project.

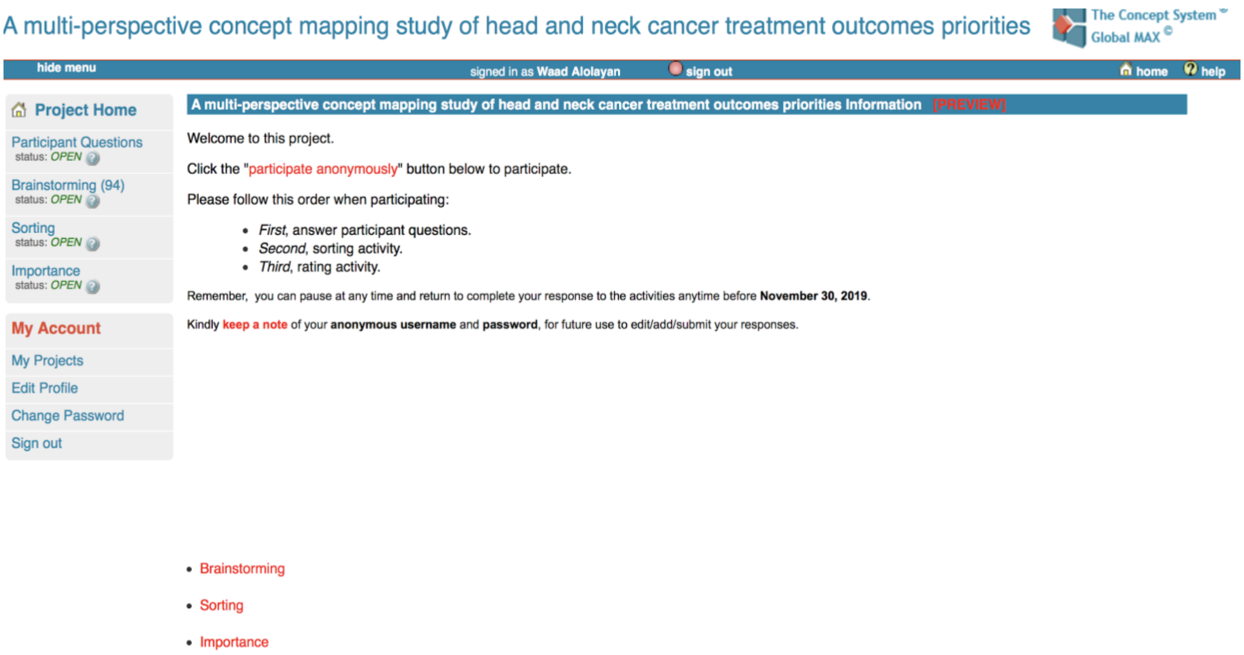
Click the "participate anonymously" button below to participate.

Please follow this order when participating:

- *First*, answer participant questions.
- *Second*, sorting activity.
- *Third*, rating activity.

Remember, you can pause at any time and return to complete your response to the activities anytime before **November 30, 2019**.

Kindly **keep a note** of your **anonymous username** and **password**, for future use to edit/add/submit your responses.



A multi-perspective concept mapping study of head and neck cancer treatment outcomes priorities

A multi-perspective concept mapping study of head and neck cancer treatment outcomes priorities Information [PREVIEW]

Welcome to this project.

Click the "participate anonymously" button below to participate.

Please follow this order when participating:

- *First*, answer participant questions.
- *Second*, sorting activity.
- *Third*, rating activity.

Remember, you can pause at any time and return to complete your response to the activities anytime before **November 30, 2019**.

Kindly **keep a note** of your **anonymous username** and **password**, for future use to edit/add/submit your responses.

Appendix B

Participant Questions

Participant Question 1

Name	Role
Question text:	I am a.. If you have different roles, please choose **one** to be your primary role that you will be responding as in the following activities.
Type	Categorical
Choice 1	Patient
Choice 2	Caregiver/family member
Choice 3	Healthcare provider

Participant Question 2

Name	Age
Question text:	How old are you?
Type	Continuous
Minimum	18
Maximum	100
Precision	0

Participant Question 3

Name	Gender
Question text:	My gender is..
Type	Categorical
Choice 1	Male
Choice 2	Female

Participant Question 4

Name	Marital status
Question text:	What is your marital status?
Type	Categorical
Choice 1	Single
Choice 2	Married, or in a domestic partnership
Choice 3	Widowed
Choice 4	Divorced, or separated

Participant Question 5

Name	Education Level
Question text:	What is the highest degree you have received?
Type	Categorical
Choice 1	Less than high school degree
Choice 2	High school degree or equivalent
Choice 3	Associate degree
Choice 4	Bachelor degree
Choice 5	Graduate degree

Participant Question 6

Name	Tumor Site
Question text:	If you are: · An individual with head and neck cancer · **Or** a family member or a caregiver of an individual with head and neck cancer. Please select the site of the cancer you or your loved one have/had. You can select multiple sites if that applies to your case
Type	Categorical

Choice 1	Nasal cavity and paranasal sinus
Choice 2	Oral cavity (jaw, mouth, lips, gum, tongue)
Choice 3	Pharynx (throat)
Choice 4	Larynx (voice box)
Other	Other reply allowed

Participant Question 7

Name	Stage at diagnosis
Question text:	If you are: · An individual with head and neck cancer · **Or** a family member or a caregiver of an individual with head and neck cancer. At what cancer stage you were or your loved one was diagnosed?
Type	Categorical
Choice 1	Early stage
Choice 2	Advanced stage
Choice 3	Not known

Participant Question 8

Name	Time since treatment
Question text:	If you are: · An individual with head and neck cancer · **Or** a family member or a caregiver of an individual with head and neck cancer. What stage of treatment are you or your loved one at?
Type	Categorical
Choice 1	Currently undergoing treatment
Choice 2	Less than 6 months post-treatment
Choice 3	6-12 months post-treatment
Choice 4	1-2 years post treatment
Choice 5	2-5 years post-treatment
Choice 6	More than 5 years post-treatment

Participant Question 9

Name	Treatment type
Question text:	If you are: · An individual with head and neck cancer · **Or** a family member or a caregiver of an individual with head and neck cancer. What type of treatment you or your loved one underwent? You can choose all that apply.
Type	Categorical
Choice 1	Surgery
Choice 2	Chemotherapy
Choice 3	Radiation therapy
Choice 4	Immunotherapy
Choice 5	Targeted therapy
Other	Other reply allowed

Participant Question 10 (phase one)

Name	HCP Speciality
Question text:	If you are a healthcare provider, what is your speciality?

Type	Categorical
Choice 1	Physician
Choice 2	Allied health clinician
Choice 3	Clinical support

Participant Question 10 (phase two)

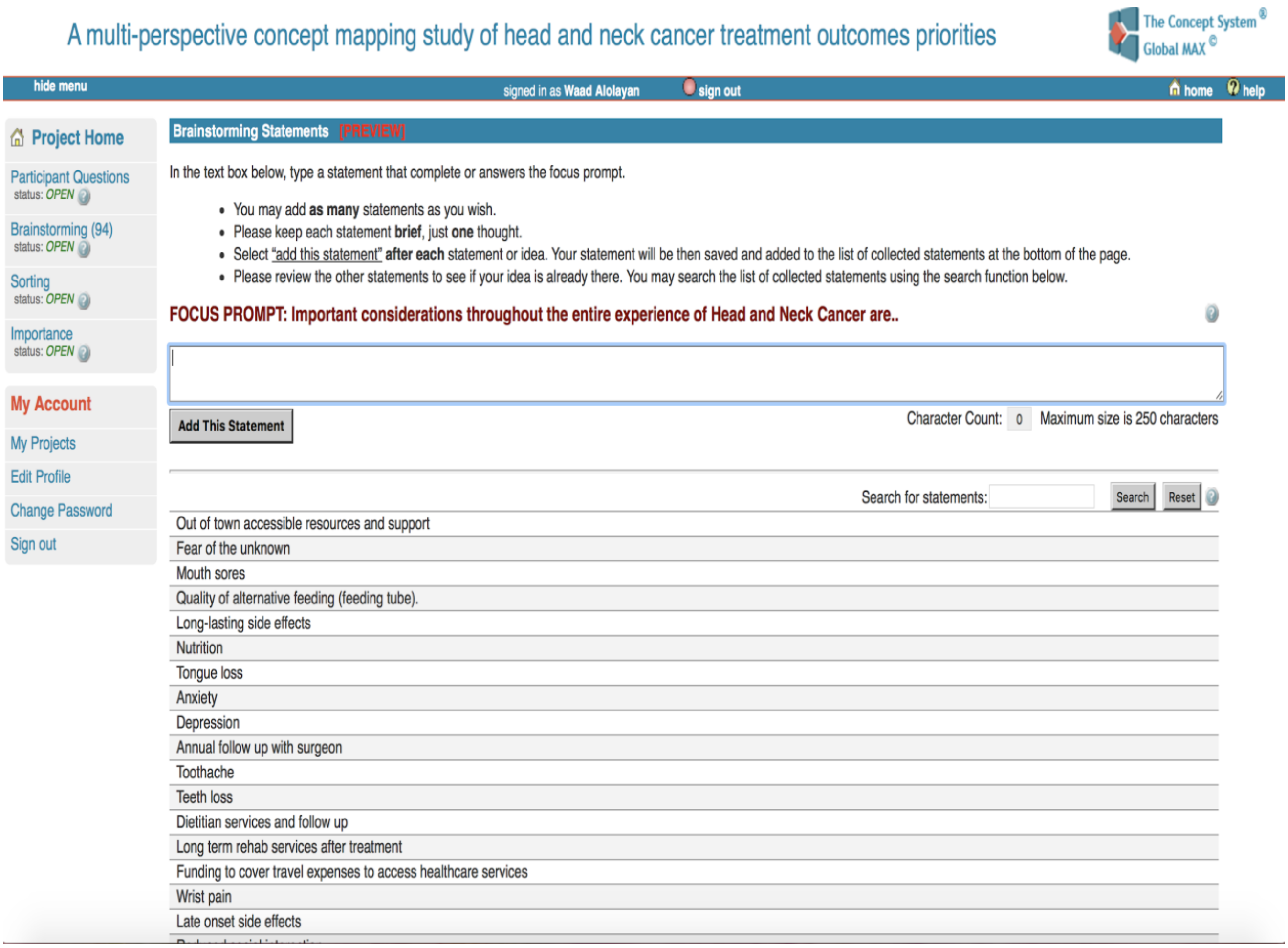
Name	HPV
Question text:	If you are: · An individual with head and neck cancer · **Or** a family member or a caregiver of an individual with head and neck cancer. Were you or your loved one diagnosed with HPV (human papillomavirus)?
Type	Categorical
Choice 1	Yes
Choice 2	No
Choice 3	Not known
Choice 4	Not applicable

Appendix C

Brainstorming Activity Instructions

In the text box below, type a statement that completes or answers the focus prompt.

- You may add **as many** statements as you wish.
- Please keep each statement **brief**, just **one** thought.
- Select <u>"add this statement"</u> **after each** statement or idea. Your statement will be then saved and added to the list of collected statements at the bottom of the page.
- Please review the other statements to see if your idea is already there. You may search the list of collected statements using the search function below.



In the text box below, type a statement that complete or answers the focus prompt.

- You may add **as many** statements as you wish.
- Please keep each statement **brief**, just **one** thought.
- Select <u>"add this statement"</u> **after each** statement or idea. Your statement will be then saved and added to the list of collected statements at the bottom of the page.
- Please review the other statements to see if your idea is already there. You may search the list of collected statements using the search function below.

FOCUS PROMPT: Important considerations throughout the entire experience of Head and Neck Cancer are..

