Curtin School of Nursing, Faculty of Health Sciences

Exploring the Psychosocial Support and Education Needs of People Diagnosed with Head and Neck Cancer, and the Health Professionals Who Care for Them

Chandrika Gibson
0000-0002-1147-6608

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number #HRE 2018 – 0691, and the ethics committees of participating tertiary hospitals (SCGOPHCG HREC number RGS0000001145).

Signature:

Date: 5th July 2022

Abstract

Aims: The aim of this study was to explore the experiences of people diagnosed with head and neck cancer, and the health professionals who care for them. The research questions were:

1. What are the psychosocial experiences of people with head and neck cancer?
2. What are the experiences of health professionals who work with people with head and neck cancer?

Background: A literature review was conducted to understand the psychosocial issues related to head and neck cancer, as well as the gaps in the existing literature. Around 4,400 people are diagnosed with head and neck cancer in Australia each year, and these patients experience high levels of psychological distress. There is limited research on patients' support and education needs following a head and neck cancer diagnosis and over time. Few studies have developed and tested interventions to address the psychosocial support needs of people with head and neck cancer specifically, and those that do are small.

Many health professionals play a role in symptom management and supporting people with head and neck cancer from diagnosis through treatment and beyond. Health professionals report difficulties in meeting patients' needs, and there are numerous barriers to the provision of such support. There is a lack of research focusing on health professionals who manage head and neck cancer patients.

Methods: This study employed an exploratory qualitative research design using a social constructionist interpretive framework. Semi-structured interviews were conducted with 21 health professionals and 21 people diagnosed with head and neck cancer. Patient interviews were conducted at different time points during the cancer journey.

Results: Health professionals find treating people with head and neck cancer highly challenging. They experience compassion fatigue and are at risk of burning out and leaving or reducing their role. People diagnosed with head and neck cancer often experience an altered appearance, which they do not feel adequately prepared for, and frequently struggle to accept. Patients have numerous barriers to communication with health professionals and others, which they experience as disempowering and silencing. Some people diagnosed with head and neck cancer described benefits, made meaning and developed inner resources by returning to meaningful activities, thereby experiencing personal growth in survivorship.

Conclusion: The findings can be used to guide nursing, allied health and medical curriculums and clinical education to identify and develop core competencies for caring for individuals with head and neck cancer. In the future, the results of this study can also be used to develop advanced communication skills training for health professionals and psychosocial content for undergraduate and postgraduate curriculums. Further, the findings can be used to inform policy change in the prevention of health professional burnout, and to support the oncology workforce to create more compassionate, trauma-sensitive treatment environments.

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I am sure I have forgotten someone significant, and I apologise. As the Thesis Whisperer says, in any project of this size, ‘perfect is the enemy of done’, and so I hope you will understand when I thank you in person if you have not had a mention in writing here. This thesis has been professionally edited by Kylie Lowe AE in accordance with the *Guidelines for Editing Research Theses* and sections D and E of the *Australian Standards for Editing Practice,* however any errors or omissions are my own.

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Contents

Chapter 1: Thesis Introduction

1.1 Chapter overview

The purpose of this chapter is to introduce the research area and the significance of this study. The chapter includes a brief background on the incidence, prevalence and morbidity of head and neck cancer (HNC) in Australia and globally. It describes the condition, introduces the participants, justifies the research and outlines the structure of the thesis.

1.2 Head and neck cancer

The number of HNCs diagnosed in Australia has increased in recent years (Australian Institute of Health and Welfare, 2014a) and is estimated to effect 4400 people annually (Australian Institute of Health and Welfare, 2017). An estimated 562,328 people were diagnosed with HNC globally in 2020 (Sung et al., 2021). Although cancers occurring in the head and neck region make up a relatively small proportion of the overall cancer incidence (3.5% of all cancers (Australian Institute of Health and Welfare, 2014a)), they are associated with significant treatment-related morbidity. Treatment advances have resulted in improved survival rates both in Australia and in other economically advanced countries (*Head and Neck Cancer Treatment Options*, 2020; Ringash, 2015). The Australian relative five-year survival rate for all HNCs is 68.2% (Australian Institute of Health and Welfare, 2014a). As survival outcomes continue to improve, there is an increased emphasis on survivorship and the effect of treatment on the quality of life of survivors (Ringash et al., 2015).

The diagnostic group of HNC encompasses tumours of the sinuses, nose, mouth and throat (Australian Institute of Health and Welfare, 2014a). HNC has historically been attributed to tobacco and alcohol consumption; however, there is an increasing incidence in the oropharyngeal region attributed to the human papillomavirus (HPV), which is a sexually transmitted disease (de Martel et al., 2017; *Head and Neck Cancer Treatment Options*, 2020). For the purpose of this study, the term 'HNC' is used for cancers of the oral cavity, larynx, oropharynx, nose and sinuses from any cause, including both HPV- and non-HPV-related cancers.

1.3 Distress experienced by patients with head and neck cancer

HNC is recognised as a highly distressing cancer type, with rates of anxiety and depression higher than other cancers, such as lung cancer, where the estimated prevalence of depression is 3% (Niedzwiedz et al., 2019). Up to 50% of HNC patients report depression (Lenze et al., 2022) compared with 13% across all cancer types (Walker et al., 2013). Psychological distress is reported by 25–30% of cancer patients (Neilson et al., 2010) and over 35% of HNC patients (van Beek et al., 2021). Anxiety is highest pre-treatment (22% of HNC patients) and rises again 18 months post-treatment (Neilson et al., 2010), highlighting issues and challenges in survivorship.

The multimodal treatment required to manage HNC causes significant physiological, functional and psychosocial effects. The issue of altered facial appearance is most associated with treatment by surgery, with or without radiation therapy (Eades et al., 2009; Semple et al., 2008). Surgical excision, neck dissection and reconstructive surgery may have other side effects, including temporary or permanent loss of voice, impaired speech, hearing loss, difficulty chewing and swallowing and, when lymph nodes have been removed, lymphoedema (Saraswathula et al., 2021; Zebolsky et al., 2021). Techniques for delivering radiation therapy have evolved over time; however, this modality still comes with a significant toxicity profile (Alterio et al., 2019). Side effects from radiation therapy include mucositis, xerostomia, tissue necrosis and fibrosis, skin conditions, and osteoradionecrosis (Alterio et al., 2019; Davies-Husband et al., 2018). Because the highly visible face and neck and major sense organs are affected, there are impacts across multiple life domains, including a disrupted sense of self, which may continue beyond the end of treatment (Gritz et al., 1999; Molassiotis & Rogers, 2012).

Treatment can also lead to functional communication impairment, which affects patients' careers, roles and social identity (Dooks et al., 2012; Nanton et al., 2016). Changes in speech and voice can be temporary or permanent, arising as a direct result of surgery such as laryngectomy or the oedema and scarring associated with surgery and radiation (Chotigavanich et al., 2016; Davies-Husband et al., 2018; Fingeret et al., 2013). Partial or total loss of voice results in patients needing to learn new ways to communicate using augmentative and alternative communication applications (Brunner et al., 2016), voice prosthesis, electro-larynx or other similar voice technology (Davies-Husband et al., 2018; Souza et al., 2020). While speech pathology and voice rehabilitation programs can decrease anxiety and depression (Bergström et al., 2017), these side effects can have detrimental consequences for a person's communication, self-concept and social identity (Fingeret et al., 2013).

Many of the risk factors for HNC, including tobacco smoking (Giraldi et al., 2017; Lee et al., 2019), drinking alcohol (Giraldi et al., 2017) and HPV (D'Souza & Dempsey, 2011; Farsi et al., 2015), have significant negative social and moral implications and assumptions that can lead to stigma (Lebel & Devins, 2008). The disease and its treatments alter the appearance and function of body organs associated with physical appearance (Ellis et al., 2019; Fingeret et al., 2015), identity (Brodsky, 1978; Goffman, 1974; Zebrowitz & Montepare, 2008) and the ability to obtain nutrition (Bossola, 2015; Jager-Wittenaar et al., 2011). Where nutritional intake is insufficient, enteral feeding methods may be required (Nugent et al., 2013). Stigma combined with physical and functional alterations may adversely affect a person's ability to engage with important social rituals associated with communicating (Chen et al., 2015), eating (Dornan et al., 2022; Nugent et al., 2013) and drinking (Cousins et al., 2013), leading to social anxiety and social isolation (Rhoten et al., 2018).

1.4 Health professionals involved in treating patients with head and neck cancer

Numerous health professionals play a role in the diagnosis and treatment of people with HNC (*Head and Neck Cancers Optimal Cancer Care Pathway*, 2021), and the interactions between health professionals and patients have meaningful effects on wellbeing for both groups (Adamson et al., 2018; Lown & Setnik, 2018). Disciplines typically include general practitioners (GPs) and dentists who may refer to specialists (including ear, nose and throat

[ENT] specialists), surgeons, radiation oncologists, medical oncologists and nurses, as well as dietitians, speech pathologists, audiologists, prosthodontists, social workers, counsellors, psychologists and, in some cases, palliative care teams (*Head and Neck Cancers Optimal Cancer Care Pathway*, 2021).

Each interaction with a health professional has a potential effect on the psychosocial wellbeing of the patient, with effects including raising or lowering of existential anxiety (Egestad, 2013) and patient satisfaction with care (Arts et al., 2020; Llewellyn et al., 2006). Pre-treatment distress can negatively affect treatment completion and survival outcomes (Chen et al., 2017). Anxiety during radiation therapy has been shown to interrupt treatment (Clover et al., 2011) and requires more time with each patient (Merchant et al., 2017). This adds to the strain on health systems, which are focused on efficiency in terms of treatment planning and delivery (Merchant et al., 2017).

Health professionals are also affected by their interactions with patients (Aranda et al., 2012; Back et al., 2007; Breen et al., 2017). The deleterious effect of vicarious trauma has been studied among health professionals, including nurses (Canfield, 2005; Martin, 2018; McCormack & Adams, 2016). The oncology workforce is generally at high risk of burnout (Eelen et al., 2014; Trufelli et al., 2008), and head and neck surgeons have been found to have high rates of burnout (Kejner et al., 2021). However, there is limited literature on the specific issues experienced by multidisciplinary health professionals in the care of people with HNC. The relationship between health professionals and patients has been highlighted as an area of interest for improving patient experiences and health professional satisfaction and retention (Moore et al., 2013), and further research is needed.

1.5 Interventions and justification for research

Communication skills training (Halkett et al., 2016) and mindfulness-based interventions (Amutio-Kareaga, García-Campayo, et al., 2017; Boellinghaus et al., 2014) have been shown to lower health professionals’ distress. Patient education ("Clinical effectiveness of psycho-educational interventions to reduce perioperative anxiety in oncology patient: A systematic review," 2010) and mindfulness-based interventions (Baydoun et al., 2021) have also been found to lower patients’ distress in other cancer types. In order to develop interventions that aim to decrease psychological distress for people affected by HNC, a greater understanding of the issues experienced by patients treated for HNC and the health professionals who work directly with them is needed. Currently, the literature is largely discipline-specific and focused on either treatment technicalities (Alterio et al., 2019; Brodin et al., 2021), speech pathology (Bergström et al., 2017; Childes et al., 2019), nursing (Banerjee et al., 2017; Chan et al., 2019), psychology (Calver et al., 2019) or dietetics (Edwards et al., 2022; Wall et al., 2016). This thesis aims to better understand the issues facing health professionals and people with HNC during and after treatment to inform future interventions aimed at reducing distress for both health professionals and people with HNC. Deeper understanding is required to improve and maintain the wellbeing of the workforce, and to improve the psychosocial education and support provided to patients and survivors.

1.6 Aims and objectives

The overarching aim of this study is to explore the experiences of people diagnosed with HNC and the health professionals who care for them. The research questions are:

1. What are the psychosocial experiences of patients with head and neck cancer?
2. What are the experiences of health professionals who work with people with head and neck cancer?

The primary aims of the study are:

1. To explore the experiences of people diagnosed with and treated for HNC in Australia
2. To explore the experiences of health professionals working directly with people with HNC in Australia.

The secondary aims are:

1. To explore the psychosocial impact of altered appearance on people treated for HNC
2. To explore the inhibitors and promoters of communication between health professionals and people with HNC
3. To explore issues of survivorship experienced after treatment for HNC.

1.7 Research setting and overall data collection strategy

This research was conducted in Perth, the capital city of Western Australia (WA). The state of WA covers an area of 2.646 million square kilometres and is home to 2.7 million people, with 75% of the population living in the metropolitan area of Perth. The state has more than 80 hospitals, including three tertiary hospitals (teaching): Fiona Stanley Hospital, Royal Perth Hospital and Sir Charles Gairdner Hospital. The health system contains a mix of public and private sector providers, and a further three hospitals are managed under private–public partnerships: Joondalup Health Campus, Peel Health Campus and St John of God Midland. Not all hospitals are equipped to manage cancer. Federal funding has been allocated to build a future Comprehensive Cancer Centre co-located at the current site of Sir Charles Gairdner Hospital and the QEII Medical Centre (*WA Cancer Centre*, 2022). A Comprehensive Cancer Centre in WA is needed to integrate care and address the fragmented care that WA patients experience, whereby their treatments can take place across several sites. The current lack of coordination frequently results in insufficient psychosocial care.

Cancer is a major cause of illness in Australia and is responsible for three out of every 10 deaths (Australian Institute of Health and Welfare, 2017). Excluding basal and squamous cell carcinomas of the skin, all cancer diagnoses are registered in the Australian Cancer Database (Australian Institute of Health and Welfare, 2019). The government-funded Medicare system subsidises universal healthcare; however, public and private patients follow different diagnosis and treatment pathways (Slavova-Azmanova et al., 2020).