Character Count: 0 Maximum size is 250 characters

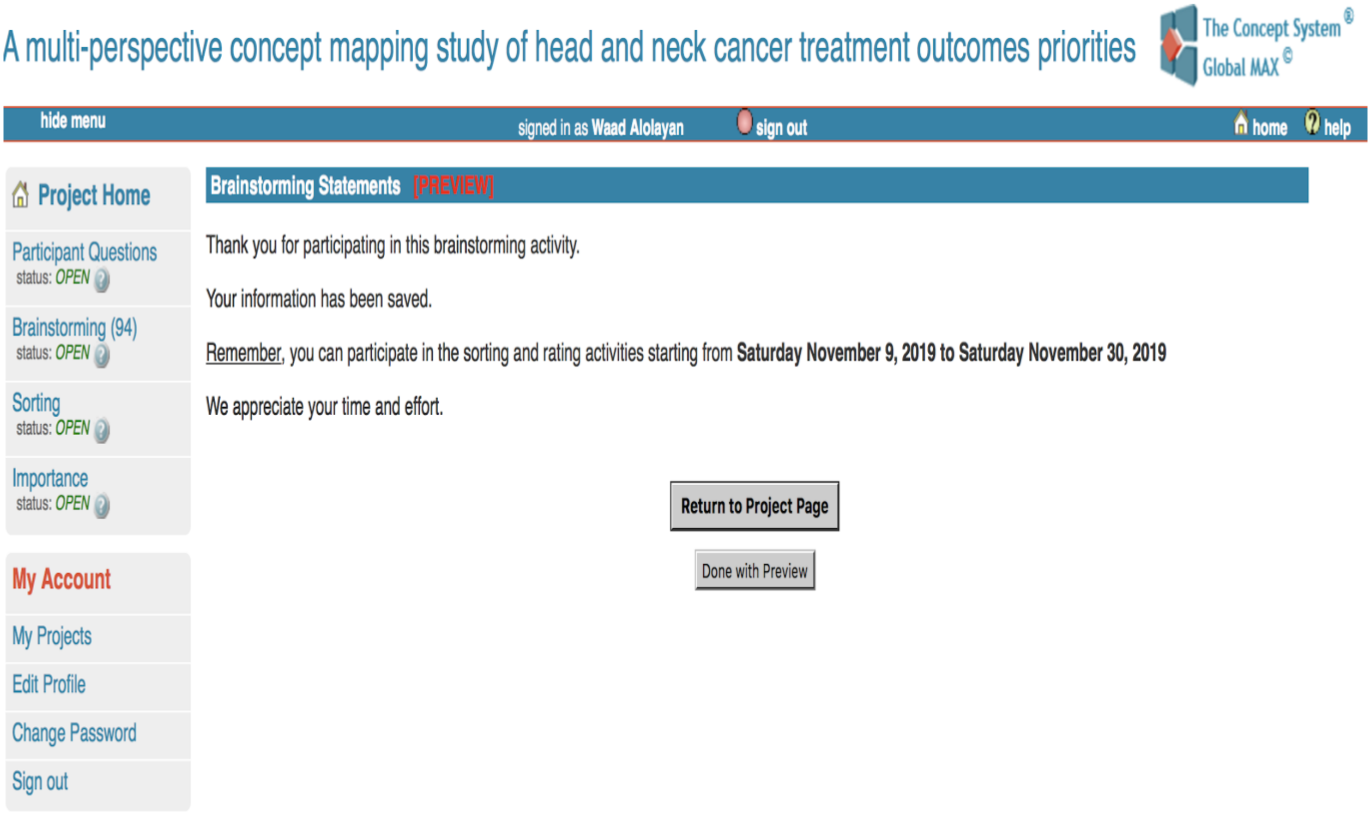
Search for statements:

Out of town accessible resources and support
Fear of the unknown
Mouth sores
Quality of alternative feeding (feeding tube).
Long-lasting side effects
Nutrition
Tongue loss
Anxiety
Depression
Annual follow up with surgeon
Toothache
Teeth loss
Dietitian services and follow up
Long term rehab services after treatment
Funding to cover travel expenses to access healthcare services
Wrist pain
Late onset side effects

Appendix D

Brainstorming Thank You Screen

This figure illustrates a preview of the “thank you” screen as it looks for participants after submitting responses.



A multi-perspective concept mapping study of head and neck cancer treatment outcomes priorities

Brainstorming Statements [PREVIEW]

Thank you for participating in this brainstorming activity.

Your information has been saved.

Remember, you can participate in the sorting and rating activities starting from **Saturday November 9, 2019 to Saturday November 30, 2019**

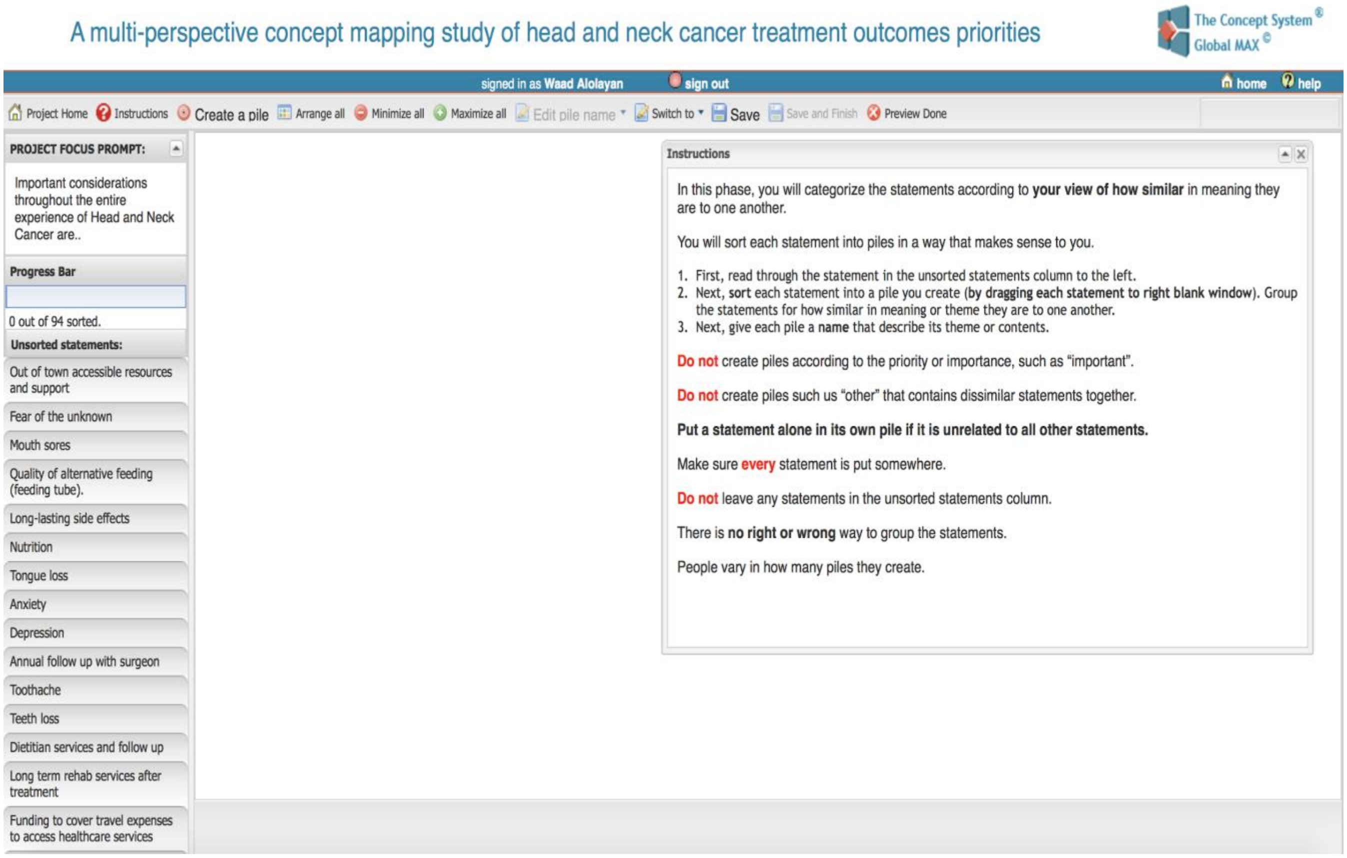
We appreciate your time and effort.

.

Appendix E

Preview of Sorting Activity Screens

This figure represents a preview of the tabletop sorting screen as it looks for participants



A multi-perspective concept mapping study of head and neck cancer treatment outcomes priorities

PROJECT FOCUS PROMPT:

Important considerations throughout the entire experience of Head and Neck Cancer are..

0 out of 94 sorted.

Unsorted statements:

- Out of town accessible resources and support
- Fear of the unknown
- Mouth sores
- Quality of alternative feeding (feeding tube).
- Long-lasting side effects
- Nutrition
- Tongue loss
- Anxiety
- Depression
- Annual follow up with surgeon
- Toothache
- Teeth loss
- Dietitian services and follow up
- Long term rehab services after treatment
- Funding to cover travel expenses to access healthcare services

In this phase, you will categorize the statements according to **your view of how similar** in meaning they are to one another.

You will sort each statement into piles in a way that makes sense to you.

1. First, read through the statement in the unsorted statements column to the left.
2. Next, **sort** each statement into a pile you create (**by dragging each statement to right blank window**). Group the statements for how similar in meaning or theme they are to one another.
3. Next, give each pile a **name** that describe its theme or contents.

Do not create piles according to the priority or importance, such as "important".

Do not create piles such us "other" that contains dissimilar statements together.

Put a statement alone in its own pile if it is unrelated to all other statements.

Make sure **every** statement is put somewhere.

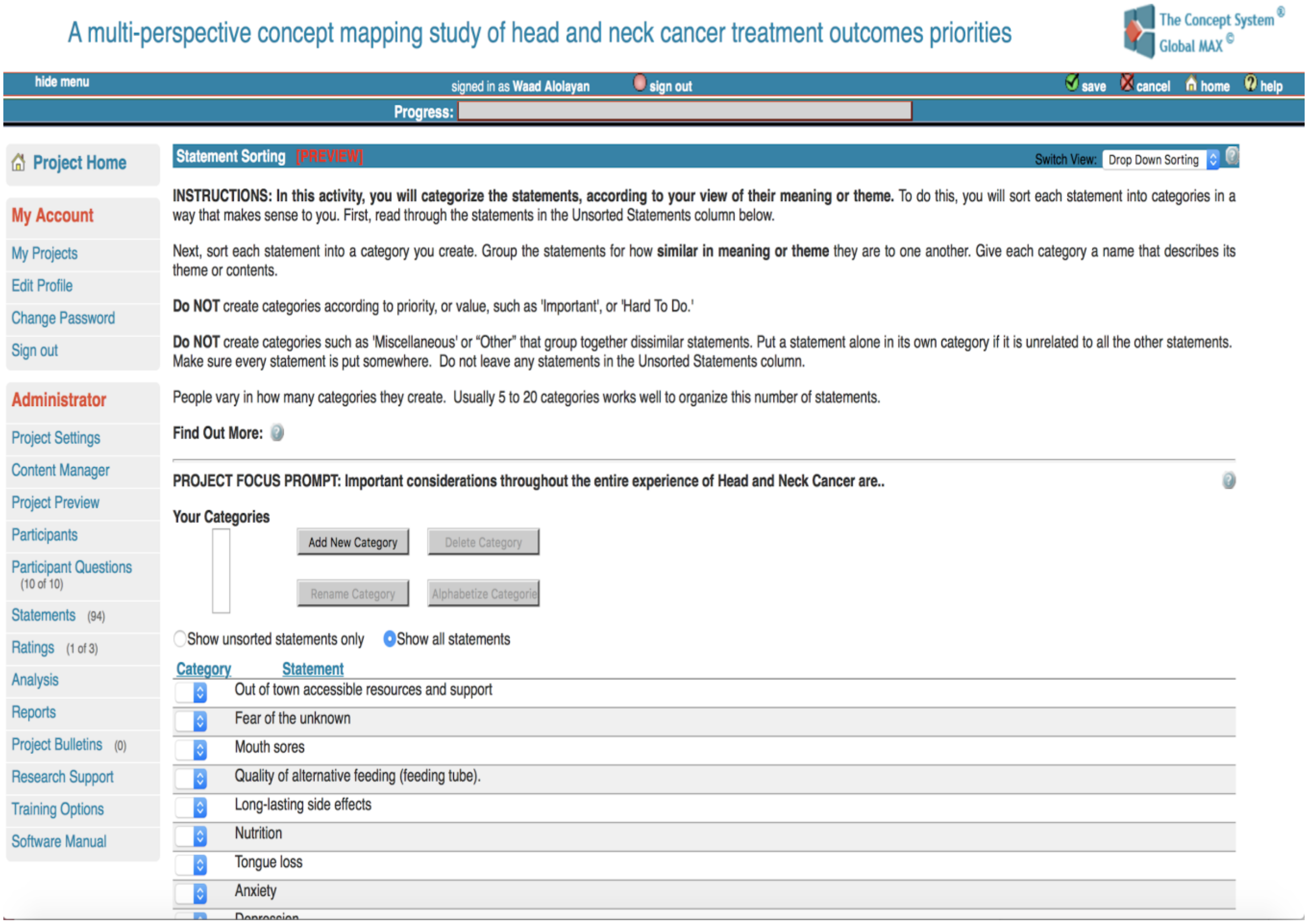
Do not leave any statements in the unsorted statements column.

There is **no right or wrong** way to group the statements.

People vary in how many piles they create.

Figure. Tabletop Sorting.

This figure illustrates a preview of the drop down sorting screen as it looks for participants.



INSTRUCTIONS: In this activity, you will categorize the statements, according to your view of their meaning or theme. To do this, you will sort each statement into categories in a way that makes sense to you. First, read through the statements in the Unsorted Statements column below.

Next, sort each statement into a category you create. Group the statements for how **similar in meaning or theme** they are to one another. Give each category a name that describes its theme or contents.

Do NOT create categories according to priority, or value, such as 'Important', or 'Hard To Do.'

Do NOT create categories such as 'Miscellaneous' or "Other" that group together dissimilar statements. Put a statement alone in its own category if it is unrelated to all the other statements. Make sure every statement is put somewhere. Do not leave any statements in the Unsorted Statements column.

People vary in how many categories they create. Usually 5 to 20 categories works well to organize this number of statements.

Find Out More:

PROJECT FOCUS PROMPT: Important considerations throughout the entire experience of Head and Neck Cancer are..

Your Categories

○ Show unsorted statements only ● Show all statements

Category	Statement
	Out of town accessible resources and support
	Fear of the unknown
	Mouth sores
	Quality of alternative feeding (feeding tube).
	Long-lasting side effects
	Nutrition
	Tongue loss
	Anxiety
	Depression

Figure. Drop Down Sorting.

Appendix F

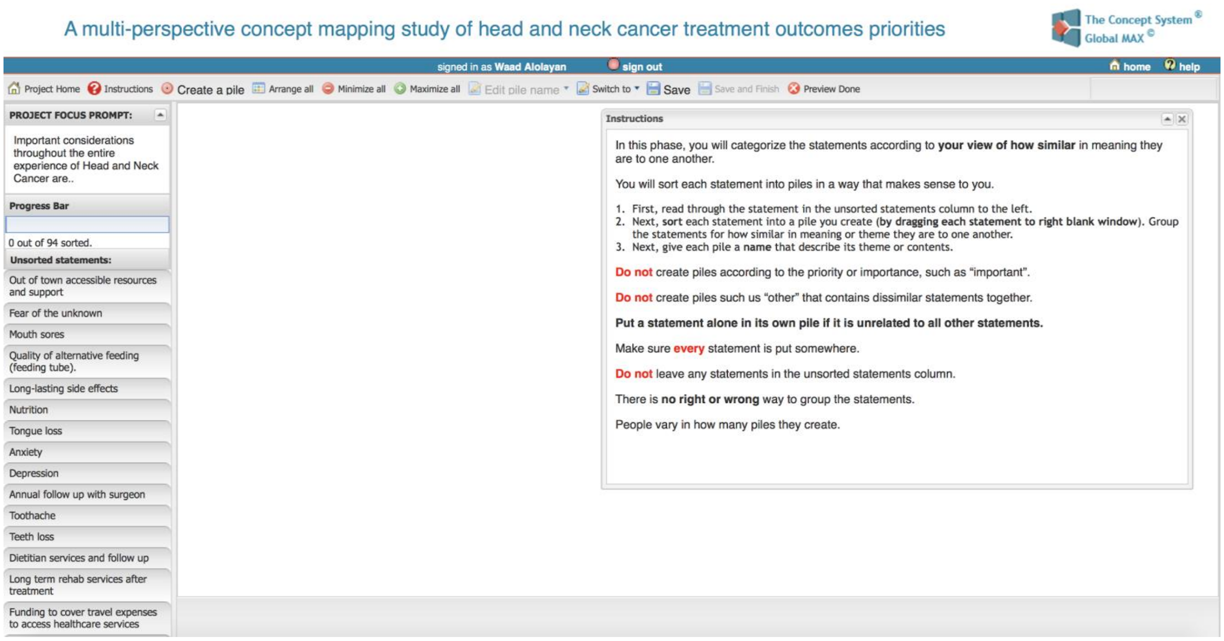
Sorting Activity Instructions

In this phase, you will categorize the statements according to ***your view of how similar** in meaning they are to one another.*

You will sort each statement into piles in a way that makes sense to you.

1. First, read through the statement in the unsorted statements column to the left.
2. Next, **sort** each statement into a pile you create (**by dragging each statement to the right blank window**). Group the statements for how similar in meaning or theme they are to one another.
3. Next, give each pile a **name** that describes its theme or content.

- **Do not** create piles according to the priority or importance, such as *"important"*.
- **Do not** create piles such as *"other"* that contain dissimilar statements together.
- **Put a statement alone in its own pile if it is unrelated to all other statements.**
- Make sure **every** statement is put somewhere.
- **Do not** leave any statements in the unsorted statements column.
- There is **no right or wrong** way to group the statements.
- People vary in how many piles they create.



Important considerations throughout the entire experience of Head and Neck Cancer are..

0 out of 94 sorted.

Out of town accessible resources and support
Fear of the unknown
Mouth sores
Quality of alternative feeding (feeding tube).
Long-lasting side effects
Nutrition
Tongue loss
Anxiety
Depression
Annual follow up with surgeon
Toothache
Teeth loss
Dietitian services and follow up
Long term rehab services after treatment
Funding to cover travel expenses to access healthcare services

In this phase, you will categorize the statements according to **your view of how similar** in meaning they are to one another.

You will sort each statement into piles in a way that makes sense to you.

1. First, read through the statement in the unsorted statements column to the left.
2. Next, **sort** each statement into a pile you create (**by dragging each statement to right blank window**). Group the statements for how similar in meaning or theme they are to one another.
3. Next, give each pile a **name** that describe its theme or contents.

Do not create piles according to the priority or importance, such as "important".

Do not create piles such us "other" that contains dissimilar statements together.

Put a statement alone in its own pile if it is unrelated to all other statements.

Make sure **every** statement is put somewhere.

Do not leave any statements in the unsorted statements column.

There is **no right or wrong** way to group the statements.

People vary in how many piles they create.

Appendix G

Rating Activity Instructions

Instructions:

On a scale of 1 to 5, rate each statement based on it is **importance/priority** to you.

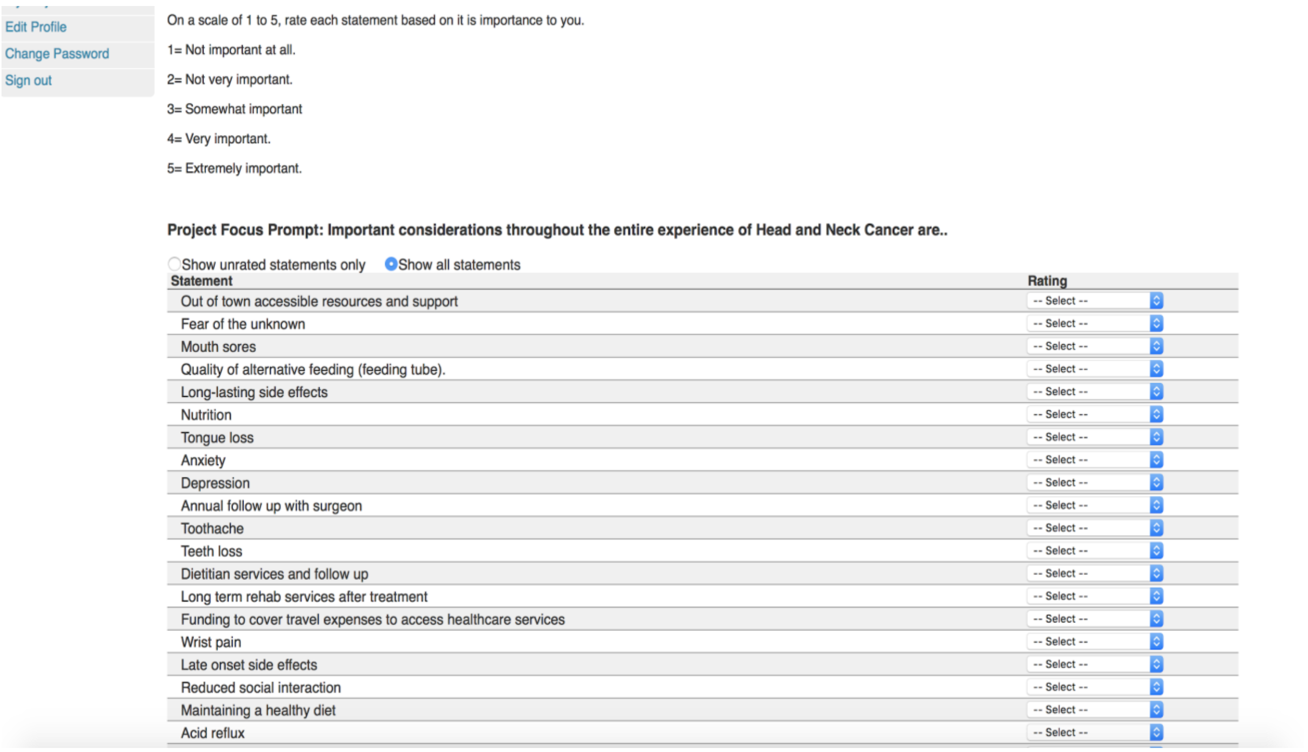
1= Not important at all.

2= Not very important.

3= Somewhat important

4= Very important.

5= Extremely important.



On a scale of 1 to 5, rate each statement based on it is importance to you.

1= Not important at all.

2= Not very important.

3= Somewhat important

4= Very important.

5= Extremely important.

Project Focus Prompt: Important considerations throughout the entire experience of Head and Neck Cancer are..

○ Show unrated statements only ● Show all statements

Statement	Rating
Out of town accessible resources and support	-- Select --
Fear of the unknown	-- Select --
Mouth sores	-- Select --
Quality of alternative feeding (feeding tube).	-- Select --
Long-lasting side effects	-- Select --
Nutrition	-- Select --
Tongue loss	-- Select --
Anxiety	-- Select --
Depression	-- Select --
Annual follow up with surgeon	-- Select --
Toothache	-- Select --
Teeth loss	-- Select --
Dietitian services and follow up	-- Select --
Long term rehab services after treatment	-- Select --
Funding to cover travel expenses to access healthcare services	-- Select --
Wrist pain	-- Select --
Late onset side effects	-- Select --
Reduced social interaction	-- Select --
Maintaining a healthy diet	-- Select --
Acid reflux	-- Select --

Appendix H

Analysis Process in Group Concept Mapping

1. Core mapping (sorting) analysis: analysis of the sorting data to create the visual point maps and cluster maps. It is conducted through three steps:
    a. Similarity matrix: the similarity matrix covers all sorting data and information in a project and it shows the number of participants who sorted each pair of statements together on a table (Figure 3.5). For one participant, there are as many columns and rows in the table (the individual matrix) as the statements that were sorted, a value of either 1 or 0 is plotted across the table. A '1' value indicates that these statements were grouped together and a '0' value indicates that the statements were not grouped together by the participant. Next, a similarity matrix is created as cells in all individual matrices are summed to include all participants' sorting. The values are more than 0 and 1in this matrix (table) and are a resembling of the number of participants who sorted the statements together. Hence, the high values indicate a high number of participants who sorted these statements in the same group.
    b. Nonmetric multidimensional scaling of the similarity matrix: This step of analysis where the qualitative data (statements) are converted to quantitative data (x,y) points. It is illustrated as the point map, it sites each statement as a distinct point on a two dimensional (x,y) map to depict the relationship among statements in terms of proximity.
    c. Hierarchical cluster analysis of the multidimensional scaling coordinates: groups (x,y) points into clusters that indicate similar concepts. It begins with

each statement as a cluster, and the algorithms then combine two clusters, and continue to combine until all statements are under one cluster.

2. Bridging-Anchoring analysis: to show the anchoring and bridging statements and/or clusters in a certain area on the maps. The bridging value is the degree to which a statement was sorted within a cluster or with other statements in different clusters by participants, in other words, it is an index of how cohesive are the statements within a cluster, and it's a measure with a value from (0-1). The closer the value to 0, indicates that the statement is related to other nearby statements "anchor". The higher the value, indicates that the statement is related to other statements elsewhere on the map "bridging" (Kane & Trochim, 2007).
3. Cluster label analysis: to choose the best representative label of each cluster, based on the labels given by participants. Although the software now suggests representative labels based on participants' input, the researcher can also add different labels without using the participants' labels if seen more representative of the cluster's content. The researcher meanwhile needs to have a rich comprehension of the relationship of statements within the cluster (Kane & Trochim, 2007).
4. Determining the final number of clusters using the hierarchical cluster analysis. Number of clusters on the cluster map can be determined by the researcher and team judgement. The bridging value of each cluster can also be used for this purpose (Kane & Trochim, 2007). This complex process depends on the researcher's knowledge of the methodology and topic studied to arrive at the most useful number of clusters that reflects sufficient contextual details across clusters and merge the ones that belong together in sense. To pursue that, it is recommended to choose a maximum and minimum number of clusters that are efficient in reflecting the

desired context, and starts examining the hierarchical analysis of the merging clusters within this band to arrive at the final number (Kane & Trochim, 2007).