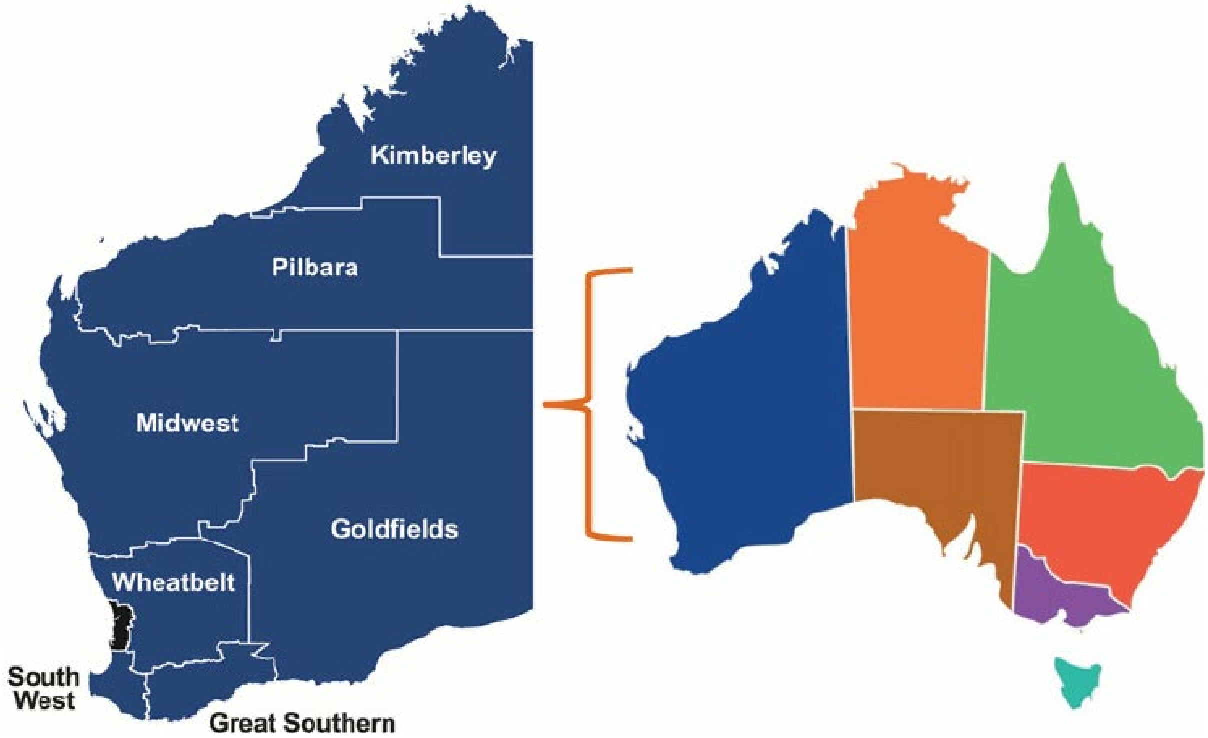

Image 1: Map of Western Australia

Participants were initially drawn from the main Perth metropolitan treatment centres of Sir Charles Gairdner Hospital and Fiona Stanley Hospital. Snowball sampling led to the inclusion of participants in other parts of Australia. Data collection involved semi-structured interviews with 21 people with HNC and 21 health professionals of different disciplines.

1.8 Structure of thesis

1.8.1 Chapter 1. Introduction

The thesis begins with an introduction to the research area and provides a brief background on the prevalence and survival rates of HNC in Australia and the world. Treatments and their side effects are explained, with a focus on the psychosocial distress known to occur for people treated for HNC. The chapter discusses the roles of health professionals involved in HNC care and the impact of their interactions on patients, followed by a brief introduction to the issues faced by health professionals, including burnout and vicarious trauma. The justification of the research is presented, and clearly defined aims and objectives then set the scene for this thesis.

1.8.2 Chapter 2. Literature Review

Chapter 2 provides a general overview of the HNC literature. Background is provided, including prevalence, causes and survival statistics, and the effects of treatment are discussed, with an emphasis on psychosocial effects on people diagnosed with HNC. The role of health professionals' existing communication skills and resilience training is reviewed, and gaps in the research literature and clinical settings are identified, providing directions for future research studies. Informed by this review of the literature, this chapter concludes with a proposal for the need to better understand the experiences of people with

HNC and the health professionals who care for them in order to inform future interventions additional to the research aims, objectives and questions.

1.8.3 Chapter 3. Methodology

Chapter 3 presents the methodological approach underlying this study. The epistemological position of this study is outlined, followed by the theoretical framework, which provides a research lens for exploring the experiences of people diagnosed with HNC and the health professionals who care for them. Following this, a detailed account of social constructionist theory is discussed as the research methodology driving this study. Social constructionism was chosen as a research methodology because of its suitability for rigorously exploring the co-construction of meaning by semi-structured interview participants. The chapter concludes with a personal reflexive piece by the researcher.

1.8.4 Chapter 4. Methods

This chapter describes the process of data collection using interviews including verbatim transcription of audio recordings. Transcripts were entered into NVivo12 qualitative data analysis software, and thematic analysis followed Braun and Clarke's six-step process (Clarke & Braun, 2017a). The Methods chapter discusses the in-depth, qualitative, exploratory interpretive research design methods and procedures that are used in this study and reported on again in Chapters 5–8. These chapters consist of the individual papers comprising the overarching qualitative research study of this thesis. Study 1 focuses on health professional experiences, while Study 2 is presented in 3 papers exploring the experiences of people with HNC. The study was approved by the Curtin University Human Research Ethics Committee (HRE2018-0691) and the ethics committees at participating tertiary hospitals (SCGOPHCG HREC number RGS0000001145).

1.8.5 Chapter 5. Study 1: Paper 1: Health professional burnout

In this paper titled 'Burnout or fade away: Experiences of health professionals caring for patients with head and neck cancer', health professionals share their challenges to retain compassionate care given the multiple pressures they face in health settings, including time and resource constraints, work–life imbalance, lack of self-care and the vicarious trauma of being close to people with HNC experiencing extreme suffering. This study was published in the *European Journal of Oncology Nursing* in February 2021.

1.8.6 Chapter 6. Study 2: Paper 2: Body image distress experienced by people with head and neck cancer

Study 2, paper 2 explores appearance-altering treatments and side effects from the perspective of HNC patients. The study, titled '"I didn't even recognise myself": Survivors' experiences of altered appearance and body image distress during and after treatment for head and neck cancer', was published in the journal *Cancers* in August 2021. It explores the experience of altered appearance during and after treatment. Participant quotes illustrate the lack of pre-treatment preparation for altered appearance and highlight the psychosocial effects of the disrupted sense of self associated with treatment-related appearance change, including changes to weight, skin and hair, as well as the highly visible face and neck.

1.8.7 Chapter 7. Study 2: Paper 3: Giving voice to the silent suffering of people with head and neck cancer

Study 2, paper 3, titled ‘Silenced: Patients’ experiences of voicelessness in head and neck cancer’, demonstrates the experience of voicelessness in HNC not just as physical or functional voice loss, but as a holistic, multifaceted experience of being silenced by health systems, a lack of health literacy, biomedical model hierarchies, and the need to entrust one’s life to health professionals. Communication issues include the pace of decision-making, the use of jargon and euphemisms, and the importance of mindfulness and tailored communication from health professionals. This paper was published in the journal *Patient Education and Counselling* in February 2022.

1.8.8 Chapter 8. Study 2: Paper 4: Life is meaningful and growth is possible

Study 2, paper 4, titled *Return to valued activities: Survivors’ experiences of adaptation and growth after treatment for head and neck cancer*’, was submitted to the journal *Psycho-Oncology* in April 2022 and is in press (December 2022). This paper explores the experiences of survivors of HNC returning to meaningful activities. For post-treatment HNC survivors, meaning making is key to finding some benefits, wisdom and personal growth from a traumatic experience. The depth of their suffering creates fertile ground for renewal, reconstruction, creative pathways back to living well, and profound appreciation, which transcends trauma.

1.8.9 Chapter 9. Discussion

In this chapter, the findings of each study and the thesis overall are positioned with reference to the existing literature, and implications for practice, health professional education and future research are described. People diagnosed and treated for HNC experience multiple, complex psychosocial issues, and this thesis highlights the need for compassion to surround patients to mitigate the effects of altered appearance, voice loss and the disrupted sense of self that inhibits recovery after treatment. The findings of this thesis support earlier research on HNC patient experiences and health professional burnout, but they go further in their depth and richness to point to the necessity of ongoing training and the cultivation of cultures that support the wellbeing and hence the retention of the highly skilled HNC workforce. The thesis illuminates specific issues related to HNC that need to be addressed within health professional education, including screening patients for the risk of body image distress, which could trigger early referrals for psychological support pre-treatment and may minimise the risk of appearance-related trauma. Based on the findings of this thesis, the development of interventions that will reduce the risk of burnout and improve the retention and capacity of health professionals may include advanced communication skills training, body image awareness, trauma-sensitivity training, and self-compassion and stress management skills.

Chapter 2: Literature Review

2.1 Background

HNC is the eighth most common cancer in Australia (Australian Institute of Health and Welfare, 2014b). The majority of the 4,400 people who receive a HNC diagnosis in Australia—approximately 3,170—are male, and 1,230 are female. Incidence rates per 100,000 increase with age, from 7.5 and 4.7 for 35–39 year-old males and females, respectively, to a peak of 107.5 and 47.5 for males and females ages 80–84 (Australian Institute of Health and Welfare, 2017). The greatest incidence of HNC in Australia is cancer of the mouth and tongue (approximately 1,370 people annually), followed by lip cancer (1,000), pharyngeal cancer (890), laryngeal cancer (590), salivary gland cancer (320) and nasal or paranasal sinus cancer (170) (Australian Institute of Health and Welfare, 2016).

More than 500,000 new cases of HNC are diagnosed each year worldwide (Starzyńska et al., 2022). There is global variation in incidence trends, with socioeconomic regions influencing exposure to causative factors such as tobacco and alcohol usage and HPV infections (Hashibe et al., 2009; Simard et al., 2014). While many economically developed countries (e.g. Australia, Northern Europe and North America) have passed peak tobacco usage, rates of persistent infection with HPV cause more than 60% of oropharyngeal cancers in these regions (Simard et al., 2014). While the typical HNC patient is male, older and has multiple co-morbidities associated with tobacco smoking and alcohol use, more recent trends indicate a greater incidence in younger populations and women as a result of HPV exposure (Auluck et al., 2010; Chaturvedi et al., 2011; Ryerson et al., 2008).

The prognosis for HNC varies depending on tumour location and disease staging (Australian Institute of Health and Welfare, 2016). Generally, the earlier the cancer is diagnosed, the better the outcome; however, people with advanced HNC may also respond well to treatment (Auluck et al., 2010). Across all HNC types, survival rates have increased from 61% in the period 1984–1988 to 69% for those diagnosed in 2009–2013 (Australian Institute of Health and Welfare, 2014b). The current five-year survival rate for all HNC types is 71% (*Head and Neck Cancer Treatment Options*, 2020). Researchers estimated that more than 68,000 men and women in the United States would be diagnosed with HNC in 2021 (Siegel et al., 2021). At the end of 2015, there were 4,355 people in Australia who had been diagnosed with HNC that year, 16,891 survivors who had been diagnosed with HNC in the previous five years (from 2011 to 2015) and 45,919 survivors who had been diagnosed with HNC in the previous 34 years (from 1982 to 2015) (*Head and Neck Cancer Treatment Options*, 2020). In 2014, there were 1,040 deaths from HNC in Australia (766 males and 274 females). It was estimated that there would be 1,026 deaths (777 males and 249 females) in 2017.

Because of the severity of the diagnosis, patients need to make treatment decisions quickly and adjust rapidly to major lifestyle changes such as slower eating (Dornan et al., 2022), role changes and communication challenges (Dropkin, 1994). The malignancy and treatments may influence some of the most fundamental activities of daily living, including speech, breathing, eating and drinking (Egestad & Emaus, 2014; Lebel et al., 2013; Threader &

McCormack, 2016b). Along with complications affecting essential functions, altered physical appearance sometimes contributes to feelings of embarrassment and shame, which can create a cascade of isolation and further deleterious health consequences (Badr et al., 2016; Lebel et al., 2013; Wali & Regmi, 2017). Patients with HNC often experience distress because of the diagnosis and then must also deal with side effects during and after treatment that affect their quality of life, particularly if their symptoms are poorly managed (Egestad & Emaus, 2014). The societal and personal importance placed on appearance (Fingeret et al., 2015), especially the face (Stone & Potton), coupled with the lifestyle-related causes of the disease and the treatment sequelae, lead to the conclusion that HNC is one of the most psychologically distressing cancer types (Callahan, 2005).

2.2 Treatments and side effects

Treatment decision-making depends on several factors, including the location of the tumour, the stage of the cancer, and the person’s age and general health. Treatments for HNC include surgery, radiation therapy, chemotherapy, targeted therapy, or a combination of treatments. People who are diagnosed with HPV-positive oropharyngeal cancers typically receive different treatments than people with HPV-negative oropharyngeal cancers (National Cancer Institute, 2021).

While surgical treatment aims to remove cancerous tissue, follow-up plastic surgery to reconstruct the facial bones and tissues is often performed (National Cancer Institute, 2021). In some cases, reconstructive surgery may not be possible because of damage to the remaining tissue from surgery and/or radiation therapy (Yeh et al., 2017). If reconstructive surgery is not possible, a prosthodontist may be able to make a prosthesis (an artificial dental and/or facial part) to restore satisfactory swallowing, speech and, as far as possible, normalise appearance (Brodsky, 1978; Kakarala et al., 2018). Scars can be unsightly immediately post-surgery, and the face and neck may be swollen. Although the swelling reduces and scarring fades over months, many scars remain visible and may not be easily disguised (Gritz et al., 1999), thus presenting appearance-related issues for both women and men (Desnoo & Faithfull, 2006).

Depending on the location of the tumour, lymph nodes may be removed, which can result in a slower rate of movement of lymphatic fluid in the area where they were removed (Rasmussen et al., 2017). Approximately 75% of HNC patients develop lymphoedema, where lymph fluid collects in the tissues, causing additional swelling (Deng et al., 2013); this swelling may appear at any time post-surgery and can last indefinitely. Symptoms include numbness, pain, heaviness, tightness, warmth and swelling, as well as difficulties breathing and swallowing, and blurry vision (Deng et al., 2016). Removal of lymph nodes as well as tumours in the neck frequently leave the shoulder and neck muscles weak and stiff (Cohen et al., 2016). Changes in the range of movement in the neck and shoulder region can affect daily living activities, including the ability to maintain or return to previous employment, household roles and recreational activities. Physiotherapy, exercise physiology and occupational therapy rehabilitation techniques are recommended to regain movement in the neck and shoulders after treatment (Boer et al., 1995; Cohen et al., 2016).

Radiation therapy is used in HNC treatment as a single modality or combined with chemotherapy as a multimodal treatment option. The high toxicity profile associated with radiation therapy is a result of the fact that curative treatment requires very high doses of radiation to be administered to a small area located very close to important structures such as the brain stem, spine, carotid artery, salivary glands, and speech and swallowing structures (Alterio et al., 2019). Side effects include mucositis, xerostomia, tissue necrosis and fibrosis, skin conditions, and osteoradionecrosis (Alterio et al., 2019; Barnhart et al., 2018; O'Neill et al., 2015). A systematic review and meta-analysis showed that not only are toxicities still significant with the use of cetuximab and radiation for HPV-positive HNC, but this combination could be inferior for long-term survival compared to standard cisplatin and radiation (Petrelli et al., 2014).