5. Rating analysis: using the rating data to create the rating maps; cluster rating maps, pattern matches, and go zones. Rating analysis is based on averaging a single statement rating across participants.

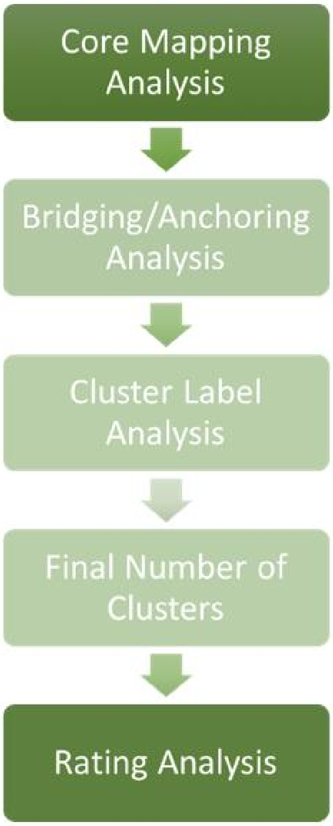


Figure. Analysis Process. This is a flowchart of the analysis process in GCM

Appendix I

Visual Maps in Group Concept Mapping

- Point Map. The point map is the foundation map for other maps. The visuals on this map will be points, representing the statements generated and sorted by participants.
- Cluster Map. The cluster map provided a visual on how the statements were related to each other and also to visualize the outcomes in terms of similarity to participants. This cluster map will serve as a base for the following maps. On the map, smaller clusters are more focused in concept while larger clusters are relatively heterogeneous.
- Cluster Rating Map. The cluster rating map is a three-dimensional (3D) map that represents the differences in statements' ratings. Choosing this map helped in initially identifying the outcomes of higher priority across participant groups.
- Pattern Match. Pattern matches is a comparison graph of average rating at a cluster level that is used to test the effect of different demographic and clinical variables in our patients' sample, including: age, sex, level of education, marital status, HPV status, treatment modality, stage of cancer at diagnosis, and time since treatment. It was also used to compare the average rating of clusters between patients and healthcare providers.
- Go-Zone. This graph is a two-dimensional representation of statement rating (importance) across two variables or groups. It showed the agreement and disagreements of ratings of statements to capture the perspectives of two subgroups or variables. Statements fell into one of four quadrants; the go zone (green) quadrant is described as of above average of importance rating for Group A and B, the left upper quadrant (orange) is of high importance for Group A, the lower right

quadrant (yellow) is of high importance for Group B, and the lower left quadrants (gray) is of low importance for both. Two Go-Zones were obtained, the first one compared the priority rating from the perspective of patients with that of healthcare providers. And since this study aims at identifying the difference in priorities between patients with and without HPV involvement, a second Go-Zone was obtained.

Appendix J

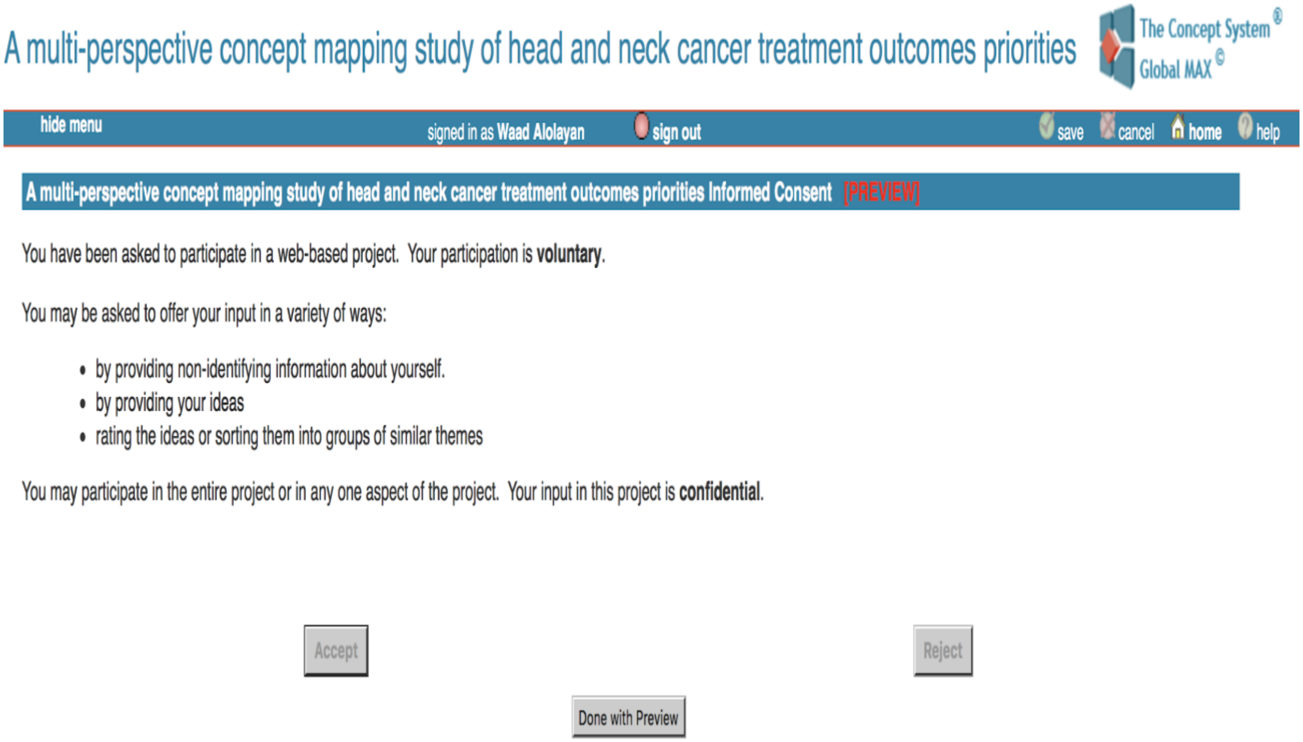
Consent

You have been asked to participate in a web-based project. Your participation is voluntary.

You may be asked to offer your input in a variety of ways:

by providing non-identifying information about yourself.
by providing your ideas
rating the ideas or sorting them into groups of similar themes

You may participate in the entire project or in any one aspect of the project. Your input in this project is confidential.



A multi-perspective concept mapping study of head and neck cancer treatment outcomes priorities

A multi-perspective concept mapping study of head and neck cancer treatment outcomes priorities Informed Consent [PREVIEW]

You have been asked to participate in a web-based project. Your participation is **voluntary**.

You may be asked to offer your input in a variety of ways:

- by providing non-identifying information about yourself.
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Appendix K

List of Statements Generated in Phase One

1. Surgeon and his team that we had explained all the possible scenarios and indeed the pt had most of them, because everything had been explained the pt was less anxious and caregiver could remind the pt of what to expect. Education works.
2. Having compassionate care from engaged health care professionals is extremely important.
3. Promptness of diagnosis and treatment is equally important.
4. I would like to see more emphasis on preventative measures with increased education for dentists and dental hygienists, specifically the signs of chronic, long-term oral cavity infections.
5. I would like to see the establishment of a dental diagnostic unit with access to CT scanning where patients with inexplicable jaw pain, chronic oral inflammation, chronically enlarged level 2 lymph nodes or spreading inflammation could be referred.
6. swallowing very difficult. Aspiration big risk.
7. Not told long term effects of radiation. e.g. bone density, teeth falling out.
8. Can't afford all dental work.Should be covered by medicare.
9. Dental options lacking
10. Thankful you're alive rang hollow.
11. People said you can be thankful you're alive. This is so true. But it sometimes rang hollow. The lasting effects and just wanting to feel healed and going back to being normal was what I really wanted.
12. For the first 2 or 3 months after treatments, looking in the mirror, seeing surgery neck and throat scars reminded me that I had cancer. I cried when I touched my neck. This visual reminded me of cancer. It was depressing.
13. Radiation has effected my mouth. Constantly have mouth sores. Easy to bite tongue, lips and sides of mouth.
14. Radiation caused loss of hearing. Experienced this effect a few years after end of treatments.

15. Changes to my voice have been significant to my life. As a teacher and public speaker voice change has been perhaps hardest adjustment. It's like losing full function of a limb.
16. Excellent counselling support post radiation at Med Hat cancer clinic
17. The counselling services moved downtown off Tom Baker site. My illness and facility inconvenience prohibited me from accessing counselling while undergoing treatments.
18. Unexpected ultra sensitivity to smells. Strong odours overwhelming causing nausea. Couldn't stay at Foothills hostel because of construction odours. Friends fortunately supplied accommodation.
19. My Med Hat ent doctor quickly diagnosed, operated on cancer. Calgary patients I met didn't receive the same expedient attention. Radiation treatments in Calgary so travels to city from Med Hat soon became exhausting. Incurred expenses.
20. Speech therapy works! Practice, practice, practice :)
21. Try to be positive, it is no fun but there is a light at the end of the tunnel and you will get there.
22. support group specific to head and neck cancer
23. It would be appreciated if there was funding or assistance for post surgery and treatment for dental issues specific to Head and Neck Cancer patients
24. Dental options were lacking 19 years ago that now make dental appearance and health a challenge
25. 19 years post 1st surgery. Quality of life is very good. Only 1 reasonably significant (to me) issue at present, that dental did not seem to be much of a concern at the time of my surgery and radiation.
26. Support by loved ones
27. Recent compelling articles compare state of post cancer treatment and recovery as PTSD...life altering...
28. Be prepared for problems with ears and eyes from radiation scatter...they don't tell you that either!!!
29. Be prepared for "Chemo and Radiation Brain"...they don't tell you that ahead of time!!!

30. Access to the Cross is abysmal...lineups to park...aren't patients taxed enough financially without having to pay $2.25/half hour. What happens if clinic is running behind, you go over and end up with a parking ticket...are you kidding me???
31. Stage 4 missed by 3 professionals...GP, ENT and Emerg...last emergency finally sent me to UofA Head n Neck...
32. Time from diagnosis to actual commencement of treatment, much to long...hurry up and wait...
33. Quality of life post treatment is a rare commodity. No where near enough attention paid to long term issues.
34. Nurse practitioner positions should quadruple...an integral extension of overworked Oncologists…
35. The surgeon, who didn't end up doing surgery, followed up better than anyone at the cancer clinic??
36. Have volunteered to mentor on several occasions and have never been contacted.
37. Support groups along with counselling should extend long beyond treatment.
38. Surgery is not absolutely necessary...can now be done robotically...get opinions before consenting to invasive procedures.
39. Many patients are alone and need some form of support.
40. One on one councillor (Social Worker) discussions should be mandatory...before, during and post treatment...for as long as is necessary
41. Cancer clinics in Alberta working at 250%...where are the resources... Oncologists don't have the time to do their jobs anywhere near to the capacity they wish to.
42. Three months of rehab post treatment, aren't anywhere near enough. Issues have cropped up six years after initial treatment.
43. When cancer treatment stops, so seems after treatment care. Chemo and Radiation...the gifts that keep on giving for years. No patient follow-up. Family docs & Specialists left to pick-up pieces. They don't have the cancer knowledge needed.
44. Exercise before and after saved me physically and mentally.
45. Post treatment support. You ring the bell (which is exhilarating) and then you go off to the unknown

46. Supporting patients with tracking information
47. The age of the patient.
48. Making connections with patients and their families.
49. We need to change our focus, treat the patient first, disease second. Bedside manners can be improved
50. Avoid sugars!! Eat green! Stay positive!
51. Waiting times are critical! The sooner you get to see your specialist the better your survival.
52. I was missed diagnosed that my tonsil had tonsil stones on it but instead it was cancer and piroity was put on two small lumps on my thyroid instead, which was not cancer. I was overlooked by my GP and radiologist. I should have been sent to a spec
53. I feel there needs to be some change in the liquid food that is being fed through the feeding tube. Cancer loves sugar and the first ingredient is sugar. Also not everyone can eat this. Eating heathy is extremely important.
54. Care after surgery,nurses and hospital caregivers, should have compassion fthat the patient there is many tubes you, can't speak or move easily. Therefore needing help. Tracheotomy is very scary when if gets clogged
55. it's great to be alive!
56. the ACE (Alberta Cancer Exercise) program was great as a follow-up to cancer and offered locally (as in other than Calgary/Edmonton)
57. My local ENT was stumped when I went to him for diagnosis (tongue cancer). When sent to Calgary they knew before biopsy what it was. More education?
58. No communication between care and surgery in Calgary and then going home to Lethbridge. Had to find out about free cancer physiotherapy from a friend. More communication needs to happen between the Tom Baker & Jack Ady (or where you live) Centres
59. prior health and the importance of preparing the body for surgery and treatment.
60. running around for diagnostics. live in lethbridge, scanned in medicine hat, operated in calgary, post surgery followup in calgary...all travel at personal expense and leave of absence financial loss

61. Diagnosis - took 3 months. Blood tests, 2 ultrasounds. Family Doctor didn't listen as I complained about pain with eating, swallowing taking meds. Had to go to emergency to get to specialist who had to perform 2 biopsies. He didn't mess around.
62. I highly recommend yoga. I started a few months after my treatment ended and it has been transformative; both physically and mentally. I love hot vinyassa flow, but there are different yoga styles to suit all tastes and abilities.
63. Managing information (what can I expect?), pain (unexpected and severe) and weight loss (one third of body weight in six weeks).
64. Having the right medical team - knowing that it is your right to choose your medical providers
65. Knowing that cancer and chemo impact bone density
66. Oral support information
67. Speed of getting the treatment
68. Medical support, family support, Knowledge
69. Patience, following treatment
70. Support; proper information and strength.
71. How do I deal with the effects of radiation afterwards? I had to figure it out on my own. I was relieved for follow up checkups at the Cross.They checked for cancer.I wanted something to help deal with the impact of radiation therapy.
72. My family doctor was unable to get me in to someone who could actually identify what kind of cancer I had. Getting in to a dermatologist he told me not to worry it was basal cell, a lazy cancer. The next doctor told me my cancer was squamous cell.
73. education to family doctors - mine had no idea what was going on - once in the hospital many other patients had exact symptoms as me! It could have been caught sooner
74. co-workers became used to my speech in time and with that came more confidence and more improvements
75. Speech - it improves by doing! listen to yourself and find ways to improve along with therapy. Mine improved drastically once back at work with the need to communicate.