Patients who receive radiation therapy to the head and neck may also experience redness and irritation of skin, mouth sores, a dry mouth or thickened saliva, difficulty in swallowing, changes in taste, and nausea (Tseng et al., 2020). Patients may also experience swelling or drooping of the skin under the chin and changes in the texture of the skin. The jaw may feel stiff, and patients may not be able to open their mouth as wide as before treatment (Cohen et al., 2016). Surgery and radiation for HNC often changes the patient’s ability to chew, swallow or talk (Egestad & Emaus, 2014). Some patients receive nutrients directly into a vein after surgery or need a feeding tube until they can eat on their own (Cohen et al., 2016; National Cancer Institute, 2017). Changes in ability to chew and swallow have wide-ranging effects, including weight loss, distress and decreased quality of life (Egestad & Emaus, 2014), particularly when a stoma is required due to body image distress and lifestyle changes (Kelly et al., 2007; Smith et al., 2017). Other side effects include loss of taste, which may decrease appetite and affect nutrition, and earaches resulting from a hardening of ear wax (Perry et al., 2015). Loss of appetite, inability to eat and associated weight loss lead to multidimensional experiences such as social shame and isolation, which are not always recognised and managed adequately (Cooper et al., 2015).

Treatments can cause changes to voice quality and reduced speech intelligibility as a result of surgical resection, laryngectomy and radiation treatment to tumour sites in the mouth or vocal tract (Giuliani et al., 2016), creating barriers to verbal communication. Depending on the tumour site, treatment-related variables, including xerostomia (dry mouth), hearing loss and altered dentition (Bolt et al., 2016; Chen et al., 2015), may also affect communication. A review of treatments for HNC found 40 studies describing swallowing-related problems, 24 describing voice-related problems and 7 describing trismus (lockjaw) (Heijnen et al., 2016), all of which present physical and functional barriers to communication and negatively affect verbal communication for people treated for HNC.

Voice and speech changes typically worsen during the course of treatment for HNC, and permanently altered vocal communication and declining voice quality may be experienced by non-laryngeal HNC patients (Davies-Husband et al., 2018), as well as by those who have laryngectomies (Dooks et al., 2012; Happ et al., 2005; Perry et al., 2015). Direct radiotherapy treatment for tumours affects the larynx and alters the voice, including pitch and volume range (Lazarus, 2009). While newer forms of radiotherapy are less damaging, they may continue to affect vocal cord function (Sanguineti et al., 2013; Tseng et al., 2020). Following chemoradiotherapy (CRT), some improvement to voice and speech is typically seen one to two months after treatment, with a return to or exceeding pre-treatment function by 12 months post-treatment (Paleri et al., 2012). Perceptions of changes in voice quality and intelligibility vary between health professionals and people with HNC (van der Molen et al., 2011). For example, survivors of HNC report impaired speech following CRT treatment, in contrast to clinician perceptions of complete intelligibility (Kraaijenga et al., 2016).

2.3 Psychosocial impact

Physical and functional barriers to communicative participation often lead to psychological distress. Nund et al. (Nund et al., 2015) explored the lived experience of *n*=14 survivors after non-glottic HNC treatment and concluded that communication changes following CRT have potentially negative psychosocial effects on HNC survivors and carers A larger qualitative study (*n*=39) found that HNC survivors experienced social isolation as a result of difficulties adapting and the increased effort required to communicate (Fletcher et al., 2019). Patients undergoing radiotherapy for HNC are commonly observed by health professionals to be emotionally distressed and disempowered (Klug et al., 2020). For a sub-population of HNC survivors, their day-to-day communication will change in ways that affect their relationships and sense of self, leading to social isolation and decreased health-related quality of life (HRQOL) (Dooks et al., 2012; Fletcher et al., 2019). Speech can be temporarily or permanently altered by treatment. Even short periods of inability to speak are experienced as anxiety-provoking (Brunner et al., 2016), leaving patients vulnerable and traumatised. Impairment of voice results in communication difficulties and subsequently decreased quality of life (Janssens et al., 2016; Karlsson et al., 2016). Although changes in ability to speak can be managed with speech therapy, some patients are unable to regain full use of their voice (Davies-Husband et al., 2018). While physical and functional interventions have proven helpful and continue to evolve with technological advances (Fletcher et al., 2019), the psychosocial effect of short- and long-term altered verbal communication is not well understood.

2.3.1 Distress, anxiety, depression and stigma

Distress is common among people diagnosed with any type of cancer, and may occur throughout the course of the illness and post-treatment (Nicholas et al., 2013). The experience of being diagnosed and treated for HNC is highly stressful and can be experienced as traumatic (Cordova et al., 2017), because it disrupts peoples' biography (Bury, 1982), threatens their established sense of self (Callahan, 2005), and is associated with multiple layers of distress, including anxiety, depression and stigma (Lebel et al., 2013). In addition to the rigours of diagnostic scans and the discomfort of treatment, including being immobilised, changes in appearance and function caused by HNC treatment can contribute to significant psychological distress, including anxiety and depression (Pandey et al., 2007). Distress, and in particular depression, is estimated to be more prevalent in people with HNC than other cancer types (Ichikura et al.). According to Pandey et al. (Pandey et al., 2007), distress often occurs alongside anxiety and depression in HNC patients. Approximately 35% may experience a significant form of distress, such as adjustment issues, anxiety and depression (Caruso et al., 2017). Estimates of clinical depression in HNC patients range from 15% to 50% (Lydiatt et al., 2009), suggesting that HNC patients experience among the highest rates of major depressive disorder of all oncology patients.

A prospective observational study of 102 outpatients at the Peter MacCallum Cancer Centre in Victoria, Australia, found that the percentage of participants classified above the cut-off for symptoms of depression on the Hospital Anxiety and Depression Scale (HADS) was 17% pre-treatment, 30% three weeks post-treatment and 8% 18 months post-treatment. On the anxiety subscale, 22% pre-treatment, 18% three weeks post-treatment and 22% 18 months post-treatment scored above the cut-off (Neilson et al., 2010). This indicates that pre-treatment anxiety, longer-term survivorship anxiety and immediately post-treatment depression affect more than one in five HNC patients.

A number of causes of distress centre on body image (Fingeret et al., 2012b; Rhoten et al., 2013), which is the perception of one’s body as a biopsychosocial unity (Deledda et al., 2013). For cancer patients, this self-perception is altered by changes in appearance caused by disease and treatments, especially facial surgery (Fingeret et al., 2014). There is dissonance between a person’s memory of their pre-treatment appearance and function, and their post-treatment status. Such alterations in body image are a common concern and cause of distress in cancer-affected populations (Rhoten, 2017). Of 280 HNC patients undergoing surgery who were surveyed, 75% reported feeling concerned or embarrassed by bodily changes following diagnosis. Of those, 42.3% were concerned about scarring and disfigurement, 35.8% were worried about the effect on their ability to speak, 30.1% were concerned about loss of teeth and 25.1% were worried about eating socially (Ninu et al., 2016).

Unlike other cancers, such as breast cancer, it is difficult for patients with HNC to camouflage the effects of treatment because the face, head and neck area are typically exposed (Callahan, 2004). Regardless of treatment type, many people receiving treatment are likely to experience altered appearance to some degree. Around 57% of people with HNC who receive surgical treatment report experiencing major disfigurement (Gamba et al., 1992). For HNC patients who receive radiation therapy, late and lasting side effects include dermatitis, neck oedema and sometimes facial lesions caused by fibrosis. This disfigurement contributes to poor body image (Blanco & Chao, 2006). The greater the disfigurement, the more likely patients are to experience dissatisfaction with body image (Chen et al.). Both males and females with HNC experience psychosocial issues related to facial appearance changes; however, the effect of treatment-related disfigurement on body image is greatest in younger females (Katz et al., 2003).

HNC diagnosis and treatment have significant effects on self-concepts due to body image concerns (Bennion & Molassiotis, 2013; Costa et al., 2014; Ellis et al., 2019; Macias et al., 2021), loss of speech, and respiratory and nutritional alterations (Bressan et al., 2017;

Granström et al., 2022; Suzuki et al., 2016). All of these changes can challenge self-esteem and self-identity. They influence many aspects of everyday life, such as capacity to work and communicate, long after the initial cancer has been treated (Fitchett et al., 2018). In addition, significant negative socially constructed meanings and assumptions about personal responsibility can surround many of the risk factors for HNCs, including tobacco smoking (Giraldi et al., 2017; Lee et al., 2019; Winn et al., 2015), drinking alcohol (Giraldi et al., 2017; Hashibe et al., 2009) and HPV (Fleming et al., 2019; Holmes & Wenig, 2019; Mehanna et al., 2013), leading to stigma (Lebel et al., 2013; Lebel & Devins, 2008). Interestingly, in a study of head and neck and lung cancer patients (*n*=82), stigma was higher for men than women, and highest when disfigurement was greatest (Katz et al., 2003). While spouses identified irritability, mood swings and anger in the partner with HNC, the patients indicated that issues with altered body image affected intimacy. Whether partners acknowledged it or not, the affected person anticipated rejection or disgust as a result of disfigurement or changed appearance (Badr et al., 2016). Altered appearance greatly affected the quality of life of partners of people with HNC (Badr et al., 2016; Zeine & Larson, 1999) as a result of changed social and recreational lifestyles, with some patients withdrawing from social interactions because they did not want to be seen (Fingeret et al., 2015). Rather than being driven by vanity or even self-consciousness, the concerns about altered appearance stemmed from a loss of sense of self and a fear of being stigmatised by others (Brodsky, 1978). The responses of 75 observers who rated their response to images of the faces of HNC patients showed that observers who had a stronger emotional response to photos tended to rate the person's disfigurement as more severe, and this was reflective of observers' investment in their own body image (Cho et al., 2018b). Similarly, an earlier study found that interactions that were deemed 'intrusive' were uncomfortable for people with orbito-facial disfigurement (Bonanno et al., 2010). This sense of altered social role and self-concept made it harder for survivors to return to their pre-cancer identities, roles and activities (Clarke et al., 2011), and so left them more socially isolated and less engaged in activities that reflected their values (Dropkin, 1994). A 2014 study using a four-item body image screening instrument administered at a single time point to *n*=248 cancer patients undergoing reconstructive surgery found that 95% had some preoccupation or avoidance because of concerns with appearance change (Fingeret et al., 2014). For people with HNC undergoing reconstructive surgeries, the highest level of preoperative body image concerns were related to distress about appearance change and perceived social consequences (Teo et al., 2016). In patients with cancer types including HNC who were screened using the Body Image Screener for Cancer Reconstruction either at the initial stage of reconstruction or for follow-up, 35% were seeking counselling, and regardless of age, sex or cancer type, concern with future appearance was the single best predictor of counselling enrolment (Fingeret et al., 2014).

Treatment for HNC can lead to significant changes in the way people socialise. Changes in speech, voice, swallowing, dentition, and hearing can be either temporary or permanent, arising as a direct result of treatment or the oedema and scarring associated with surgery and radiation (Fingeret et al., 2013), causing difficulty communicating verbally. Lymphoedema after treatment for HNC negatively affects quality of life because of its impact on swallowing, voice, and speech function (Jeans et al., 2021; Jeans et al., 2019). These outcomes can also adversely affect the person’s ability to eat and drink, and difficulties with social eating have been linked to higher rates of depression (Patterson et al., 2022) and decreased quality of life (Chan et al., 2019). Sequelae such as taking longer to eat; changes in the ability to smell, taste and chew food; uncontrolled drooling; and changes in speech and voice can be a result of surgery and radiation or a combination of both (Bressan et al., 2017). These side effects can have significant consequences for a person’s social structures and social identity, and there is a need for further research to support the development of tailored psychosocial interventions.

2.4 Unmet needs

In a cross-sectional postal survey (*n*=280) that used the distress thermometer and Patient Concerns Inventory, 74% of people with HNC had at least one unmet need. The most common concerns and unmet needs were in the areas of oral and eating problems, fear of recurrence, and fatigue. Multivariate analysis revealed that factors such as being unemployed, younger, having ever had a feeding tube, living alone and having a greater number of co-morbidities were associated with higher levels of distress, a greater number of concerns and more unmet needs (Wells, Cunningham, et al., 2015). A separate survey of health professionals by the same author reinforced the view that patients have a need for self-management strategies to help them cope with treatment and post-treatment survivorship issues (Wells, Semple, et al., 2015).

Patients diagnosed with HNC experience high levels of distress and unmet needs, which affects their quality of life to a greater extent than other cancer types (Fang & Heckman, 2016). In a 2016 survey of 158 HNC patients, increased unmet needs were reported in younger people, those who were earlier in the survivorship phase and those who scored lowest in quality of life measures. Overall, 61% had at least one unmet need. There was no significant difference in the nature or number of unmet needs between men and women (Giuliani et al., 2016). A qualitative study of the experiences of six patients and six partners found that the unmet needs identified in the semi-structured interviews included better preparation related to the severity of physical side effects, a clearer explanation of the likely timeline for recovery post-treatment, and relationship skills and strategies for responding to their own and their spouse’s emotional reactions. Issues reported included changes in intimacy, challenges arising from altered and competing roles, and changes in social and leisure activity involvement (Badr et al., 2016).

Jabbour et al. (Jabbour et al., 2017) surveyed 597 people with HNC across multiple institutions regarding their education and support needs. The majority reported receiving adequate information about their disease, prognosis and treatment. However, around 50% did not feel they had received enough information regarding skills or strategies for coping with anxiety and stress related to their health condition and treatment. Most participants did not receive information about support groups and reported a lack of communication about psychosexual health. A 2016 literature review also identified that patient–provider communication around HPV-related issues was an unmet need noted by both health professionals and patients (Fang & Heckman, 2016). Their preferred method of receiving such information was in one-to-one meetings with a health educator, although 72% believed that multimodal information delivery would be suitable (Jabbour et al., 2017).

Although unmet needs have been identified in the literature, current clinical practice and supports do not address these needs; in particular, the specific psychosocial needs of HNC patients undergoing treatment are not well met (Jabbour et al., 2017; Wells et al., 2015). While information about physical, functional and treatment-related side effects is routinely provided to patients, psychosocial needs are less commonly addressed (Fang et al., 2012). There is an identified need for future research that focuses on the development of novel programs that will be acceptable and feasible to meet the unmet needs of this group (Fang & Heckman, 2016).

2.4.1 Survivorship issues

Survival is improving for a number of patients with HNC as a result of evolutions in therapy (Tseng et al., 2020) and shifts in the aetiology of some cancers, such as HPV-associated oropharyngeal carcinoma (Cohen et al., 2016). Alongside follow-up cancer care, survivors must also be responsible for the daily management of often intrusive physical and psychological symptoms (Saeidzadeh et al., 2021). Issues of survivorship are not limited to the first five years after treatment but may continue for the rest of the person’s life. In a study of HNC survivors (>5 years), 53% reported delayed complications that occurred after five years. Survivors who had received CRT reported greater difficulties with swallowing, sticky saliva, feeding tubes and weight gain. Survivors who were treated with surgery and postoperative radiotherapy reported more problems with trismus (lock jaw) (Payakachat et al., 2013). Dunne et al. (Dunne et al., 2017) conducted a systematic review of literature that included 19 studies (n=2,263), where depression, anxiety and distress were correlated with lower quality of life outcomes in post-treatment HNC survivors (Dunne et al., 2017). A review of psychosocial issues across the diagnosis to survivorship continuum found that issues of HNC survivorship include disproportionately high incidences of depression, substance dependence/abuse and distress related to relationship conflict, social isolation, altered appearance and damage to self-image, relative to other cancer types (Smith et al., 2017).

Recovery takes time, with many symptoms and side effects of treatment—particularly nutritional symptoms and fatigue—present a year after treatment ends (Molassiotis & Rogers, 2012). For survivors who have had laryngectomies, there is a common experience of constant accommodation to life after treatment, requiring psychosocial support and adaptive communication technology (Dooks et al., 2012). Adapting to altered appearance continues to be challenging 12–24 months post-diagnosis for men, some of whom manage their distress by prioritising function and distancing themselves from appearance concerns (Rennie et al., 2018). Psychological adjustment to the experience of HNC has recently begun to be explored in small qualitative studies (Calver et al., 2019), as has self-management in post-treatment survivors (Saeidzadeh et al., 2021); however, much remains to be understood.

Active self-management after treatment is encouraged, yet there are numerous barriers to self-management, including inadequate health literacy, which was evident in 47% of the sample HNC survivors in a population-based study (n=395) (Clarke et al., 2021). Other barriers to active self-management have been reported by HNC survivors as including emotional barriers such as fear of recurrence, symptom-related barriers including loss of taste, structural barriers including access to appropriate services, and self-evaluative barriers (Dunne et al., 2018). While adjustment-focused interventions have been trialled, engagement has been low (Coffey et al., 2016), reflecting the highly individualised needs of survivors (Dunne et al., 2018) and pointing to the need for innovative, tailored interventions.

Returning to work following diagnosis and treatment of various cancer types has been explored to some extent (Baxi et al., 2016; Keesing et al., 2018; Weaver et al., 2021), and rehab programs, which are an important indicator of recovery, have been developed (Sheppard et al., 2020). Parsons and Eakin argue in their work on bone cancer survivorship that the definition of work should be conceptually broadened to include three types of work: illness work, identity work and vocational work (Parsons et al., 2008). It is rare that survivorship research touches on all of these aspects of recovery, and although some studies have explored returning to valued roles and activities in other cancer types (Keesing et al., 2018), this has not been investigated in survivors of HNC.

2.5 Psychosocial interventions for people with head and neck cancer

Health professionals agree that many psychosocial support needs of this patient group are unmet, and that they experience difficulty in meeting these needs (Chen et al.; Wells et al., 2015). Support programs need to be developed and tested to reduce patient distress levels and meet unmet needs. In one study, 19 people with HNC who were undergoing radiotherapy with curative intent participated in seven sessions of individualised mindfulness-based stress reduction. Those with higher self-reported mindfulness post-intervention reported higher total quality of life, including social and emotional quality of life, along with lower psychological distress (Pollard et al., 2017). However, in a randomised controlled trial (RCT) (*n*=28) using two different types of meditation (one group received meditation with a coach, while the other practiced self-meditation using a recording, there were no significant differences between the two groups on the three outcomes of anxiety, depression and emotional distress, with both groups reporting less distress from baseline and at 6 and 12 weeks, as measured by the HADS anxiety scale (Boxleitner et al., 2017).

Despite evidence that altered appearance and resultant body image distress is a common concern for people undergoing treatment for HNC (Fingeret et al., 2014; Fingeret et al., 2015; Fingeret et al., 2012a; Henry et al., 2014), few interventions are aimed at addressing this cause of distress in this population. More work has been conducted with breast cancer patients, where body image–focused interventions have included mindfulness-based interventions (Deledda et al., 2013), physical activity (Lewis-Smith et al., 2018), writing (Sherman et al., 2018) and self-compassion (Mifsud et al., 2021). Self-compassion and hope have been found to be inversely correlated with body image disturbance, depression, anxiety and stress in breast cancer survivors (Todorov et al., 2019). The ‘My Changed Body’ intervention integrates self-compassion with reflective writing (Przezdziecki et al., 2016; Przezdziecki et al., 2013) and has been shown to lower body image–related distress and increase self-compassion in breast cancer survivors (Przezdziecki & Sherman, 2016; Sherman et al., 2018). More recently, similar results were found when 'My Changed Body' was piloted for individuals with visible skin conditions (Sherman et al., 2019), and for HNC patients, where 10% of n=87 showed a clinically relevant improvement in body image distress (Melissant et al., 2021). Most studies measure post-treatment interventions; however, a pre-treatment psychological intervention has been found to promote positive adjustment to body image changes in women having prophylactic mastectomies (Glassey et al., 2018). Body image distress–focused interventions for people with HNC have included a single-arm pilot trial of a cognitive-behavioural-based telehealth intervention, which was found to be feasible, accessible and effective at reducing body image disturbance (Graboyes et al., 2020). A 2017 RCT (*n*=66) in Taiwan found that a camouflage face mask decreased anxiety and improved body image in the immediate weeks following surgery (Chen et al., 2017); however, this study only included women, and follow-up ceased three months after surgery (Chen et al., 2017). Richardson et al. (Richardson et al., 2017) conducted a pilot RCT using a brief self-regulatory intervention for people with HNC. Health psychologists delivered three 60-minute face-to-face sessions and a 30-minute phone follow-up aimed at improving HRQOL and reducing distress. The control group received standard care alone, while the intervention group had greater psychosocial support and education. At three months, the intervention group reported improved treatment control perceptions, and at six months improved social quality of life, although overall HRQOL did not change. The self-regulatory intervention based on Leventhal's common sense model of illness (Leventhal et al., 2016) was delivered early after diagnosis and was most helpful for people who reported the highest levels of distress at baseline.

Despite individual articles reporting success, a Cochrane systematic review found no evidence to suggest that the existing psychosocial interventions for patients with HNC promote global quality of life or reduce anxiety and depression (Semple et al., 2013b). The systematic review included RCTs and quasi-RCTs of psychosocial interventions for adults with HNC. Seven trials were conducted with a total of *n*=542 participants who met the eligibility criteria. The authors concluded that evidence for psychosocial interventions was limited by the small number of studies, methodological shortcomings such as lack of statistical power, and heterogeneity of the types of interventions and outcome measures used (Semple et al., 2013a). Importantly, few studies have addressed preparation for the changes in self-concept, appearance, roles and function that HNC and its treatments can cause.

2.6 Health professionals working with people diagnosed with head and neck cancer

In the process of diagnosis, treatment and follow-up, HNC patients see a wide variety of health professionals. The first professional consulted is often a GP, who then arranges tests and referrals to specialists. The multidisciplinary team may include ENT specialists, a head and neck surgeon, oral (maxillofacial) surgeon, reconstructive surgeon, radiation oncologist, medical oncologist, radiation therapists, nurses and cancer nurse coordinators, possibly an audiologist, dentist or oral medicine specialist, prosthodontist, gastroenterologist, speech pathologist, dietitian, social worker, counsellor or psychologist, physiotherapist, occupational therapist and, in some cases, a palliative care team (Cancer Australia, 2017). Each health professional is affected by their interaction with the patient (Aranda et al., 2012; Back et al., 2007; Breen et al., 2017). This relationship has been highlighted as crucial to health professionals' satisfaction (Moore et al., 2013), yet they report difficulties in meeting patients' needs (Chen et al.; Wells et al., 2015), and there are numerous barriers to the provision of such support, including time constraints (Kleiner & Wallace, 2017; Vinckx et al., 2018), length of time in the role (Naholi et al., 2015), demographical variables (Contag et al., 2010; Wardle & Mayorga, 2016), personality factors (Hallberg et al., 2007), patient factors (Zoffmann et al., 2008), education and training (P. M. Moore et al., 2013), and organisational and work-related issues (Girgis et al., 2009). These challenges have been explored across health professionals generally (Bhutani et al., 2012) and within oncology settings (Girgis et al., 2009), including recent studies demonstrating the additional strain of the COVID-19 pandemic, which has contributed to accumulating caseloads, delayed surgeries (Lee et al., 2020), increased personal risk (Kowalski et al., 2020) and greater prevalence of vicarious trauma (Shuman & Campbell, 2020), burnout, anxiety and distress among health professionals working with people diagnosed with HNC (Civantos et al., 2020).

The provision of complex cancer care can have negative effects on health professionals, including psychiatric morbidity, compassion fatigue and burnout (Boyle, 2015; Eelen et al., 2014; Figley, 2002). Compassion fatigue has been conceptualised as comprising secondary traumatic stress and burnout (Martin, 2018). Secondary traumatic stress has been described as stress brought on by working in settings where exposure to traumatic situations or events is common (Canfield, 2005). Burnout refers to the erosion of the physical and psychological wellbeing of professionals as a result of an overly taxing work environment, and it can be experienced by both frontline and support staff in health settings (Eelen et al., 2014). The hallmarks of professional burnout are emotional exhaustion, cynicism and depersonalisation, and a feeling of inefficacy in the role (Maslach, 2012). This is highly relevant to the oncology workforce, whereby clinical implications of burnout include increased risk of medical errors, higher staff turnover and subsequent loss of talent and knowledge, and decreased quality of patient care and satisfaction (Trufelli et al., 2008; Wu et al., 2016). Episodes of burnout adversely affect health professionals both personally and professionally.

Health professionals are more susceptible to burnout than people in the general working population, where 13–27% of people report burnout, and while estimates vary across disciplines, up to 70% of physicians report burnout (Lamothe et al., 2014). Earlier studies report high levels of burnout and psychological distress for oncology clinicians, with 56% of US oncologists reporting at least one episode of burnout (Whippen & Canellos, 1991). A study conducted in Belgium of 550 health professionals of varied disciplines found that oncology staff suffered more symptoms of burnout than other health professionals, with medical oncologists most affected. Of the medical oncologists surveyed, 51% experienced emotional exhaustion, 31.8% suffered from depersonalisation, and just 6.8% reported a lack of job satisfaction (Eelen et al., 2014). Thirty-five per cent of young (under 40 years) radiation oncologists in Italy (n=112) had experienced burnout (Ciammella et al., 2013).

Japanese physicians engaged in end-of-life care of cancer patients (n=697) had also experienced high rates of burnout, with 22% experiencing emotional exhaustion, 11% depersonalisation and 62% low personal and professional accomplishment (Asai et al., 2007a). Recognised predictors of burnout include high workload (Grunfeld et al., 2000; Ramirez et al., 1996), perceived need for communication skills training (Asai et al., 2007a; Fallowfield et al., 2002; Messerotti et al., 2020), perceived need for stress-management skills (Blanchard et al., 2010) and perceived interference of work on home life (Blanchard et al., 2010; Kleiner & Wallace, 2017). Previous studies have explored burnout in oncology generally and found that it can result in decreased work–life balance (Shanafelt et al., 2014) and may also affect mental health and wellbeing (Asai et al., 2007b; Rath et al., 2015). In one of the only HNC-specific studies on burnout, Contag et al. found that for surgeons who perform complex flap surgeries for HNC patients, 75% had moderate to high burnout (n=60) (Contag et al., 2010). There is a lack of research focusing on health professionals working with people with HNC specifically yet supporting HNC patients is particularly challenging for health professionals because of their complex needs.

2.7 Interventions for health professionals

Cancer diagnoses and treatments are stressful and potentially traumatic for health professionals as well as for patients (Gieseler et al., 2018), and the risk of burnout in oncology workforces has been found to be high (Eelen et al., 2014; Girgis et al., 2009). One way to address health professionals' needs is to provide communication skills training (De Vries et al., 2014). This approach has been used in oncology to improve patient education and support (Longacre et al., 2015). A systematic review of communication skills training programs found that they improve health professionals' communication skills in terms of conducting psychological assessments and interviews, and they improve their attitude towards communicating with patients and their confidence in their ability to communicate effectively with patients (Gysels et al., 2004). Communication skills training has a positive effect on communication between health professionals and patients (Butow et al., 2008; Kissane et al., 2012) and can lead to integration of effective communication skills into clinical practice (Back et al., 2007). Eliciting and responding to emotional cues has been found to be useful for oncologists in terms of improving empathy and communicating bad news. Two recent systematic reviews showed that training that focuses specifically on responding to patients' emotions and needs improves the quality of their communication and may improve patient outcomes (De Vries et al., 2014; Moore et al., 2013).

Halkett et al. (Halkett et al., 2016; Halkett et al., 2013; Halkett et al., 2012) demonstrated that patient anxiety was significantly reduced when radiation therapists were trained in communication skills and strategies to reduce patient pre-treatment anxiety. Similarly, Aranda et al. (Aranda et al., 2012) demonstrated that nurses were able to reduce pre-treatment anxiety when they provided patients with a pre-chemotherapy education intervention. Interventions that may decrease the risk of burnout include communication skills training for hospital social workers (n=25), where, following training, personal accomplishment rose by 12.39% and depersonalisation fell by 29.75% (Cohen & Gagin, 2005). Communication skills training has been found acceptable by radiation therapists (Halkett et al., 2016; Merckaert et al., 2015), oncologists (Fallowfield et al., 2002), surgeons

(Lebares et al., 2020) and nurses (Darban et al., 2016). Trauma-sensitive training for social workers and mental healthcare providers has shown significant improvements in compassion satisfaction (Butler et al., 2017; Vermilyea, 2014). Kuehn et al. found that trauma-informed care may decrease patient fear, increase patient trust in health professionals and reduce health professional burnout (Kuehn, 2020).

Mindfulness-based interventions are the most common and have been found to be effective in improving mental wellbeing, with mixed results in reducing factors associated with burnout (Amutio-Kareaga et al., 2017; Duarte & Pinto-Gouveia, 2016; Kinnunen et al., 2019; Ofei-Dodoo et al., 2020; Slatyer et al., 2017). Mindfulness that includes compassion has been shown to improve physician–patient communication in health settings (Amutio-Kareaga et al., 2017). Compassion-based interventions commonly emphasise self-compassion, and studies suggest that self-compassion is a promising construct for psychologists in terms of the ability to promote psychological wellbeing and stress resilience (Finlay-Jones et al., 2015). A recent evaluation of compassion-based interventions for palliative care professionals showed benefits such as decreased anxiety, decreased compassion fatigue, increased self-compassion and increased compassion satisfaction (Watts et al., 2021). The emergence of literature on compassion in healthcare points to a shift in understanding which integrates the needs of health professionals and their patients, whereby caregiving benefits the provider as well as the patient (Cameron et al., 2015; Epstein & Privitera, 2016). Focus groups and interviews with 11 oncology nurses found that communication skills training was not considered effective, and nurses felt deficient in their ability to manage strong emotions (Chan et al., 2019). Communication skills training often includes responding to patients with empathy (Pehrson et al., 2016) and simulating having difficult conversations around death and dying (Banerjee et al., 2017); however, there remain gaps in understanding relating to health professional burnout, patients' preparation for altered appearance and functional loss.