76. Phlegm/sticky saliva - an oral vacuum like the dentists use (cheaper version) I think would be a huge asset
77. stay socialable, accept visitors
78. Use imagination when it comes to eating, things you disliked before may become a favorite just because it is easy to get down and/or taste buds change
79. My entire medical team was awesome, from pre surgery through to end of chemo,radiation and physio. Use every available option accessible
80. Throw vanity out the window, be comfortable and be selfish while you recouperate
81. Everyone is different, recuperation times and quality of life issues will be effected differently for each person. Do what you have to for yourself, not based on the outcome of others.
82. Exercise and eat well otherwise the fatigue will get you.
83. You become a hermit over a period of time as your health deteriorates.
84. Hungry always hungry. Feeding tube gets kind of boring and tedious after a while, I do not eat enough even though I know I have to. Gnaw at the sides of my mouth when sleeping and dream of all sorts of fattening foods. Pizza, burgers, fries etc.
85. Constantly dealing with phlegm
86. Bad metallic taste in mouth
87. Social interaction dramatically reduced
88. Reduced ability to communicate
89. Overall loss of quality of life
90. Food as a part of life
91. Active, direct and consistent caregiver/spouse support throughout diagnosis and treatment of loved one....compassion fatigue is overwhelming
92. Provide awareness for cancer treatment teams of EMS Mobile Integrated Health, paramedics which can provide in-home hydration, pain control, lab draws, POCT, blood administration...preventing unnecessary hospital visits and infection exposure
93. Physical rehab support needs to be provided and funded for at least two years...radiation fibrosis, lymphedema, surgical rehab is critical in providing physical support for patients to recover and progress towards a new normal

94. Develop and implement patient navigator positions to follow-up, guide and support patients in post treatment journey...a huge gap exists in support once patients are released from treatment, despite ongoing affects/effects; both physically & mentally
95. GP's in many cases do not know the issues - this is who you see after the clinic kicks you out.
96. Chest pains caused by swallowing issues and dry mouth
97. Dental - what dentists outside of the hospital understand and especially knowledgeable dental hygenists
98. Knowledge - be your own advocate
99. Saving saliva glands
100. Meeting with Dietitians very important.
101. Swallowing and speech specialists very important.
102. Glaxal lotion very important
103. Don't change the chemo rooms it's good to have others around.
104. Having a nurse to be your health advocate would have been excellent.
105. Keep your life as normal as you can.Keep routines as best you can. Keep trying to eat. I went to support group during radiation 'cause I want to know what's next.
106. Not enough information is given about long term side effects:dental issues,breathing problems swallowing problems,neck mobility.
107. Be up front and totally open and honest with patient (and caregiver)
108. Attitude. It is very important to have and foster a positive attitude throughout the process and beyond.
109. Quality of life post treatment.
110. 13 years post surgery and treatment, just continuing to have faith in God. He will not leave or forsake those that are His.
111. Not enough information is given about long term side effects: dental issues, breathing problems, swallowing problems, neck mobility, restriction of shoulder movement. There needs to be an accessible list of dentists that are familiar with survivors of head and neck cancer so that dental problems can be dealt with in a competent manner with the least amount of harm done.

112. out of town patients need to know what resources are available such as housing locations, support groups.

113. Keep your life as normal as you can. Keep routines as best as you can. Modify them like exercise, BUT still do them. Eat -even if it is just a bit -keep trying to eat. I went to the support group during my radiation 'cause I want to know what's next.

114. Having a nurse assigned to be your health advocate would have been excellent.

115. Introduction to others going through the same experience is critical.

116. Remember it is not your fault you got cancer. In my case I was a never smoker, not overweight, ate all the right things, was healthy and active, and only It's just bad luck.

117. Not enough information is given about long term side effects: dental issues, breathing problems, swallowing problems, neck mobility, restriction of shoulder movement.

118. There needs to be an accessible list of dentists that are familiar with survivors of head and neck cancer so that dental problems can be dealt with in a competent manner with the least amount of harm done.

119. Long term survivors still need regular appointments with ENTs to make sure everything is fine, any re occurrence can be caught early, and to give a feeling of control .

120. social support and support group network connecting with patients through recovery process would have a positive impact.

121. social support after surgery and during treatment

122. provide information on and while staying in ICU after surgery.

123. the appearance and poor speech intelligibility to apply for a job after treatment.

124. not being able to return to workforce after treatment due to physical limitation.

125. reconstruction of sensation areas to maintain full function.

126. follow up for some sort of dentition to maintain smile.

127. provide information, support and continuity of care on how to deal with cancer after surgery.

128. psychological support and recommendations to be available after surgery for patients.

129. the physical treatment is not sufficient, and the concerns are long lasting than the surgery room

130. understanding the traumatic nature of treatment outcomes

131. the surgery outcomes were fine, but the psychological impacts were unclear

132. couldn't grow beard "appearance change" after radiation therapy, which changed identity

133. loosing teeth and having dentures fit properly after surgery.

134. the ability to speak intelligibly

135. Make sure you have them zap the hairs off of any skin graft they put in your month, if not it can lead to a pretty hairy experience.

136. RSM have swallowing and speach specialists, ask your doctor to set you up with them.

137. You go through so much from your initial diagnosis through surgery, radiation or chemotherapy, to perhaps infection and a second surgery, through rehab, hyperbaric chamber, new implants, feeding tube 6 month check-ups then hopefully 1 year check-ups.

138. Depression, Anxiety, Stress, fatigue, these are some of the things that you will experience after surgery.

139. I never knew I was going to have radiation until the day I was being released. I was dressed and packed waiting for my wife to pick me up and instead it was an ambulance to take me from the U of A to the Cross. Shocking mis-communication.

140. Other than surgery Be prepared for some things you never expected. Like radiation, hyperbaric chamber and chemotherapy. Or eventual tube feeding. Lots of hours 31 days straight after your surgery. Then if you are lucky enough to qualify for implants.

141. I received Implants on my lower teeth. Nothing but good things to say about Doctor Oswald at RSM and misericordia dental team.

142. Get up and about when you are able after your surgery. Hospitals can be kind of boring but you would be surprised all the stuff you can discover there. I did the halls a lot after my surgery and became very familiar with whats to see and do.

143. If you are on your second surgery and know a lot more try and help the patients on the ward with suggestions and share your first experience with them.

144. After your surgery when you are in lots of pain make sure that your doctor has good drugs for this on his orders for you. I used Morphine, percoset and Dilated worked good. Had every 4 hours. I made sure I was in no pain always.

145. See your Dietitian at U of A for group meetings, I think that they have them every 2nd thursday of each month. I am not sure if someone who has not gone through the surgery yet can attend these or not. I believe that they start around 2:00 PM.

146. Get into your dentist early, to ensure that your dental care is addressed prior to radiation therapy.

147. To think that I brought this upon myself due to smoking. As the saying goes "I would not wish this on my worst enemy" or the saying "you reap what you sew" you think these types of things as you experience this type of surgery.

148. Nutrition, I am fading away over the years and I still wish that I could eat a cheeseburger.

149. The entire team work very well together, I have had nothing but good care from the beginning to where I am now 9 years later where my care is ongoing with my home nutrition feeding team. Surgeons, nurses, dietitians, physio therapists. All of them.

150. Your appearance is different after a while. You will probably look a bit gaunt as you will lose weight over a period of time. 9 years after my 2 major surgeries I have lost A LOT of my body weight.

151. When you ask what the odds are of something happening? and are given 50/50 it's usually the negative 50 that happens, be prepared.

152. Be prepared to have a second surgery. I had radiation and developed a infection about a year after my surgery and ended up in the hosp. for a couple of weeks, after that I was on heavy duty antibiotic for 6 mths then a year after that another surgery

153. Find out as much as you can about the initial surgery, perhaps go to some of the group sessions for patients who have already done the surgery. Or go up to the ward and discuss with current patients (if they approve). See what you are going into.

154. The big plus is that I am still alive after my first surgery 9 years ago, a serious infection due to radiation (my opinion) and a second surgery 6 years ago. I have no complaints as here I am writing this. However I do have thoughts to improve care.

155. Be compassionate with loved ones. We only have to be sick and they have all the worries and the regular living stuff to contend with. We only have to be sick and fight.

156. A lot of information from old procedures and outcomes (horror stories about relatives etc.) that don't pertain because of new procedures and breakthroughs. Warn new ones when searching internet and talking with people.

157. How do I deal with the constant fear that now treated my cancer will some back.

158. Why was I not given all the information regarding side effects from my various stages of treatment from surgery, radiation and chemo.

159. Being diagnosed with cancer how can I connect with others who have gone through treatment to see what lies ahead for me.

160. Don't change the chemo rooms (some want single private spaces), it's important to be with others and see their different struggles. It is support and learning.

161. Glaxal based lotion with vitamin E should be recommended to all high dose radiation patients with burning(would have went nuts without it)

162. Dry mouth was terribly painful but with learning about Zylimelts (sticking on roof of mouth) it got better. Four years after(chemo radiation radical neck

dissection), have had 50% improvement. There is hope but new ones need to know this.

163. Lack of family doctors trained in cancer care. Because of my cancer my family doctor doesn't want to see me. No idea on how to check for reoccurrence or how to deal with the damaging and painful effects from the radiation treatments.

164. Lack of follow up. Once punted out of the hospital you are on your own to try and survive. You are told to come back in 3 months but you can't book the follow up appointment when you leave. You are totally on your own to try and rebuild your life.

165. The damage radiation causes to healthy bone was not adequately articulated. The new bone that was exposed to radiation broke down within 2.5 years causing extensive damage and infection compounded by re-occurrence of cancer which led to 2nd surgery.

166. Little to no support for patients outside of Edmonton.

167. More emphasis on nutrition and food prep when being sent home. Learning to rely on food that is not processed. Knowing what equipment will help with food preparation - get a good quality blender.

168. Quick effects of radiation. Lost voice. Difficulty swallowing. Mouth/tongue food sensitivity. Loss of energy/tiredness. Stomach sickness, needing intravenous. Long recovery post radiation. Dealing with pain sensitive to T3, morphine

169. The expense of parking at the Cross is large burden on cancer patients that have to be there for countless weeks of treatment

170. Was not told my stage of cancer by any oncologist until coldly stated by chemotherapist. Should have been told about radiation arcing on dental fillings previous to treatment. This caused major pain and damage to teeth for lifetime. Extreme expense.

171. When I was first diagnosed, I asked my Oncologist, "What is the five-year survival rate for my cancer?" He said, "85-90%". At that point, my dread disappeared and I decided, I'm not going to die so let's concentrate on fighting this and getter better.

172. No support (Edmonton) for out of town elderly man with no family. He was alone taking morphine for pain. I feel he slipped through the cracks in our system

173. I lost my ability to taste food after radiation & chemotherapy. I gradually got it back with mindful eating & gastronomy courses. My taste is now better than it was previous to treatments. Things can be done to improve the long term side effects

174. The more information given out during and immediately post treatment on the expected trajectory of longer term side effects and things that can be done to mitigate them.

175. How to avoid getting depressed.

176. Follow-up appointments with the surgeon yearly, even after 15 years is very helpful for putting your mind at ease. Having my throat scoped every year is important to me to catch the cancer early if it returns.

177. After successful treatment, quality of life becomes the paramount issue. Patients need to know what lies on the the road ahead and how to best navigate the road ahead to give them the best quality of life.

178. Each person is different. It's so hard to make blanket statements for each person as to what their considerations will be. After treatments, I got shingles. After, I got Postherpetic Neuralgia. Other patients had other experience.

179. Keeping active, staying positive, relax when your energy depletes, surround yourself with positive people, remove negativity.

180. It is very serious and go into this with an open mind knowing how serious is and your expectations may have underestimated what you will experience. I thought I'd return to work after a couple of months. I was off work 2 years.

181. Weight loss over a period of time. Get fat before your surgery and indulge yourself in all of the delicious foods that you like. Have one really, really good last meal. Before treatments started, I gained 20 lbs. Ate my favorite foods&weight trained

182. I think it is important to treat the whole person, not just the cancer. It can cause other mental and emotional issues such as depression.

183. The lack of upfront information regarding radiation side effects. These were not fully explained. Radiation is the gift that keeps on giving with side effects show up years later. There are many short term and long term side effects from treatments.

184. When first diagnosed fear can set in. It might be helpful to have counselling available and I would even go so far as to say mandated. There were many thoughts that I could not share with family or friends because they could not possibly relate.The lack of upfront information regarding radiation side effects. These were not fully explained. Radiation is the gift that keeps on giving with side effects show up years later.

185. It might be helpful to have a mentor - someone who has gone through the same procedures to learn from, to be able to ask questions, and to offer support.

186. I believe that more individual and concentrated assistance around the swallowing and speaking would have been helpful.

187. I would have liked more up front information about the failure of implants.

188. When first diagnosed fear can set in. It might be helpful to have counselling available and I would even go so far as to say mandated. There were many thoughts that I could not share with family or friends because they could not possibly relate.

189. I think it is important to treat the whole person, not just the cancer.

190. The lack of upfront information regarding radiation side effects. These were not fully explained. Radiation is the gift that keeps on giving with side effects show up years later.

191. Weight loss over a period of time. Get fat before your surgery and indulge yourself in all of the delicious foods that you like. Have one really, really good last meal. Over a period of nine years I have lost about 30% of my body weight.

192. It is very serious and go into this with an open mind knowing how serious is and your expectations may have underestimated what you will experience. Mine did, I thought that I would lick the cancer right away after surgery and this was not the case.

193. Oh to eat solid food again! it's been nine years for me since my first surgery and I would do anything to have a cheeseburger or any food that I constantly dream about every night. I wish that they could grow me a tongue.

194. That after your first surgery you may need to have another surgery due to infection and lose more of your body parts such as your entire jaw, all or some of your teeth your ability to speak properly and slobber or drool on yourself.

195. That you may not ever eat solid food again. That you will lose your tongue. That you will have a feeding tube eventually. That you may get an infection after surgery that can be very serious and may need to be in the hospitalized again.

196. I think that each patient needs to know and decide prior to treatment weather they will have surgery, chemotherapy and radiation, a combination of two of these or all three.

197. Keeping active, staying positive, relax when your energy depletes, surround yourself with positive people, remove negativity on how much pain you will endure, most important is to trust our lord and savior that he still has a plan for you.

198. Each person is different. It's so hard to make blanket statements for each person as to what their considerations will be. In my case, I got thrush and I couldn't eat or drink during the last part of the treatments and when they were over.

199. After successful treatment, quality of life becomes the paramount issue. Patients need to know what lies on the the road ahead and how to best navigate the road ahead to give them the best quality of life.

200. The patients GP should be knowledgeable on what to look for at checkups and post treatments that would be helpful years down the road as a result of having radiation or chemo, etc.

201. Follow-up appointments with the surgeon yearly, even after 15 years is very helpful for putting your mind at ease.

202. Dealing with post treatment pain. Stiff neck, sore shoulder, dry mouth, aching teeth, cracked lips, head aches, insomnia, shortness of breath, acid reflux, aching wrist, tongue pain, conditions H and N cancer patients live with without relief.

203. Social isolation due to speaking and swallowing issues. Without a voice and not being able to swallow ostracizing one from society.

204. The lack of clear upfront information on what post treatment will look like. The nurse navigator vaguely tells you what the surgery will entail but does not prepare you for post treatment life. You are left to fumble along on your on.

205. Emotional support, more upfront information, better understanding of post treatment options

206. The timelines for diagnosis and possible treatments. Patient communications for treatment necessities and forecasted outcomes.

207. Communicating with busy doctors

208. Accepting grief and loss - tools to move forward to understand change and transition

209. Despite the issues life maybe different but can be good after treatment

210. How to avoid getting depressed

211. Understanding the experience of head and neck cancer will be with you for the rest of your life

212. Long term survival

213. Sensible and practical recommendations about returning to a more "normal" life post treatment including work, exercise, activities.

214. Communication

215. Education, information, someone to talk to who understands (best if they have been there a done it)

216. Education of things one can do to help mitigate the serious effects of treatment both short and long term e.g. swallowing, saliva, speech, dental issues, radiation burns, bone weakening, pain, energy, weight loss etc.

217. Clearly identification of support groups and cancer resources e.g. Wellspring

218. Understanding statistics

219. The more information given out during and immediately post treatment on the expected trajectory of longer term side effects and things that can be done to mitigate them

220. Swallowing issues appear to get worse many years after stabilizing. This becomes a serious lifestyle issue.

221. There should be scheduled follow-up with an ENT doctor who understands the long term implications of treatment on swallowing and speech at least once every two years after the five year mark.

222. Need for detailed consult with a speech and swallowing consultant soon after treatment. They can provide appropriate exercises to try to mitigate future decline in swallow ability.

223. Options

224. Survival rates

225. Not knowing the questions that should be asked, we should be told of the worst possible results from radiation, etc, it would be helpful in making decisions regarding quality of life issues

226. Make more after-treatment considerations, info & care plans available. Care Info for radiated tissue, scar tissue. Information on post treatment issues should be more available, easy to find.

227. Current statistics and outcomes needed to make informed choice on treatment options.

228. A "new patient starter kit" would be welcomed. Notepad & pen for questions, list of FAQ, list of online resources for information, records keeping forms for lab results, daily health questionnaire, etc, combined into a small notebook and given out

229. Some Albertans do not proceed with treatment because of the fear of the unknown or perceived poor outcome, timely data on outcomes need to be published

230. Patients need information on communication strategies pre-op to have success post-op

231. Mentoring videos from long term survivors accessible through internet as the internet is first place you go once diagnosed

232. More cohesive assistance with mental health during treatment. Significant depression, anxiety, fear increase the challenges of treatment, and medication without counseling is not adequate. One on one and group discussions are critical

233. We need more effort towards long term survivors mentoring newly diagnosed patients. Many questions arise that may not be directly treatment related & difficult to answer for new patients. Long term patients often have first hand experience that helps

234. Dental challenges aren't adequately managed. Complete extraction recommended, with limited restoration options. Dentures seldom work well, implants usually needed but most can't afford them. SK has special funding available for this, not Alberta

235. Follow up. Well beyond the 5 year norm, Oral cancer patients frequently develop treatment related problems, i.e. oesteoradionecrosis, graft resorption, fibrosis, baroreflex disorders, etc.. These significantly effect quality of life.

236. Make it clearly understood how important exercise is for the entire body and the cancer affected area, in order to properly rehabilitate. Exercise is not to be done for a just week or a month but to continue forever, to ensure the maximum recovery.

237. Be introduced to what therapies are available re-enable the ability to swallow properly.

238. Be introduced to what therapies are available re-enable the ability to speak clearly.

239. Have interaction with the head and neck cancer support group BEFORE the surgery and treatments, so as to know, from a patient perspective, what to expect and how to deal with things that will come up.

240. Have somebody with you during treatment

241. Eating may become an issue. Try to eat

242. Take advantage of as many information seminars

243. Ask questions

244. Keep your mind active

245. Be aware of changes to yourself

246. Transportation to and from treatment

247. Keep family informed

248. Comfortable accommodations while in treatment

249. Stay as active as possible

250. Keep a positive attitude

Appendix L

List of Final Statements Included in Phase Two

1. Out of town accessible resources and support
2. Fear of the unknown
3. Mouth sores
4. Quality of alternative feeding (feeding tube).
5. Long-lasting side effects
6. Nutrition
7. Tongue loss
8. Anxiety
9. Depression
10. Annual follow up with surgeon
11. Toothache
12. Teeth loss
13. Dietitian services and follow up
14. Long term rehab services after treatment
15. Funding to cover travel expenses to access healthcare services
16. Wrist pain
17. Late onset side effects
18. Reduced social interaction
19. Maintaining a healthy diet
20. Acid reflux
21. Scheduling/booking follow-up appointments with healthcare providers (e.g., specialists)
22. Changes in voice
23. Access to treatment services in home to prevent unnecessary hospital visits and infection exposure
24. Headache
25. Inability to return to the workforce
26. Tongue pain

27. Dental service providers specialized/experienced in head and neck cancer
28. Surgical scars
29. Accessibility to healthcare services for out of town patients
30. Promptness of diagnosis
31. Ability to communicate and speak intelligibly
32. Costs of parking permits
33. Aspiration
34. Dental follow up after treatment
35. Physical limitation
36. Clear detailed upfront information of the case and treatment plan
37. Stress
38. Prompt Speech and Language Pathology consultation, services and follow up
39. Having mentors who share the same experience
40. Swallowing difficulty
41. Psychological support and recommendations before treatment
42. Education on how to manage and cope with long-term side effects
43. Shortness of breath
44. Post-surgery infections
45. Accessibility of counseling services in cancer treatment centres
46. Understanding statistics and current outcomes
47. Growing beard
48. Dry mouth
49. Ability to taste food
50. Survival
51. Identification of support groups and resources specific to head and neck cancer
52. Hearing loss
53. family/caregiver/loved one/social support
54. Insomnia
55. Support through treatment and recovery
56. Support and guidance after treatment
57. Tracking patients' progress throughout treatment and post treatment

58. Coverage for allied health and clinical services i.e: dental, rehab
59. Knowledgeable and experienced healthcare providers in head and neck cancer
60. Lymphedema (Lymph fluid retention causing limb swelling where lymph nodes are affected by cancer treatment)
61. Sticky saliva and phlegm
62. Social isolation
63. Keeping the family informed
64. Oesteoradionecrosis (bone death secondary to radiation therapy)
65. Changes in bone density
66. Weight loss.
67. Hair-free skin grafts
68. Graft resorption
69. Pretreatment education on post treatment outcomes
70. Tongue pain
71. Stiff neck
72. Saving saliva glands
73. Promptness of treatment
74. Having an advocate health care provider/nurse/clinician
75. Information on the available treatment options and new advancements
76. Postherpetic Neuralgia (complication of an infection causing burning sensation to skin and fibers)
77. Fear of recurrence
78. Information on long-term side effects and the possible traumatic experience
79. Ultra sensitivity to smell
80. Involve patient in decision making
81. Fibrosis
82. Cracked lips
83. Sore shoulder
84. Stomach sickness
85. Freedom to choosing the medical care providers
86. Accommodation for out of town patients

87. Engaged healthcare providers with compassionate care
88. Fatigue
89. Continue to follow up after 5 years
90. Social worker/counselling support (individual or group)
91. Proper fit of dentures after surgery
92. Communication with healthcare providers
93. Metallic taste in mouth
94. Providing an accessible resource/tool for information and common questions

Appendix M

Statements Synthesis Process

	Statements	Reference statement
1	Nutrition.	82, 84, 90, 113, 148, 167, 191, 193, 195, 198, 241
2	Quality of Alternative feeding (feeding tube).	53, 84
3	Maintaining a Healthy diet.	50, 78, 167, 173
4	Stomach sickness.	168
5	Physical limitation	44, 56, 124, 179, 236
6	Fatigue.	82,138, 168
7	Swallowing difficulty.	6, 168, 203, 220
8	Aspiration	6
9	Dry mouth.	96, 162, 202
10	Saving saliva glands	99
11	Mouth sores	13, 198
12	Metallic taste in mouth	86
13	Ability to taste food	173
14	Sticky saliva and phlegm	76, 85
15	Changes in voice	168
16	Hearing loss	14
17	Ultra sensitivity to smell	18
18	Ability to communicate and speak intelligibly	88, 123, 134, 194, 203
19	Post-op infections	137, 152, 194, 195, 178
20	Surgery scars	12
21	Growing beard	132
22	Weight loss.	63, 150, 181, 191
23	Hair-free skin grafts	135
24	Survival	10, 11, 55, 154, 171, 212
25	Quality of life after treatment	11, 33, 89, 109, 177, 199
26	Long term rehab services after treatment	168, 42