2.8 Conclusion

HNC diagnosis, treatment and rehabilitation brings with it multiple, overlapping unmet needs, particularly in the domains of distress, anxiety and depression related to altered body image and function. Late and lasting effects are challenging for survivors to adapt to, and issues typically continue for the long term beyond the end of treatment. Psychosocial interventions that have proven effective in other cancer types have not yet been extensively trialled in the HNC population. Health professionals who work with people with HNC also face numerous challenges and are at risk of compassion fatigue and burnout. Communication skills training for health professionals has been shown to lower patient distress and improve health professionals' resilience in other cancer types and in distinct disciplines. Many discipline-specific studies have investigated interventions to address the functional effects of HNC, but there is a paucity of holistic, psychosocial interventions that address patient needs. Questions remain about the efficacy and timing of interventions for both health professionals and people treated for HNC. Thus, there is a need for rich data to inform future pre-treatment preparation, health professionals' resilience, and survivorship interventions specific to the needs of people affected by HNC.

Chapter 3: Methodology

3.1 Introduction

The aim of this study was to explore the experiences of people diagnosed with HNC, and the health professionals who care for them. The research questions were:

a) What are the psychosocial experiences of patients with head and neck cancer?
b) What are the experiences of health professionals who work with head and neck cancer patients?

Semi-structured interviews were conducted with a total of 42 participants using an exploratory qualitative interpretive research design, as well as a social constructionist interpretive framework designed to understand the social and psychological experience of HNC from both patient/survivor and health professional perspectives (Holliday, 2007). Interviews were conducted with 21 health professionals from different disciplines who were working in a range of settings, as well as 21 adults who had been diagnosed with, and treated for, HNC in Australia within the previous six years. This chapter seeks to explain the positioning of the research in terms of ontology, epistemology, theoretical perspective and methodology (Crotty, 1998) (see Figure 3.1).

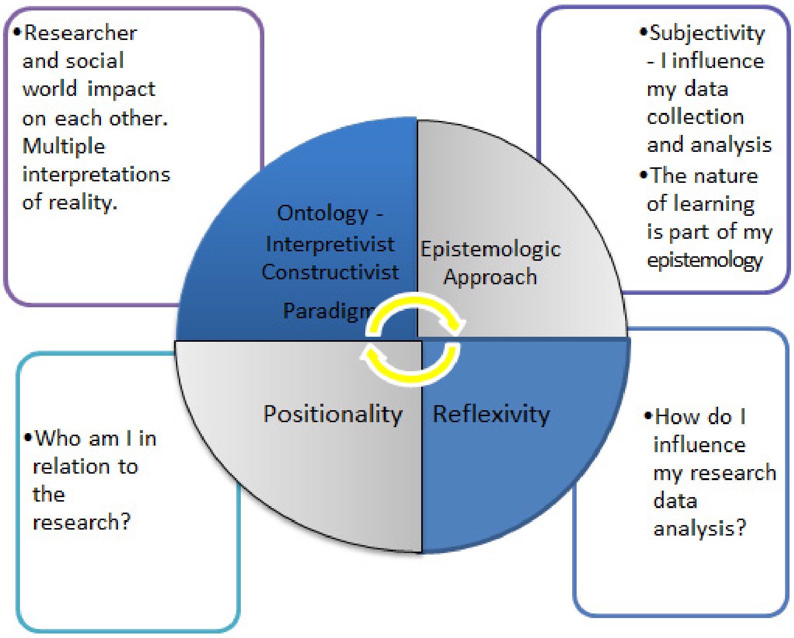

Figure 3.1. Relationships between ontology, epistemology, positionality and reflexivity in the social constructionist research paradigm in the present study.

3.2 Ontology

Ontology is the philosophical study of being; it describes what can be known and what we believe can exist (Berryman, 2019). It is the metaphysical science of what is, and it studies concepts such as existence, being, becoming and reality in order to answer questions, including what exists and how to group different entities within existence. Ontology is a system of beliefs that reflects an interpretation by an individual or group about what constitutes reality (Heidegger, 1999). Ontology helps researchers recognise how certain they can be about the nature and existence of what they are researching. For example, in this study, the use of a reflexive diary enabled the researcher to interrogate internal bias and challenge assumptions. It sits alongside epistemology in informing the theoretical perspective of this study, which seeks to understand what is (ontology) and what it means to know (epistemology) in relation to the needs of people diagnosed with HNC, and the health professionals who care for them (Crotty, 1998).

Since the sixteenth century, Western medicine and science has focused on the material world, a physicalist ontology that touted that reality could only consist of measurable, physical matter (Bolton, 2019). Health was necessarily reduced to biochemistry, and by the seventeenth century was inclusive of physics as an explanatory framework for disease. This gave rise to Cartesian dualism, which continues to be the dominant paradigm in biomedicine, despite the challenges posed by evolutionary biology and developmental embryology since the late 1600s (Adler, 2009). Vitalism, which is the theory that the origin and phenomena of life are dependent on a force or principle distinct from purely chemical or physical forces (Coulter et al., 2019), arose in contrast to physicalism, creating a duality between accepted causal sciences and so-called pseudo-sciences. As the field of psychology developed, efforts were made to ground psychological science in biology and chemistry in order to give it credibility. Engels' biopsychosocial model of health was an ontological leap forward (Engel, 1977) that upended Cartesian dualistic assumptions and heralded a new era of hermeneutics.

There are four categories of ontology—object, kind, mode and attribute—and the main ontological debate has been between realists and idealists—that is, positivist or interpretivist paradigms (Berryman, 2019; Crotty, 1998). The ontology of realism holds that the world, including all things natural and social, possesses qualities independent of ideas, and these things can be empirically measured. In contrast, idealism holds that we have access to knowledge only through our ideas and subjective experience (Bourgeault et al., 2010). In this study, interview data are collected and analysed through an interpretivist–constructivist paradigm.

The subjectivity of the researcher and their interactions with the world are acknowledged when seen through interpretivist–constructivist paradigms. Knowledge is constructed with participants by building strong connections between our individual and shared being and constructions of reality (Trauger & Fluri, 2014). This meaning-making process does not happen in isolation: there is a social origin of meaning whereby basic assumptions about cancer are shared, and then differing perspectives and ways of communicating illuminate these shared and distinct understandings (Fish, 2013).

3.3 Epistemology

Epistemology is the theory of knowledge, especially with regard to its methods, validity and scope, and the distinction between justified belief and opinion. Epistemology concerns the nature of knowledge and the way knowledge is attained (Depoy & Gitlin, 2016). In most forms of qualitative research, the worldview of the researcher is considered, to some extent, as a perspective that acknowledges that rather than a deductive process, naturalistic inquiry involves inductive processes of reasoning. Qualitative research starts with a specific situation—in this case, the experiences of people diagnosed with and treated for HNC—and seeks to identify patterns that illuminate a broader (non-deductive) understanding of the phenomenon or circumstance being studied.

The three major epistemologies are objectivism, subjectivism and constructionism (Crotty, 1998). Objectivism is a view of the world that is quantifiable, measurable and, while useful, does not include the rich and varied experiences of people's everyday lives (Nightingale & Cromby, 2002). Subjectivism is the opposite of objectivism and centres on meanings made by the interpretation of individuals. Constructionism brings together objectivity and subjectivity and mirrors the concept of intentionality. Intentionality, as described by Brentano (Brentano, 1973), is when the mind becomes conscious of something the person feels that they know, and they reach out to attend to that object. In contrast to other epistemologies of the nineteenth century, intentionality describes an intimate, intertwined relationship between the knower (researcher) and the known (people diagnosed with HNC and the health professionals who care for them). Constructionism teaches that meaning is always both objective and subjective (Crotty, 1998); hence, social constructionism was the methodology adopted for this study.

Epistemology has multiple terms for similar concepts, and different authors have been known to use terms interchangeably, which may cause confusion. The terms 'social constructionism' and 'social constructivism' are one such example. Social constructivism is a thread of cognitive constructivism that emphasises the collaborative nature of much learning. Social constructivism was developed by post-revolutionary Soviet psychologist Lev Vygotsky (Vygotsky, 1962), whose theory of social learning has been expanded upon by numerous theorists and researchers. Crotty suggested that it would be useful to reserve the term 'constructivism' for epistemological considerations focused on the meaning-making activity of the individual mind, and 'constructionism' for when the focus includes the collective generation (and transmission) of meaning (Crotty, 1998). Based on these definitions, the methodology used in this study is social constructionism. This viewpoint of constructionism was taken because the constructed meanings of people with HNC, and how they understand their world, are central to understanding the experience and needs of people with HNC. Equally, the constructed meanings of how health professionals understand their work with people with HNC provide an understanding that can be combined with insights gleaned from the constructed meanings of patients to inform future training for health professionals who care for people with HNC.

The research methodology of social constructionism is appropriate for this qualitative study because it acknowledges the researcher as having had surgery experiences similar to the study participants, which rendered her neither insider nor outsider but somewhere in between—a position of being 'insider-ish' (Gibson, 2020). At the outset of the research, the lead researcher had experience as a health professional and cancer services director, and limited experience as a patient. During the data collection phase, I (the researcher) was diagnosed with recurrent basal cell carcinomas and required a cervico-facial flap surgery—a treatment similar to that experienced by people with HNC. This change in perspective meant that the researcher was not able to stay completely neutral as an outside observer, as one (arguably) might in positivist, quantitative empirical research, where researchers can measure testable propositions with instruments that extend the reach of the five physical senses. Instead, in qualitative research such as this, the researcher and the participants, including people diagnosed with HNC and oncology and supportive care health professionals, are socially co-constructing the meaning of HNC. Research of this type is more like a collaborative dance where subject and object blur.

Hence, social constructionism is a suitable methodology for seeking to understand patients' cancer experiences and the gaps in the services provided to them, as well as the experiences of health professionals. Participants and the lead researcher live in a society where cancer and its effects are somewhat understood; however, outsiders to the experience may hold rigid or false beliefs and cannot understand the experiences of those being diagnosed, treated or working with people with HNC. Participants in this study who had experience with HNC personally or professionally shared their insider knowledge generously, seemingly without censorship. This provided rich data that enabled us to identify common themes and develop a detailed understanding of the experience.

3.4 Social constructionism

Constructionism is the theory that all knowledge is contingent upon human practices, and that knowledge is being constructed through interactions between human beings and their world in an essentially social context (Nightingale & Cromby, 2002). This theory goes beyond the material science of objectivism and allows for a space of 'not knowing', which is needed when conducting semi-structured interviews. This approach allows participants—in this case, health professionals and people diagnosed with HNC—to share their subjective truths. As Merleau-Ponty noted, meaning is made by human interaction, and there is no meaning without mind (Merleau-Ponty, 1962). Thus, the interviews seek to understand and articulate the inner experience of having or treating HNC. The use of thematic analysis allowed a socially constructed reality to emerge from the 42 interview transcripts. The six-step process of thematic analysis provided a rigorous yet flexible structure and interpretive lens from which to derive meaning from the data. The participants' language and stories expressed their diverse backgrounds and experiences; yet by using thematic analysis, it became clear that, regardless of the language used, individual meaning-making processes were shared experiences that had been co-constructed in various settings, influenced by the hegemonic culture and participants' own subcultures.

A review of the social constructionism literature reveals different orientations, as evidenced in the various research concerns, designs, methods and ways of theorising of scholars (Cunliffe, 2008). The origins of social constructionism can be traced back to a number of intellectual traditions, notably sociology, social philosophy and the sociology of knowledge. The first basic thesis of the social constructionist point of view is Vygotsky's idea that individual psychological skills and capacities are derived from participation in collective psychological phenomena (Vygotsky, 1962). Given that social practices are culturally and historically diverse, there are local variations in such individual skills. As Wittgenstein (Wittgenstein, 1953) highlighted, there is a human form of life; however, there are various tribal variations on it. Wittgenstein emphasised that a person is necessarily embodied, although the forms of embodiment that are regarded as acceptable vary widely.

Sociologically based work emphasises the experiential nature of reality. For example, Garfinkel (Garfinkel, 1967) believed that a sense of the real is a practical accomplishment achieved through the contextual, embodied, ongoing interpretive work of people. This orientation often focuses on the context in which the interaction takes place, as well as the interaction itself. Within social philosophy, Schutz (Schutz, 1970) focused on the life-world, proposing that our personal experiences are shaped by social interaction and taken-for-granted uses of language. He later worked with Thomas Luckmann (Schutz & Luckmann, 1973) to explore the implications of such a position for knowledge. A third root—the acknowledged origin of social constructionism—lies in the sociology of knowledge, from which emerged Berger and Luckmann's influential book *The Social Construction of Reality* (Berger, 1966). Berger and Luckmann proposed that society exists as both an objective and subjective reality and argued that our social world can be understood as a dialectical process of externalisation, objectivation and internalisation—that is, "Society is a human product. Society is an objective reality. Man is a social product" (p. 61). They argued that the social world is humanly produced in ongoing activity and routines (externalisation), yet it is experienced as being objective in that it affects our lives on an ongoing basis, and we have to go out and learn about it (objectivation). We are socialised in the world as we interpret meanings of events and others' subjectivities, and in doing so we take on the world, the identity of others and therefore our own place and identity (internalisation). Berger and Luckmann (Berger, 1966) believed that it is when we become conscious of our identity as a "generalised other" that we are "an effective member of society and in subjective possession of a self and a world" (p. 137). From this perspective, knowledge is socially constructed, and facts are social products.

Constructionism is not purely subjective; it considers the object important and it is not arbitrarily imagined meaning, rather constructionism is a thorough exploration leading to an understanding of the meanings conveyed. However, critics suggest that to understand the other person in such intimacy must require leaps of imagination, thereby creating the risk of psychological transference or misunderstanding as a result of unexamined bias. It is useful to accept that there must be some creativity in interviewing and interpreting interview transcripts, but there is also an exactness that comes from focusing on the object with unbiased/nonjudgmental attention (mindful listening) (Nicholls, 2019). Theodor Adorno called this process "exact fantasy" (p. 21) (Cook, 2014).

3.5 Criticisms of social constructionism and researcher reflexivity

A common criticism levelled at social constructionist qualitative research is that it centres the researcher too much, moving the methodology towards auto-ethnography. Burr argued that a major weakness of social constructionism is that it effectively negates the work of mainstream psychology as a study of the experience and subjectivity of persons, referred to as the 'death of the subject' (Burr, 2015). Hence, to maintain focus on the participants (the subject), the researcher used reflexive practices (Clarke & Braun, 2017a) such as keeping a self-reflexive journal in the form of private notes, public social media posts and public vlogs (reflective videos published to social media platforms Instagram and Facebook), plus teaching and speaking publicly about the research, being in therapy, and prompting discussions among the research team to identify bias, centre the evidence provided by the participants, and acknowledge and then decentre the researcher's personal experiences. Throughout this study, the student researcher documented and shared personal reflections on the PhD journey privately and publicly, particularly when her own cancer experiences challenged her to reflect on objectivity. The researcher became skilful at switching from an internal to external focus, and from subject to object. Public blogging and vlogging enabled the researcher to centre her own experience for one audience, while simultaneously centring the experience of participants when writing peer-reviewed journal article manuscripts. For example, this video, published to Facebook on 15 November 2018, was a personal reflection on recovery from surgery and shared insights into manuscript development and conference presentation experiences. The vlog was viewed 584 times and received comments and engagement from 57 social media followers. This was a helpful reflexive technique for disentangling the personal from the professional, while also disseminating de-identified research findings to a lay audience.

Practicing mindful self-compassion (Neff et al., 2018) was important to attend to personal suffering, self-regulate emotions and make space for immersion in the stories of HNC survivors and health professionals who shared their suffering. The value of the insider perspective includes understanding just how deep the trauma can be, and having felt something akin to what participants felt became a strength in conveying compassion during interviews and creating psychologically safe interview dynamics (Breen, 2007.). At times, this inner work by the researcher slowed progress, and it was a breakthrough to realise in therapy that what may appear as procrastination is actually a deep and difficult healing process (Asselin, 2003). This process clearly identified the compassionate position taken by the researcher, and likely had a positive effect on the experience of the interview participants—particularly people with HNC who recognised inauthentic expressions of sympathy, empathy and compassion from health professionals and others (Gibson et al., 2022).

3.6 Positionality

Feminist geographers and others have long argued that researcher subjectivity is always affected by the experience of being involved in the research process (Gibson-Graham, 1994; Moss, 2002; Rose, 1997; Trauger & Fluri, 2014). Creating a social location somewhere between subjectivity and objectivity with research participants, or what is called 'intersubjectivity', is a strategy promoted by feminist geographers to subvert the God trick (McDowell, 1999), which refers to the convention in research of trying to distance oneself from the process to maintain a semblance of objectivity. Relocating the subjectivity of the researcher thus expands traditional notions of objectivity in research and makes an important claim to the partiality of knowledge. Intersubjectivity supports sharing power between the researcher and participants because it circumvents the Marxist power imbalance, whereby the socially dominant cultural power holder tends to dictate the outcomes of research through a dominant communication style and underlying assumptions of power ("The SAGE Encyclopedia of Communication Research Methods," 2017). This non-hierarchical communication model fosters trust and empowers participants to speak freely. Conversational interviews, such as those in this study, integrate multiple dynamic and sometimes contradictory worldviews (Burgess-Limerick & Burgess-Limerick, 1998). Disengaging with the binary structure of subjects and objects also acknowledges that knowledge can be constructed through building affinity with research participants. Within the communal construction of knowledge in this study lies a search for meaning rather than absolute truth (Gergen, 2001). However, this strategy is not without its problems, because it leaves the researcher open to the criticism of being too close to the subject and therefore unable to be objective (Denzin, 2017).

In this research, 95% of participants with HNC were culturally similar to the researcher, who identifies as a Caucasian, cisgender Australian woman, and they shared some of their experiences of medical treatments to the head and neck region. There was more cultural diversity among the health professionals; however, the shared culture of education in health sciences between the researcher and health professionals allowed for numerous assumptions and generally shared language of “a system of significant symbols” (Geertz, 1973).

It is also relevant to note that I, as the researcher, have an unconventional academic background. I graduated in 2000 with an Advanced Diploma in Applied Science (Naturopathy), trained as a Yoga teacher in 2005, undertook a Masters’ degree program at RMIT University from 2010 to 2012, and became a certified Yoga Therapist (C-IAYT) in 2016. The philosophical underpinnings of my worldview are Eastern and holistic, informed by both the dualism of Samkhya Philosophy, which has parallels to Cartesian dualism, and the monism of Advaita Vedanta (Kaplan, 2009; Rambachan, 1987). As an evidence-based complementary therapist, I have respect for biomedicine and the rigour of evidence-based health sciences, while maintaining an integrative, biopsychosocial, person-centred approach to practice.

3.7 Theoretical perspective

A theoretical perspective is a concept or philosophy that is used to inform and position the research (Crotty, 1998). This research project involved interpreting and making meaning of the experiences of people diagnosed and treated for HNC, and the health professionals who care for them, by exploring the constructed meanings of their world and how they have come to find meaning in their cancer-related experiences. This interpretivist position is considered appropriate within the epistemology of social constructionism, where meaning is co-constructed by people interpreting the events of their lives in a collaborative discourse with others (Burr, 2015; Crotty, 1998).

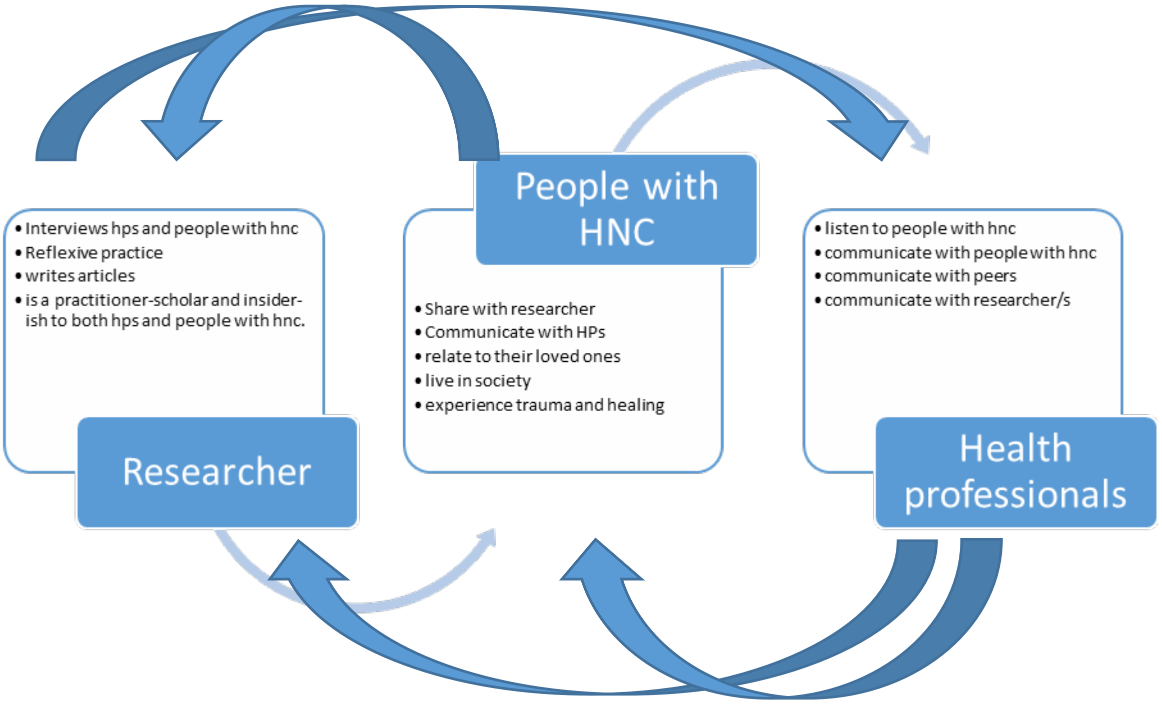

Figure 3.2. Social constructionism in qualitative research—how meaning-making happens as a co-constructed process between the subjects and the researcher.

While social constructionism forms the overarching theoretical framework of this study, there are several content theories that align with the epistemological position and assist with understanding the data. The interdisciplinary perspective allows the researcher to view and interpret the findings through different theoretical lenses that are integrated to advance the literature on psychosocial education, provide support for people diagnosed with HNC, and inform the future training of the health professionals who care for them. The integrated theories include social representations theory (SRT), Mead's symbolic interactionism and embodiment theory, particularly Merleau-Ponty's perspective on embodiment.

3.7.1 Social representations theory (SRT)

SRT is a theory of social knowledge that is specifically concerned with how individuals, groups and communities collectively make sense of socially relevant or problematic issues, ideas and practices (Markova, 2008). SRT suggests that mental activity is fundamentally and intrinsically rooted in the body's interaction with the outer world (O'Connor, 2017). Social representations (SRs) are systems of communication and social influence that constitute the social realities of different groups in society. They serve as the principal means for establishing and extending the shared knowledge, common practices and affiliations that bind social members together (Duveen, 2008; Moscovici, 2001) and thereby act to support systems of identity, community, inclusion and exclusion. Therefore, SRs are depicted as both the process and the result of social construction.

The concept of SR was developed by Serge Moscovici in 1961 as a social psychological approach that merged individual thinking and feeling with collective interaction and communication (Moscovici, 2001). SRs are conceived as symbolic forms that come about through interpersonal and media communication. They are the ways individuals think, interact with others and shape social objects in their interaction with the local world. SRT can be considered a more *societal* social psychology because the object of the discipline is the study of the inherent conflict between, and the mutual constitution of, the social and the individual (Moscovici, 2001). SRT (Antaki, 1991) has contributed to the development of this more *societal* social psychology and constitutes an epistemological turning point in the discipline (Abreu Lopes & Gaskell, 2015). It primarily examines social knowledge and practices, how they are constructed, and how they evolve when moving from one lifeworld to another. This is highly relevant to survivors of HNC—especially those who experience altered appearance—because their self-concepts are deeply affected as they move from pre-diagnosis into the role of patient, and then post-treatment, where they face multifactorial psychosocial issues of survivorship.

By situating the processes of knowledge and belief transformation in the *social setting of communication*, Moscovici called for a holistic approach to the phenomenon under study, and used observational methods rather than an experimental method, with the latter only enabling partial analysis of some specific elements of knowledge transformation. Moscovici was concerned with issues of validity and the shortcomings of observations, underlining the lack of *technical* solutions to explore the processes by which humans construct their everyday knowledge and beliefs. He believed that the limits of observational methods (e.g. interviews, surveys, media analyses) could be overcome by conducting comparisons with other similar studies or by confirmation through experimentation (Moscovici & Marková, 1998). Finally, this research enabled Moscovici to draw up some of the general principles that characterise everyday knowledge and common sense—principles that still guide and inspire social psychologists in this field today.

Reflecting the work of Herzlich (Herzlich, 2018) and other social researchers, this study adopted an interdisciplinary approach, used exclusively qualitative methods and borrowed methods from sociology and anthropology. This style of research does not use questionnaires, scales, or statistical analyses. It recognises that, while sophisticated methods may be considered more professionally respectable by some, they have been less well adapted to the object of their inquiry and therefore make a less genuine contribution to the progress of science (Herzlich, 1973). Denzin (Denzin, 1970, 2017) developed the idea that every research method is a type of symbolic interaction (including experimental methods); therefore, they should be analysed as an observational encounter. This is highly relevant to this study, in which meanings were co-constructed from interview data whereby two social interactants—the observer and the observed—meet in a specific situation during a time sequence and develop a relationship, such as the researcher and the interview subject. Echoing Moscovici's theory, each research method creates, to a certain extent, a specific *social setting of communication*. All the elements of this encounter introduce potentially distorting factors that the researcher needs to be aware of; hence, SRT as a theoretical framework provides important scaffolding to the study.

3.7.2 Mead's symbolic interactionism and the sociology of the body

Symbolic interactionism is derived from pragmatic writers including John Dewey, William James, Charles Peirce, Charles Cooley and George Herbert Mead, whose work shaped the argument that the body is more than a complicated machine or a tangible, corporeal object (Waskul & Vannini, 2016). The authors shared the perspective that the body is of great significance to both the individual and society, and there is an interrelated, constantly reconfiguring dance between the body, the self and society (Waskul & Vannini, 2016). This plays out in this study in interview interactions between the researcher and the participants (i.e. the people with HNC and the health professionals). Symbolic interactionism can be a strong analytical tool for deepening insights when applied as a theoretical framework for understanding participant and researcher perspectives. The framework provided by symbolic interactionism is used to understand participants' biographical experiences and contextualise changes to the physical body in a psychosocial milieu from which themes emerge (Klunklin & Greenwood, 2006).

A social constructionist approach to illness is rooted in the widely recognised conceptual distinction between disease (the biological condition) and illness (the social meaning of the condition) (Eisenberg, 1977), including how these constructions relate to the society and culture that shape them (Conrad & Barker, 2010). In modern society, health is constructed as the normal state, and diseases such as HNC are seen as a deviation from the norm (Conrad & Barker, 2010). The role of biomedicine is to treat diseases such as cancer and return people to their "normal" condition. Cancer is socially constructed through metaphors, images and analogies that have been entrenched for centuries (Mukherjee, 2011), such as cancer treatment as a war, wherein health professionals are "heroes" and patients are "victims" (Marron et al., 2020).

A well-recognised power imbalance plays out in the dynamic between health professionals and patients who embody health and illness respectively (Berry et al., 2017). The ill body with HNC, visibly altered by surgery and radiotherapy, is easily "othered" by the healthy world, especially for over-worked, under-resourced health professionals who often depersonalise their patients as a survival mechanism (Kushner, 2003). Through this dance and deflection between people with HNC and the health professionals who care for them, bio-power is expressed as a subtle, constant and ubiquitous power over life. Foucault referred to this power imbalance as the "anatomo-politics of the human body" (Petersen & Bunton, 1997).

In contrast to the modern ideal of a biopsychosocial model of health, anatomo-politics, or biopower, focuses on the body as a machine (Bolton, 2019). Foucault identified docility and usefulness as ways to integrate the body into economic and social life (Petersen & Bunton, 1997). To achieve this, the operation of disciplinary power pervades relations in families, schools, hospitals and work. In the case of medicine, the effect of discipline is for the therapeutic space to become a political space. Individuality has been constructed based on symptoms, disease and lifestyle, and control over these processes is at the core of medical care (Petersen & Bunton, 1997).

In this study, there was a relationship between the SRs of cancer that people with HNC experienced and the role that health professionals played, whereby the healthy bodies of health professionals held power over the sick and altered bodies of people with HNC. The lens of social interactionism was used to understand the impact of treatment on physical function (Coleman-Fountain & McLaughlin, 2012; Waskul & Vannini, 2016). O'Connor argued that incorporating concepts gleaned from embodiment research may facilitate a more comprehensive account of the aetiology of SRs (O'Connor, 2017).