27	Inability to return to the workforce	15, 123, 124, 180
28	Stiff neck	202
29	Sore shoulder	202
30	Toothache	202
31	Loss of teeth	133
32	Cracked lips	202
33	Headache	202
34	Insomnia	202
35	Shortness of breath	202
36	Acid reflux	202
37	Tongue pain	202
38	Changes in bone density	65
39	Fibrosis	93, 235
40	Lymphedema	93
41	Tracking patients progress	46, 94
42	Proper fit of dentures after surgery	133
43	Social isolation	83, 203
44	Reduced social interaction	87
45	Social worker discussion (individual/group).	232
46	Fear of the unknown	184, 188, 229
47	Fear of recurrence	157
48	Depression	12, 138, 175, 182, 210, 232
49	Anxiety	138
50	Stress	138
51	Psychological support and recommendations before treatment	91, 128, 184, 205, 232 , 40
52	Identification of support groups and resources specific to head and neck cancer	22, 159, 184, 188, 215, 217, 233, 239
53	Having mentors who share the same experience	36, 115, 143, 159, 185, 215, 231, 233, 239
54	Support through treatment and recovery	36, 37, 54, 68, 70, 91, 94, 113, 120, 121, 122, 127, 160, 240, 105

55	Support and guidance after treatment	16, 33, 37, 43, 45, 46,68, 70, 94, 121, 127, 128, 105
56	Family/caregiver/loved one/social support	26, 68, 74, 91, 155
57	Long term side effects	13, 43, 129, 190, 202, 220, 202
58	Late onset side effects	14, 43, 129, 190, 220
59	Coverage for allied health and clinical services i.e: dental, rehab	8,23, 93
60	Costs of parking permits	169
61	Promptness of treatment	3, 19, 32, 51, 67, 146, 206
62	Promptness of diagnosis	3, 19, 32, 51, 61, 206
63	Dental follow up after treatment	111, 118
64	Dental services providers specialized/experienced in head and neck cancer	9, 24, 25, 97, 111, 118
65	Prompt SLP consultation, services and follow up	20, 75, 101, 136, 186, 221, 222, 136
66	Dietitian services and follow up	100, 126, 145
67	Scheduled and confirmed follow up appointments with healthcare providers	43, 119, 163, 164, 221
68	Annual follow up with surgeon.	35, 175, 201
69	Continue to follow up after 5 years.	176, 201, 235
70	Communication with healthcare providers	207, 214
71	Engaged healthcare providers with compassionate care	2, 48, 54
72	Having advocate healthcare provider/nurse/clinician.	104, 114
73	Knowledgeable and experienced healthcare providers in head and neck cancer	43, 95, 163, 200, 221
74	Understanding statistics and current outcomes	171, 218, 224, 227, 229
75	Clear detailed upfront information of the case and treatment plan	1, 107, 139, 140, 170, 196, 199, 204, 205, 206,

76	Information on the available treatment options and new advancements	27?, 38, 139, 156, 205, 206, 237, 238
77	Involve patient in decision making	196, 225
78	Choosing medical team	64
79	Involving family	247
80	Pretreatment education on post treatment outcomes	1, 7, 29, 63, 174, 183, 187, 190, 199, 206, 225, 230
81	Information on long-term side effects and its' traumatic experience	7, 28, 29, 63, 106, 111, 117, 130, 158, 165, 170, 174, 183, 190, 199, 219, 225
82	Education on how to manage and cope with long-term side effects.	33, 71, 94, 199, 204, 213, 216, 219, 226, 208
83	Providing an accessible resource/tool for information and common questions.	66?, 68, 94, 226, 228, 231, 208
84	Accessibility to healthcare services for out of town patients	60, 112, 172
85	Accommodation for out of town patients	112, 248
86	Out of town accessible resources and support	58, 166
87	Accessibility of counseling services in cancer treatment centres	17
88	Funding to cover traveling expenses to access healthcare services	30, 60, 246
89	In-home services	92
90	Postherpetic Neuralgia (complication of an infection causing burning sensation to skin and fibers)	178
91	Tongue loss	193, 195
92	Wrist pain	202
93	Tongue pain	202
94	Graft resorption	235
95	Oesteoradionecrosis (bone death secondary to radiation therapy)	235

Initially included and then Excluded	Reason/clarification
Barriers to socialize.	Can be a label of a group of statements
Psychological impacts of disease and treatment.	131 Can be a label of a group of statements
Patient's expectation	Merged with: pre-treatment education
Post-treatment pain.	Can be a label of a group of statements
Appearances change./ Identity change.	Can be a label of a group of statements
The importance of exercise physically and mentally.	More of an advice and a recommendation than a priority
Thrush	Mouth sores can replace
Education on how to deal and reduce side effects.	Merged with: Education on how to manage and cope with long-term side effects.
Scheduled ENT F/U	Merged with: Scheduled and confirmed F/U appointments with HCP
Compassionate care.	Merged with: Engaged HCP with compassionate care.
Lasting side effects	Merged with: Long term side effects
Having someone around during treatment.	Merged with: Support through treatment and recovery.
Probability of second surgery.	Merged with: Post-op infections.
The comfort of the patient (to be comfortable).	No statements referenced
Food sensitivity.	Could be merged with: Ability to taste food.
Social status of patients	39, not outcomes
Merged with other statements having the same idea	**The new merged statement**
Transportation to and from treatment.	Funding to cover traveling expenses to access HC services.
Understanding the traumatic experience of treatment outcomes.	Information on long-term side effects and its' traumatic experience

Sharing new advancements in treatment options and procedures.	Information on the available treatment options and new advancements/
F/u with GP experienced with HNC.	Knowledgeable and experienced HCP in HNC
SLP services and F/U / Prompt SLP consultation. / Compliance to speech therapy.	Prompt SLP consultation, services and F/U
Dental services./ coverage for rehab services.	Coverage for clinical services i.e: dental, rehab
Recovery time./ Period of rehab post treatment./	Long term rehab services for recovery after treatment
Ability to speak intelligibly. / Ability to communicate	Ability to communicate and speak intelligibly
Healthy diet/ maintaining healthy eating/ Mindful eating./Gastronomy courses.	Maintaining a Healthy diet.
Staying active.	Physical limitation after treatment

Other statements that don't apply to treatment outcomes were discussing:
(Personal Experience).

- Patients were describing their personal experience with HNC, and the journey from diagnosis, treatment, outcomes, recovery. (151, 192, 209)
- Patients discussing the misdiagnosis experience they had. (31, 52, 72)
- Patients requesting a better education and training for GP, ENT and HCP who might diagnose HNC. (57, 73)
- Patients discussing the interrupted transition in care from big cities back to hometown, due to poor communication (58)
- Patients sharing their positive experience with healthcare provided to them (79, 141, 149)
- Unique (81)
- Medications or prescriptions that help in the post-treatment side effects. (144)
- Baroreflex disorders (rare disorder of changes and alterations in blood pressure) (235)

(Advice).

- Patience.(69)
- Positive attitude and faith (108, 110, 197, 250, 21)

- Socialize. (77, 142)
- Be comfortable (80)
- Self-learning. (98, 153, 242, 243, 244, 245)
- Routine and normal life (105)
- Not to self-blame (116, 147)
- Recommending clinical f/u and medications that help (136, 144)
- Accepting grief (208)
- Staying active (249)
- Wellness and well-being (62)
- Treat the whole person (189)
- Hydration recommendation for RT (102, 161)

*(Unclear meaning) (*223)

(HCP recommendation to enhance healthcare services and quality of care delivered) (4, 5, 49)

(*not outcomes)*
- Age (47)
- Prior health and preparation for treatment (59)
- Social status of patient (39)
- Work load on oncologists (34, 41)

Statements count:
250 - 120 - 97 - 93 - 92 - 90- 96 - 94

Appendix N

List of Clusters and Statements (Ascending Bridging Value)

Cluster		Statement	Bridging
1. Monetary Support			**0.8**
	29	Accessibility to healthcare services for out of town patients	0.67
	1	Out of town accessible resources and support	0.76
	58	Coverage for allied health and clinical services i.e: dental, rehab	0.79
	86	Accommodation for out of town patients	0.82
	15	Funding to cover travel expenses to access healthcare services	0.83
	32	Costs of parking permits	0.9
2. Continuing care			**0.6**
	21	Scheduling/booking follow-up appointments with healthcare providers (e.g., specialists)	0.52
	45	Accessibility of counseling services in cancer treatment centres	0.52
	10	Annual follow up with surgeon	0.54
	89	Continue to follow up after 5 years	0.55
	23	Access to treatment services in home to prevent unnecessary hospital visits and infection exposure	0.56

	34	Dental follow up after treatment	0.6
	13	Dietitian services and follow up	0.62
	38	Prompt Speech and Language Pathology consultation, services and follow up	0.64
	27	Dental service providers specialized/experienced in head and neck cancer	0.73
	14	Long term rehab services after treatment	0.76
3. Psychosocial concerns			**0.71**
	37	Stress	0.54
	9	Depression	0.57
	62	Social isolation	0.59
	18	Reduced social interaction	0.69
	8	Anxiety	0.72
	77	Fear of recurrence	0.73
	25	Inability to return to the workforce	0.86
	2	Fear of the unknown	1
4.Nutriton			**0.66**
	4	Quality of alternative feeding (feeding tube).	0.61

	6	Nutrition	0.64
	50	Survival	0.65
	19	Maintaining a healthy diet	0.69
	91	Proper fit of dentures after surgery	0.73
5. Education			**0.65**
	94	Providing an accessible resource/tool for information and common questions	0.47
	75	Information on the available treatment options and new advancements	0.61
	42	Education on how to manage and cope with long-term side effects	0.62
	69	Pretreatment education on post treatment outcomes	0.62
	46	Understanding statistics and current outcomes	0.65
	36	Clear detailed upfront information of the case and treatment plan	0.7
	78	Information on long-term side effects and the possible traumatic experience	0.77
	30	Promptness of diagnosis	0.78
6. Person-centred care			**0.49**
	56	Support and guidance after treatment	0.41
	87	Engaged healthcare providers with compassionate care	0.42

	92	Communication with healthcare providers	0.42
	90	Social worker/counselling support (individual or group)	0.45
	74	Having an advocate health care provider/nurse/clinician	0.45
	51	Identification of support groups and resources specific to head and neck cancer	0.46
	57	Tracking patients' progress throughout treatment and post treatment	0.46
	39	Having mentors who share the same experience	0.47
	80	Involve patient in decision making	0.47
	59	Knowledgeable and experienced healthcare providers in head and neck cancer	0.5
	41	Psychological support and recommendations before treatment	0.5
	55	Support through treatment and recovery	0.51
	53	family/caregiver/loved one/social support	0.54
	85	Freedom to choosing the medical care providers	0.54
	63	Keeping the family informed	0.55
	73	Promptness of treatment	0.66
7. Treatment Side Effects			**0.16**
	48	Dry mouth	0

71	Stiff neck	0
88	Fatigue	0
79	Ultra sensitivity to smell	0.01
83	Sore shoulder	0.01
40	Swallowing difficulty	0.03
26	Tongue pain	0.04
70	Tongue pain	0.04
81	Fibrosis	0.06
66	Weight loss.	0.06
3	Mouth sores	0.06
82	Cracked lips	0.07
20	Acid reflux	0.07
52	Hearing loss	0.08
43	Shortness of breath	0.08
84	Stomach sickness	0.08
93	Metallic taste in mouth	0.09
24	Headache	0.09
16	Wrist pain	0.09

49	Ability to taste food	0.12
65	Changes in bone density	0.12
61	Sticky saliva and phlegm	0.14
76	Postherpetic Neuralgia (complication of an infection causing burning sensation to skin and fibers)	0.14
11	Toothache	0.16
64	Oesteoradionecrosis (bone death secondary to radiation therapy)	0.2
54	Insomnia	0.24
60	Lymphedema (Lymph fluid retention causing limb swelling where lymph nodes are affected by cancer treatment)	0.24
35	Physical limitation	0.27
33	Aspiration	0.29
47	Growing beard	0.34
44	Post-surgery infections	0.38
68	Graft resorption	0.4
67	Hair-free skin grafts	0.66
72	Saving saliva glands	0.85
8. Lifelong Challenges		**0.29**
22	Changes in voice	0.12

7	Tongue loss	0.19
12	Teeth loss	0.21
28	Surgical scars	0.23
17	Late onset side effects	0.31
5	Long-lasting side effects	0.45
31	Ability to communicate and speak intelligibly	0.55

Appendix O

List of Clusters and Statements (Ascending Rating Value)