3.7.3 Embodiment philosophy

Historically, social constructionism has attracted criticism from feminist philosophers who have considered it lacking in terms of embodiment (McVee et al., 2021). Feeling and emotion are conspicuously absent from much of the constructivist and social constructionist literature. Both strands of literature tend to focus on construction as a conceptual (i.e. disembodied) activity that is primarily done cognitively and linguistically (Nightingale & Cromby, 2002). This oversight partly prompted John Cromby and colleagues to critique social constructionists in an influential volume of work as the previous millennium was ending (Strong, 2017). However, Harre (Harre, 1995, 2000; Harré, 2002) and others (McVee et al., 2021) have begun to reconcile social constructionism with embodiment, effectively integrating mind with body and overturning Cartesian dualism.

The body is the ground or zero-point of sense perception and motor skills: it is the centre from which experience radiates outwards (Gili et al., 2017; Harre, 1995). Embodiment is not a theory per se, but a philosophy originating from Merleau-Ponty's phenomenology. According to this philosophy, embodiment is the experience of living in the world through our bodies. For Merleau-Ponty, the body is both the point of departure and the point of return in this journey of self-discovery; he contends that it is a "subject destined to the world"; it is the *subject* that takes up a *point of view* of the world within the perceptual and practical field; and pivotally, it is *embodiment*, which forms the very basis of perception (Merleau-Ponty, 1962). This philosophy directly contrasts with Cartesian dualism, the view of the mind and body as separate entities (Maurice, 2013).

Social constructionism epistemology assumes that the body is part of the social world, carrying the symbols of social structures within it through both appearance and function (Turner, 1992). The body is understood as contested territory in social constructionism, where it can be situated as a site of power and knowledge imbalance between patients and health professionals (Fuller & Loogma, 2009; Turner, 1995). This perspective speaks directly to the experiences of people with HNC in this study who described feeling disempowered and silenced by the biomedical model and its cultural norms. The contested territory of the body may arise in part from Foucault's concept of the medical gaze, which seeks to reduce the body to its pathologised parts (Petersen & Bunton, 1997). Busfield (Busfield, 2017) and others have critiqued the medical sociology concept of medicalisation as being too negative towards biomedicine. It should be noted that the participants in this study were roundly grateful for the technical advances of biomedicine, but also felt dehumanised at times by the mechanistic nature of the care provided.

3.8 Conclusion

The primary lens through which this study has been conducted is that of social constructionism. Aligned with the qualitative, interpretivist, constructionist philosophical underpinnings of this study are the content theories of embodiment inclusive of SRT and symbolic interactionism. Together, these theories give structure to the methodology of semi-structured interviews and thematic analysis that has led to the findings in this study. The co-construction of realities between researcher and participants, and between health professionals and people with HNC, is an intricate dance of communication that has been interpreted through transcripts of spoken words yet carries the weight of communication between embodied humans who bring with them to each interaction their own lifeworlds. As far as practically possible, the researcher has endeavoured to be rigorous and to objectively observe all the realities expressed in order to find the relative truth of participants' realities, while acknowledging her own role in the co-construction of those realities.

The researcher used repeated engagement with the data to familiarise herself as deeply as possible. Following each interview, the researcher reflected and then made notes that informed the debriefing and thematic discussions with the research team. This reflects Levi-Strauss's assertion that the bricoleur is in a dialogue with the materials, interrogating all of the heterogeneous objects and indexing their possible uses (Lévi-Strauss, 1972). In this way, thematic analysis and coding are as scientific as any method(ology), and simultaneously an artform that acknowledges the whole person, who thinks, feels, perceives and makes meaning in a creative process. Research in a constructivist vein, in the mode of the bricoleur, requires not remaining straightjacketed by the conveyed meanings we have been taught to associate with the object. We are invited to approach the object in a radical spirit of openness to its potential for new or richer meaning (Crotty, 1998). In stepping into participants' worlds so deeply, the researcher felt very close to the participants, deepening her understanding with every re-reading of their transcripts. This experience reflects that which Adorno calls the "mimetic moment" of knowledge—affinity with the object (Adorno, 2005). Thus, as Crotty says, constructionism is not subjectivism (Crotty, 1998). It is curiosity not conceit.

3.9 Reflective Discussion Paper

In this discussion paper, the researcher described their experience of undergoing treatment for skin cancer which is similar to the treatments people with HNC undergo.

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Discussion

Seer and seen: Becoming insider-ish in research

Chandrika Gibson

School of Nursing, Midwifery & Paramedicine, Curtin University, Perth, Australia

As a cancer researcher, I try to get as close to people affected by cancer as I can – by reading as much literature as possible, interviewing health professionals, and talking and listening to people with lived experience. As my understanding of cancer and all its impacts has deepened, I have experienced shifts in perspective, from deep empathy and compassion, to distance, academic rigour, and objectivity. Occasionally as part of the research experience, I find myself closer to the person than I imagined. Sometimes that's because of dual relationships that blur professional boundaries, sometimes it's because someone I know personally has a diagnosis or, as in my recent experience, it's because I have been through something similar to what the people I study endure.

Studying and supporting people diagnosed with cancer developed into a passion after both of my parents suffered from the disease. Yoga is central to my lifestyle, and I started as a yoga and meditation teacher for cancer patients and carers, uniting my passions of eastern philosophy and cancer support. In my work as a researcher, my position is that of an outsider, 'parachuting in' to observe and support participants. When I began looking at the experiences of people with head and neck cancer, I didn't know much about this particular tumour group or have personal experience to draw on. I could not have guessed how closely my experience would come to resemble some of theirs. However, I had some brushes with non-melanoma skin cancer in my twenties, and then melanoma at 30. In the subsequent twelve years I've had numerous basal cell carcinomas removed, many off my face and neck. This is not classified as head and neck cancer and I didn't draw any connection when I was fortunate to be offered a scholarship to do a PhD in psychosocial education and support for people with head and neck cancer. Because my diagnosis is different, I was not an 'insider' to the group I am studying. However, when the next line of treatment for my recurring skin cancers was proposed (a cheek replacement, technically known as a cervico-facial flap), my experience became more similar to patients with head and neck cancer, some of whom undergo this type of surgery.

As the date for surgery drew nearer, my anxiety increased. I wondered how painful and disfiguring surgery would be. I catastrophized about losing my livelihood as a yoga teacher, and being shunned by peers. I didn't want to see graphic images or read the technicalities of how surgery would be done. I wanted to read about someone's lived experience and have them walk me through the experiences, perhaps with some hints about how best to cope during recovery. Most of all I wanted reassurance that looks really don't matter, and that living with facial disfigurement is possible, and can be rich and wonderful.

The first mention from my surgeon of a 'cheek replacement' was a year earlier. I'd avoided thinking about this reality, until the topic of avoidance came up while participating in a workshop. Consciously recognising my avoidance, making an appointment with the plastic surgeon and checking into hospital all happened within six weeks.

Each day after surgery I took a photo of myself. This helped me to see what was happening as peering in the mirror was awkward and with a swollen right eye and glasses, it helped to be able to enlarge the image. It was clear there was some necrosis at the top of the flap, and sending the photos to the surgeon's office helped him advise me without me needing to leave home. Along with the dark scab near my eye, there was also an oddly shaped lump of tissue remaining at my jawline. The surgeon decided to schedule a 'tidy up' operation to remove the lump, and also some further basal cell carcinomas in my right eyebrow. At the six week milestone after the cheek replacement, I was booked in for another operation. When I reached the six-week milestone after this second surgery, I started a six-week topical immunotherapy treatment for residual cancer cells in my eyebrow.

All the treatment was challenging, but it was that initial cervico-facial flap that required staying in hospital for three days, then having nurses visit for another week. Having someone else observe the healing and give their perspective was reassuring. By Day 8 I had serious cabin fever and felt like I was missing out on school holiday activities. I decided to take my sons to an event. I realised I could exist and experience the world completely from behind my own eyes, rather than as an object viewed by others. However, this was also my first experience of being a visibly different member of the public. People stared, gave me a wide berth, and when I interacted with stall holders, their curiosity was clear. Things became awkward when one woman asked me what had happened and I told her it was surgery for skin cancer. She then began to console me with how fortunate I was that they 'got it all' and how I must use sunscreen. This intrusive advice giving is

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E-mail address: c.gibson1@postgrad.curtin.edu.au (C. Gibson).

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something patients complain about. I didn't need advice, nor did I appreciate having my suffering minimised.

I don't think I'm vain. My life decisions and career have not been based on looks, and most of my work over 20+ years has been in the space of yoga, mindfulness, and self-enquiry practices. While there's an element of needing to look well, and to have professional images online, I make a practice of seeing and valuing people as far more than their appearance. But I'm part of the online wellness world whether I like it or not. In order to share my teaching, I record videos where I talk straight to camera (vlogging). I did not feel comfortable doing this after my initial surgery, and then not for a few more weeks after the second surgery. My challenge post-surgery was to see and accept myself as whole and good enough, even with my altered face. I tested the waters of public reaction with close friends and family. Some did not want to see my traumatised face. One of my dearest friends burst into tears when she saw me. I declined invitations, and hired cover teachers. As the world at large began to feel less welcoming, I withdrew to my inner life, through yogic meditation.

My meditation practice draws on the eastern philosophical tradition of *Advaita Vedanta*, or non-dualism. It appeals to me as a central concept is the unity of the seer and the seen. In other words, the individual is not separate from the whole. Just as the space within a pot is not different from the space outside it, my consciousness is not different from cosmic consciousness. This became my daily practice. Quietly closing my eyes, I began with identifying the roles I play – partner, mother, sister, daughter, friend, PhD student, educator, public speaker, health professional. One by one I observed that my essential self would still exist if I did not play that role. Then I moved to observing my breath, just as it is, without effort or control. I felt the breath like a bridge uniting mind and body, until there was a visceral sense of embodied presence. Through this mindful practice, I was able to accept my Self beyond the limits of my physical body. I feel more compassionate towards myself, and this carries over to my interactions, especially as a researcher. I am slower to comment or judge, more comfortable with silence, able to let stories unfold. I feel less responsible for solving what's wrong, less controlling of outcomes, and more accepting of nuance.

As my face healed, I returned to my roles, including interviewing people with head and neck cancer for my PhD. Sometimes it feels appropriate to describe my own experiences, but mostly I am practicing listening deeply. When told about their pre-treatment anxiety, the stares and reactions of people, the burdens they feel due to health issues, I feel the ripples of my own experience. Rather than being distressing, having visceral memories helps me feel attuned to their stories. My experience of disfiguring facial reconstruction surgery gives me more compassion, and has helped me to more easily understand the medical experiences, suffering and humanity of patients. While I would not wish for anyone to go through such a health crisis, my experience fuels my dedication to alleviating suffering for people diagnosed with cancer, and supporting survivors to live well.

It is my sincere hope that all of us involved in the care, treatment and research of cancer, remember and stay open to our shared humanity. As I have learned, there is no separation between the seer and the seen.

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Chapter 4: Methods

4.1 Design

An in-depth qualitative design was adopted using an exploratory interpretive research approach, and a social constructionist interpretive framework. The study was designed to understand the social and psychological experience of HNC from both patient/survivor and health professional perspectives through semi-structured interviews (Holliday, 2007). Social constructionist theory underpinned the design which provided a basis for understanding how realities and views of the world are experienced, interpreted and constructed through an individual's relationships, and via a combination of complex interactions with society, as well as the meanings that individuals attribute to such interactions (Given, 2008). Social constructionism was chosen because it aligns with the epistemology of intentionality, which describes the relationship between researcher and participants and enables meaning to be co-constructed from the analysis of interview data generated by health professionals and people with HNC (Vogl et al., 2019).

4.2 Ethics

The project was approved by the Curtin University Human Research Ethics Committee (HRE2018-0691) and the ethics committees at participating tertiary hospitals (SCGOPHCG HREC number RGS0000001145). At all times, the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council, 2018) was followed, adhering to principles of honesty and integrity, respect for human research participants, good stewardship of public resources used to conduct research, appropriate acknowledgement of the role of others in research, responsible communication of research results, conducted in an environment of responsible research at Curtin University Bentley campus and in the field. All participation was voluntary, and confidentiality was maintained by ensuring transcripts were de-identified prior to analysis.

4.3 Participants

Semi-structured interviews were conducted with a total of 42 participants: 21 health professionals from different disciplines working in a range of settings, and 21 adults who had been diagnosed with, and treated for, HNC in Australia within the previous six years.

Study 1 included 21 health professionals who provided medical and allied health services for people diagnosed with HNC in Australia in 2018/2019. Their disciplines included radiation oncologists, medical oncologist, nurses, social workers, psychologist, counsellors, dietitians, speech pathologist, radiation therapists, oral medicine specialist and ENT specialist. Using convenience sampling, participants were recruited from several settings, including cancer centres in tertiary hospital settings, private practice and not-for-profit cancer support organisations. All health professional participants who agreed to the study completed their interviews. Snowball sampling, whereby participants recruit from their contacts, was used to recruit additional participants. See Table 1 for the demographics of the health professionals.

Participants in studies 2–4 included 21 adults who had been diagnosed with HNC and treated in Australia since 2012, regardless of HPV status. Participants were recruited from several settings, including cancer centres in tertiary hospital settings, private practice and not-for-profit cancer support organisations using convenience sampling, which is a type of non-probability sampling using conveniently available participants. Snowball sampling was used to recruit additional participants by asking participants to recommend their suitable contacts. These two strategies enabled the selection of participants of different ages, genders and geographical areas. All patient participants who agreed to the study completed their interviews. See Table 2 for the demographics of the patients.

Table 1. Demographics of Health Professionals Interviewed (*n*=21)

Setting	Hospital Private practice Not-for-profit organisation	15 3 3
Profession	Radiation oncologist Nurse Social worker Dietitian Psychologist/counsellor Speech pathologist Medical oncologist Oral medicine specialist ENT specialist Radiation therapist	5 5 2 2 2 1 1 1 1 1
Gender	Female Male	16 5
Age	Mean 43.39	SD 7.97
Years in Role	Mean 8.44	SD 10.3
Hours Worked per Week	Mean 36.26	SD 16.1

Table 2. Participant Demographics – People diagnosed with HNC (*n*=21)

Age	Min 34, max 79	Mean 64 years	SD 10.75
Gender	Male 15	Female 6	Other 0
Time since diagnosis	Min 60 days, max 1827 days	Mean 646 days or ~21.5 months	SD 713.00
Diagnosis	HPV (P16+) 47% 10/21	Non-HPV 33% 7/21	Unknown 19% 4/21
Treatment received	Surgery 43% 13/21	Radiation therapy 95% 20/21	Chemotherapy 76% 16/21
Race	Caucasian 95% 20/21	Aboriginal 5% 1/21	Other 0

Education level	Less than school graduation 33% 7/21	School graduation 24% 6/21	Beyond Year 12 qualification 38% 8/21

4.4 Materials

Semi-structured interview guides were informed by previous research in this area. The health professional guide was developed with input from health professionals and experienced researchers, with topics including information about their role, pre-treatment processes, providing patient information, managing distressed patients, providing support, communication, team structure, job satisfaction, stress management and career paths. Questions included, 'Tell me about your role' and 'Do you feel satisfied that the patient understands you?' In response to participants' answers, a typical prompt would be, 'Can you give me an example of that?'