Cluster		**Statement**	**Average Rating**			
1. Monetary Support			**3.47**			
	58	Coverage for allied health and clinical services i.e: dental, rehab	4.14			
	29	Accessibility to healthcare services for out of town patients	3.82			
	86	Accommodation for out of town patients	3.59			
	15	Funding to cover travel expenses to access healthcare services	3.45			
	1	Out of town accessible resources and support	3.3			
	32	Costs of parking permits	2.5			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
6	**0.51**	**0.26**	**2.5**	**4.14**	**3.47**	**3.52**
2. Continuing Care			**4.08**			
	27	Dental service providers specialized/experienced in head and neck cancer	4.57			
	34	Dental follow up after treatment	4.41			

	89	Continue to follow up after 5 years	4.36			
	10	Annual follow up with surgeon	4.3			
	45	Accessibility of counseling services in cancer treatment centres	4.05			
	38	Prompt Speech and Language Pathology consultation, services and follow up	4.05			
	13	Dietitian services and follow up	4.04			
	14	Long term rehab services after treatment	4.04			
	21	Scheduling/booking follow-up appointments with healthcare providers (e.g., specialists)	3.87			
	23	Access to treatment services in home to prevent unnecessary hospital visits and infection exposure	3.09			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
10	**0.39**	**0.15**	**3.09**	**4.57**	**4.08**	**4.05**
3. Psychosocial Concerns			**3.87**			
	77	Fear of recurrence	4.18			
	62	Social isolation	4.14			
	37	Stress	4.05			
	2	Fear of the unknown	3.91			

	8	Anxiety	3.91			
	9	Depression	3.87			
	25	Inability to return to the workforce	3.52			
	18	Reduced social interaction	3.39			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
8	**0.26**	**0.07**	**3.39**	**4.18**	**3.87**	**3.91**
4. Nutrition			**4.15**			
	50	Survival	4.68			
	6	Nutrition	4.35			
	19	Maintaining a healthy diet	4.22			
	4	Quality of alternative feeding (feeding tube).	4.17			
	91	Proper fit of dentures after surgery	3.32			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
5	**0.45**	**0.2**	**3.32**	**4.68**	**4.15**	**4.22**
5. Education			**4.28**			
	30	Promptness of diagnosis	4.86			
	36	Clear detailed upfront information of the case and treatment plan	4.64			

	75	Information on the available treatment options and new advancements	4.55			
	78	Information on long-term side effects and the possible traumatic experience	4.41			
	94	Providing an accessible resource/tool for information and common questions	4.27			
	42	Education on how to manage and cope with long-term side effects	4.23			
	69	Pretreatment education on post treatment outcomes	3.86			
	46	Understanding statistics and current outcomes	3.45			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
8	**0.42**	**0.18**	**3.45**	**4.86**	**4.28**	**4.34**
6. Person-Centred Care			**4.2**			
	73	Promptness of treatment	4.91			
	59	Knowledgeable and experienced healthcare providers in head and neck cancer	4.82			
	55	Support through treatment and recovery	4.59			
	87	Engaged healthcare providers with compassionate care	4.59			
	80	Involve patient in decision making	4.36			
	56	Support and guidance after treatment	4.32			

	53	family/caregiver/loved one/social support	4.27			
	92	Communication with healthcare providers	4.27			
	57	Tracking patientsâ€™ progress throughout treatment and post treatment	4.18			
	74	Having an advocate health care provider/nurse/clinician	4.05			
	90	Social worker/counselling support (individual or group)	4			
	41	Psychological support and recommendations before treatment	4			
	63	Keeping the family informed	4			
	85	Freedom to choosing the medical care providers	3.73			
	51	Identification of support groups and resources specific to head and neck cancer	3.68			
	39	Having mentors who share the same experience	3.41			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
16	**0.4**	**0.16**	**3.41**	**4.91**	**4.2**	**4.23**
7. Treatment Side Effects			**3.43**			
	40	Swallowing difficulty	4.36			
	72	Saving saliva glands	4.32			

64	Oesteoradionecrosis (bone death secondary to radiation therapy)	4.23
44	Post-surgery infections	4.18
88	Fatigue	4.05
48	Dry mouth	4
35	Physical limitation	3.95
49	Ability to taste food	3.91
61	Sticky saliva and phlegm	3.86
54	Insomnia	3.82
33	Aspiration	3.82
65	Changes in bone density	3.77
52	Hearing loss	3.77
3	Mouth sores	3.65
66	Weight loss.	3.64
11	Toothache	3.59
60	Lymphedema (Lymph fluid retention causing limb swelling where lymph nodes are affected by cancer treatment)	3.5
70	Tongue pain	3.5
84	Stomach sickness	3.45

	76	Postherpetic Neuralgia (complication of an infection causing burning sensation to skin and fibers)	3.41			
	71	Stiff neck	3.36			
	43	Shortness of breath	3.36			
	26	Tongue pain	3.35			
	81	Fibrosis	3.18			
	79	Ultra sensitivity to smell	3.18			
	20	Acid reflux	3.05			
	93	Metallic taste in mouth	3			
	24	Headache	2.96			
	83	Sore shoulder	2.86			
	68	Graft resorption	2.77			
	82	Cracked lips	2.55			
	67	Hair-free skin grafts	2.36			
	16	Wrist pain	2.13			
	47	Growing beard	1.68			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
34	**0.62**	**0.38**	**1.68**	**4.36**	**3.43**	**3.5**

8. Lifelong Challenges			**3.74**			
	7	Tongue loss	4.36			
	31	Ability to communicate and speak intelligibly	4.32			
	5	Long-lasting side effects	4.17			
	12	Teeth loss	4.04			
	17	Late onset side effects	3.78			
	22	Changes in voice	2.91			
	28	Surgical scars	2.59			
Count	**Std. Dev.**	**Variance**	**Min**	**Max**	**Average**	**Median**
7	**0.66**	**0.43**	**2.59**	**4.36**	**3.74**	**4.04**

Appendix P

List of Statements in Go-Zone 1; Patients and HCP

Statements in Go-Zone quadrant:

4. Quality of alternative feeding (feeding tube).
5. Long-lasting side effects
6. Nutrition
7. Tongue loss
8. Anxiety
10. Annual follow up with surgeon
13. Dietitian services and follow up
14. Long term rehab services after treatment
27. Dental service providers specialized/experienced in head and neck cancer
30. Promptness of diagnosis
31. Ability to communicate and speak intelligibly
34. Dental follow up after treatment
36. Clear detailed upfront information of the case and treatment plan
37. Stress
38. Prompt Speech and Language Pathology consultation, services and follow up
40. Swallowing difficulty
42. Education on how to manage and cope with long-term side effects
44. Post-surgery infections
45. Accessibility of counseling services in cancer treatment centres
50. Survival
53. family/caregiver/loved one/social support
55. Support through treatment and recovery
56. Support and guidance after treatment
57. Tracking patients' progress throughout treatment and post treatment
58. Coverage for allied health and clinical services i.e: dental, rehab
59. Knowledgeable and experienced healthcare providers in head and neck cancer
62. Social isolation
63. Keeping the family informed

64. Oesteoradionecrosis (bone death secondary to radiation therapy)
73. Promptness of treatment
75. Information on the available treatment options and new advancements
77. Fear of recurrence
78. Information on long-term side effects and the possible traumatic experience
80. Involve patient in decision making
87. Engaged healthcare providers with compassionate care
88. Fatigue
89. Continue to follow up after 5 years
90. Social worker/counselling support (individual or group)
92. Communication with healthcare providers
94. Providing an accessible resource/tool for information and common questions

Statements in orange quadrant:

3. Mouth sores
9. Depression
15. Funding to cover travel expenses to access healthcare services
25. Inability to return to the workforce
29. Accessibility to healthcare services for out of town patients
33. Aspiration
41. Psychological support and recommendations before treatment
61. Sticky saliva and phlegm
68. Graft resorption
69. Pretreatment education on post treatment outcomes
70. Tongue pain

Statements in yellow quadrant:

2. Fear of the unknown
12. Teeth loss
17. Late onset side effects
19. Maintaining a healthy diet

21. Scheduling/booking follow-up appointments with healthcare providers (e.g., specialists)
35. Physical limitation
48. Dry mouth
49. Ability to taste food
52. Hearing loss
54. Insomnia
65. Changes in bone density
72. Saving saliva glands
74. Having an advocate health care provider/nurse/clinician
85. Freedom to choosing the medical care providers

Statements in gray quadrant:
1. Out of town accessible resources and support
11. Toothache
16. Wrist pain
18. Reduced social interaction
20. Acid reflux
22. Changes in voice
23. Access to treatment services in home to prevent unnecessary hospital visits and infection exposure
24. Headache
26. Tongue pain
28. Surgical scars
32. Costs of parking permits
39. Having mentors who share the same experience
43. Shortness of breath
46. Understanding statistics and current outcomes
47. Growing beard
51. Identification of support groups and resources specific to head and neck cancer
60. Lymphedema (Lymph fluid retention causing limb swelling where lymph nodes are affected by cancer treatment)

66. Weight loss.

67. Hair-free skin grafts

71. Stiff neck

76. Postherpetic Neuralgia (complication of an infection causing burning sensation to skin and fibers)

79. Ultra sensitivity to smell

81. Fibrosis

82. Cracked lips

83. Sore shoulder

84. Stomach sickness

86. Accommodation for out of town patients

91. Proper fit of dentures after surgery

93. Metallic taste in mouth

Appendix Q

List of Statements in Go-Zone 2; The Role of HPV

Statements in Go-Zone quadrant:

4. Quality of alternative feeding (feeding tube).
6. Nutrition
7. Tongue loss
10. Annual follow up with surgeon
12. Teeth loss
19. Maintaining a healthy diet
27. Dental service providers specialized/experienced in head and neck cancer
30. Promptness of diagnosis
31. Ability to communicate and speak intelligibly
34. Dental follow up after treatment
36. Clear detailed upfront information of the case and treatment plan
37. Stress
38. Prompt Speech and Language Pathology consultation, services and follow up
40. Swallowing difficulty
42. Education on how to manage and cope with long-term side effects
49. Ability to taste food
50. Survival
52. Hearing loss
53. family/caregiver/loved one/social support
55. Support through treatment and recovery
56. Support and guidance after treatment
57. Tracking patients' progress throughout treatment and post treatment
59. Knowledgeable and experienced healthcare providers in head and neck cancer
62. Social isolation
65. Changes in bone density
72. Saving saliva glands
73. Promptness of treatment
74. Having an advocate health care provider/nurse/clinician

75. Information on the available treatment options and new advancements
78. Information on long-term side effects and the possible traumatic experience
80. Involve patient in decision making
85. Freedom to choosing the medical care providers
87. Engaged healthcare providers with compassionate care
88. Fatigue
89. Continue to follow up after 5 years
92. Communication with healthcare providers
94. Providing an accessible resource/tool for information and common questions

Statements in orange quadrant:

11. Toothache
13. Dietitian services and follow up
14. Long term rehab services after treatment
15. Funding to cover travel expenses to access healthcare services
21. Scheduling/booking follow-up appointments with healthcare providers (e.g., specialists)
29. Accessibility to healthcare services for out of town patients
41. Psychological support and recommendations before treatment
44. Post-surgery infections
45. Accessibility of counseling services in cancer treatmentcentres
58. Coverage for allied health and clinical services i.e: dental, rehab
63. Keeping the family informed
76. PostherpeticNeuralgia (complication of an infection causing burning sensation to skin and fibers)
86. Accommodation for out of town patients
91. Proper fit of dentures after surgery

Statements in yellow quadrant:

2.Fear of the unknown

5. Long-lasting side effects
8. Anxiety
9. Depression
17. Late onset side effects
20. Acid reflux
35. Physical limitation
48. Dry mouth
54. Insomnia
61. Sticky saliva and phlegm
64. Oesteoradionecrosis (bone death secondary to radiation therapy)
77. Fear of recurrence
90. Social worker/counselling support (individual or group)

Statements in gray quadrant:

1. Out of town accessible resources and support
3. Mouth sores
16. Wrist pain
18. Reduced social interaction
22. Changes in voice
23. Access to treatment services in home to prevent unnecessary hospital visits and infection exposure
24. Headache
25. Inability to return to the workforce
26. Tongue pain
28. Surgical scars
32. Costs of parking permits
33. Aspiration
39. Having mentors who share the same experience
43. Shortness of breath
46. Understanding statistics and current outcomes
47. Growing beard

51. Identification of support groups and resources specific to head and neck cancer
60. Lymphedema (Lymph fluid retention causing limb swelling where lymph nodes are affected by cancer treatment)
66. Weight loss.
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68. Graft resorption
69. Pretreatment education on post treatment outcomes
70. Tongue pain
71. Stiff neck
79. Ultra sensitivity to smell
81. Fibrosis
82. Cracked lips
83. Sore shoulder
84. Stomach sickness
93. Metallic taste in mouth