Interview schedules for people diagnosed with HNC were based on previous research by the team and expanded with input from experienced researchers, clinicians and consumers. Consumer input was invited and gratefully received from two HNC survivors, one of whom had a background as a health professional and the other was an active health equity advocate. Each provided rich insights into the most appropriate order and content of the interview questions, while also sharing their unique perspectives as participants. Topics included diagnosis, pre-treatment information, treatment experiences, prognosis, unmet needs, emotional wellbeing and the effect of HNC on roles and relationships. Participants were asked questions and prompted to elaborate and provide examples from their experience to ensure data were grounded in their realities. Questions included, 'What type of information have you needed?' and 'Do you feel like you are getting the support you need?'

4.5 Procedure

Recruitment began with the researcher explaining the study, their background and reasons for the study to potential participants at hospital team meetings. A range of health professionals from the multidisciplinary team were invited to participate. Written informed consent was gained prior to conducting each interview. Nineteen face-to-face interviews were conducted at the participants' workplace or home, and two were conducted via Zoom. Participants were alone with the interviewer in private spaces such as workplace meeting rooms and offices, or at private kitchen tables. Interviews lasted for 28–67 minutes (mean=52 minutes, SD=9.41). The health professionals were asked questions and prompted to elaborate and provide examples from their work to ensure the data were grounded in their realities. All interviews were digitally audio-recorded and transcribed verbatim. Transcripts were not returned to participants.

Some of the health professionals were also involved in recruiting patients to the study. They recruited suitable participants by providing information sheets and requesting their permission to provide contact details to the researcher, who contacted them by email or phone based on their stated preference. Two of the contacted potential participants declined to participate due to poor health. Nineteen interviews were conducted face-to-face, and two were conducted via an online video conferencing platform. Most face-to-face interviews took place at the participants' home, and one was conducted at a treatment centre. A partner was present during one interview; otherwise, participants were alone with the interviewer. Interviews lasted for 45–75 minutes (mean=61 minutes, SD=9.40).

Trust-building and rapport were established through open-ended questions and a conversational interviewing style (Burgess-Limerick & Burgess-Limerick, 1998), whereby the researcher entered the participants' social worlds without judgment and used appreciative enquiry to gather rich and deep data. Listening to participants' stories, allowing time frames for interviews to be flexible, and adding questions that built on responses to previous questions positioned the researcher as an active and reflexive learner. When participants had questions about the research or the researcher, these were answered clearly and openly. Following each interview, the researcher made brief notes and, after a few days' reflection, shared the participants' stories in supervision meetings, where colleagues challenged and assisted with the development of emerging ideas, contributing to a responsive and cyclical process of research (Burgess-Limerick & Burgess-Limerick, 1998).

4.6 Data Analysis

Initial analysis was conducted by the student researcher and discussed with all authors. It involved reading and rereading the transcripts to understand the participants' perspectives. Data were transported into NVivo12 (qualitative data analysis software) for data management. To rigorously analyse the large volume of interview data, the first author methodically worked through the six steps described by Braun and Clarke (Clarke & Braun, 2017b), and conducted reflexive thematic analysis using inductive methodology. This entailed (1) familiarisation with the data through repeated readings of transcripts, (2) generation of initial codes line by line, (3) identification of recurrent themes using collation of similar codes, (4) theme checking throughout single transcripts, followed by the entire dataset, (5) creation of labels and definitions for identified themes, and (6) utilisation of codes and themes to construct findings related to the research question and tied to the literature reviewed. This process was applied to patient data and health professional data separately, and then all data was discussed amongst the research team and integrated , reflecting the iterative process described in recent work by Braun and Clarke (Braun et al., 2022).

The coding process became a system for understanding multiple, complex threads of information with sometimes contradictory meanings (Strauss, 1998). Coding the interview transcript text into substantive categories facilitated the grouping of ideas into themes (Burgess-Limerick & Burgess-Limerick, 1998). As themes were generated from the datasets, they were given working titles such as for patients "negative interactions" and "who was helpful", and for health professionals "practical preparation" and "life outside work". Concept maps were created to explore and organise the data, providing visual models to develop ideas and identify patterns, which became the themes in each study. For example, within the original codes of "negative interactions" and "who was helpful", all quotations relating to communication between health professionals and patients were saved and later became themes of inhibition and promotion of communication in study 3 (Gibson et al., 2022). Through repeated engagement with the data and the interrogation of possible meanings of quotations, supported by the framework of Braun and Clarke's six-step process (Clarke & Braun, 2017a), the central organising concepts were observed as having multiple facets that evolved into themes (Braun et al., 2022). As data analysis progressed, no new themes arose, and data saturation was considered to have been reached. It is acknowledged that the concept of data saturation is contested (Denzin, 2017; Sebele-Mpofu, 2020); however, in this study, recurrent themes and similarities across the interview data were clear.

4.7 Rigour

Methodological rigour was present in the form of data collection involving the transcription of recorded interviews, and deep and repeated analysis of data was conducted concurrently until saturation was reached. Saturation is a contended concept (Braun et al., 2022), however in this study was deemed to have occurred when no new information emerged and themes recurred (Strauss, 1998). The first author conducted the majority of the interviews and led the data analysis. The co-authors participated in data interpretation, with discussion among the research team until agreement was reached, contributing to the dependability of the findings (Lincoln, 1985). While the appropriateness of reliability, validity and generalisability as measures of rigour have been challenged in qualitative research (Denzin, 2017), the trinity along with authenticity, trustworthiness and goodness as embedded and integral components of the research process are accepted as providing rigour in a naturalistic research setting (Tobin & Begley, 2004).

The researcher used an actively reflexive approach to understand participants' experiences and kept an audit trail (Creswell & Miller, 2000) that included keeping a reflexive diary, frequently recounting and summarising de-identified stories using mediums such as blogging and vlogging (video diary) to challenge the researcher's own assumptions, acknowledging their own bias (particularly that of the insider-researcher) (Asselin, 2003), and deconstructing and reconstructing a thematic understanding of the data in collaboration with supervisory team members. According to Denzin (Denzin, 2017), the thick descriptions provided by participants create verisimilitude, allowing the reader to enter the social world of both patients and health professionals, and this contributes to the validity of the study. According to Whittemore (2001), the validity criteria include credibility, for which direct quotes demonstrate accurate interpretation of participants' meaning; authenticity, for which a variety of different voices were quoted; criticality, which is ensured in the peer review process; and integrity, for which reflexive practice was used in the form of a reflexive diary, co-author discussions and public presentation of research findings to both lay and academic audiences (Whittemore et al., 2001). The consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007) guidelines were adhered to closely.

Chapter 5: Study 1: Paper 1: Burnout or Fade Away

The objective of this study was to explore the experiences of health professionals who work with patients diagnosed with HNC, with a focus on work–life balance, mental health and wellbeing. The oncology workforce has been found to have high levels of burnout; however, limited research has focused on the HNC workforce specifically. Semi-structured interviews were conducted with 21 health professionals, and questions centred on work–life balance, mental health and wellbeing.

The following health professionals participated: radiation oncologists, medical oncologist, nurses, social workers, psychologist, counsellors, dietitians, speech pathologist, radiation therapists, oral medicine specialist and an ENT specialist. In sharing their experiences, health professionals offered a range of insights into caring for patients diagnosed with HNC and the effect this work has on them. Thematic analysis through a social constructionist lens showed that health professionals who work with HNC patients and survivors are conscientious and empathic and face numerous challenges in delivering high-quality treatment and support services. The key themes that emerged were conscientiousness, empathy, challenges, coping, and burnout or fade away. Within the theme of challenges, subthemes were identified, including time and resource constraints; difficulty maintaining self-care as they navigate between the demands of their professional and personal lives; and communication issues with patients who have complex needs.

The support and education of health professionals within their workplace is crucial to changing the culture of overwork that leads to burnout and the loss of highly educated, skilful and empathic workers. There is an expectation that health professionals will engage in self-care strategies outside of work time; but systemic change is needed. Workplace wellbeing initiatives such as communication skills training, trauma-sensitivity training, self-awareness, yoga and mindfulness-based programs must be supported by leaders and policymakers, and strategies need to be multipronged and tailored to suit the different work styles and needs of health professionals. More research is required to develop and evaluate targeted interventions for health professionals who work with people with HNC.

This study was published as *Burnout or fade away; Experiences of health professionals caring for patients with head and neck cancer* in the European Journal of Oncology Nursing (Impact Factor 2.588) in February 2021 (Gibson et al., 2021). According to Google Scholar data retrieved on July 13th, 2022, the published article has 3 citations, 56 shares, likes and comments on social media and 5 tweets.

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Burnout or Fade Away; experiences of health professionals caring for patients with head and neck cancer

Chandrika Gibson [a,*], Moira O'Connor [b], Rohen White [c], Siddhartha Baxi [d], Georgia Halkett [a]

[a] *School of Nursing, Midwifery and Paramedicine, Curtin University, Perth, WA, Australia*
[b] *School of Psychology, Curtin University, Perth, WA, Australia*
[c] *Department of Radiation Oncology, Sir Charles Gairdner Hospital, Perth, WA, Australia*
[d] *Radiation Oncology, Genesis Care, Queensland, Australia*

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ABSTRACT

Purpose: The oncology workforce has been found to have high risk of burnout; however, limited research has explored the experiences of health professionals working with head and neck cancer patients. The objective of this qualitative study was to explore the experiences of health professionals who work directly with patients diagnosed with head and neck cancers, with a focus on work-life balance, mental health and wellbeing.

Method: A total of 21 in-depth semi-structured interviews were conducted with health professionals including radiation oncologists, medical oncologists, nurses, and associated medical and allied health professionals. A qualitative research approach based on social constructionist theory was used. Thematic analysis was used to identify and code themes.

Results: Five main themes emerged: 1. Conscientiousness; 2. Empathy; 3. Challenges; 4. Coping; and 5. Burnout or Fade Away. Challenges included sub-themes of Time & Resource Constraints, Work-Life Imbalance, Patients with Complex Needs, and Lack of Self-Care.

Conclusion: It is vital to the sustainability of head and neck oncology services that this highly skilled workforce is retained. The development of interventions that will reduce the risk of burnout and improve retention and capacity of health professionals may include advanced communication skills training, trauma sensitivity training, self-compassion and stress management skills.

1. Introduction

The annual incidence of head and neck cancers (HNC) worldwide is more than 550,000 cases with around 300,000 deaths each year (Jemal et al., 2011). Each year, approximately 4400 people in Australia receive a head and neck cancer diagnosis (Australia, 2019). Many health professionals (HPs) play a role in symptom management and supporting people with head and neck cancer from diagnosis through treatment and beyond (Australia, 2019). Positive interactions with HPs can help patients adjust to treatment effects (Konradsen et al., 2009), and good relationships with HPs help them express their needs and make decisions (Zoffmann et al., 2008). HPs are also affected by their interactions with patients (Aranda et al., 2012; Back et al., 2007; L. J. Breen et al., 2017). This relationship has been highlighted as crucial to HPs' satisfaction (Moore et al., 2013), yet they report difficulties in meeting patient needs (Chen et al.; Wells et al., 2015) and there are numerous barriers to the provision of such support including time constraints (Kleiner and Wallace, 2017; Vinckx et al., 2018), length of time in the role (Naholi et al., 2015), demographical variables (Contag et al., 2010; Wardle and Mayorga, 2016), personality factors (Hallberg et al., 2007), patient factors (Zoffmann et al., 2008), education and training (Moore et al., 2013), and organisational and work-related issues (Girgis et al., 2009). These challenges have been explored across HPs generally (Bhutani et al., 2012) and within oncology settings (Girgis et al., 2009).

The provision of complex cancer care can have negative effects on health professionals who care for them, including psychiatric morbidity, compassion fatigue, and burnout (Boyle, 2015; Eelen et al., 2014; Figley, 2002). Compassion Fatigue (CF) has been conceptualised as comprising secondary traumatic stress and burnout (Martin, 2018). Secondary traumatic stress has been described as stress brought on by working in

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* Corresponding author. School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences Curtin University, Western Australia GPO Box U1987, Perth, WA, Australia.

E-mail address: c.gibson1@postgrad.curtin.edu.au (C. Gibson).

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settings where exposure to traumatic situations or events is common (Canfield, 2005) Burnout refers to the erosion of physical and psychological wellbeing of professionals due to an overly taxing work environment, and can be experienced by both front-line and support staff in health settings (Eelen et al., 2014). The hallmarks of professional burnout are emotional exhaustion, cynicism and depersonalisation, and a feeling of inefficacy in their role (Maslach, 2012). This is highly relevant to the oncology workforce, as clinical implications of burnout include increased risk of medical errors, staff turnover and subsequent loss of talent and knowledge, decreased quality of patient care and satisfaction (Trufelli et al., 2008; Wu et al., 2016). Experiencing an episode of burnout adversely affects HPs personally and professionally.

In the general working population 13–27% of people report burnout. Estimates vary across disciplines but up to 70% of physicians report burnout (Lamothe et al., 2014). In one of the only HNC specific studies on burnout, Contag et al. found that for surgeons who perform complex flap surgeries for HNC patients, 75% had moderate to high burnout (n = 60) (Contag et al., 2010). Earlier studies report high levels of burnout and psychological distress for oncology clinicians, with 56% of US oncologists reporting at least one episode of burnout (Whippen and Canellos, 1991). A study conducted in Belgium of n = 550 HPs of varied disciplines, found that oncology staff suffer more symptoms of burnout than other HPs, with medical oncologists most affected. Fifty one percent of the medical oncologists surveyed experienced emotional exhaustion and 31.8% suffered from depersonalisation, and just 6.8% reported a lack of job satisfaction (Eelen et al., 2014). Thirty five percent of young (under 40 years) radiation oncologists in Italy (n = 112) had experienced burnout (Ciammella et al., 2013). Japanese physicians engaged in end of life care of cancer patients (n = 697) also experienced high rates of burnout, with 22% experiencing emotional exhaustion, 11% depersonalisation, and 62% reporting low personal and professional accomplishment (Asai et al., 2007a).

Recognised predictors of burnout include high workload (Grunfeld et al., 2000; Ramirez et al., 1996), perceived need for communication skills training (Asai et al., 2007a; Fallowfield et al., 2002; Messerotti et al., 2020), perceived need for stress-management skills (Blanchard et al., 2010) and perceived interference of work on home life (Blanchard et al., 2010; Kleiner and Wallace, 2017).

Interventions include communication skills training for hospital social workers (n = 25), where, following training, personal accomplishment rose by 12.39% and depersonalisation fell by 29.75% (Cohen and Gagin, 2005). Communication skills trainings have been found acceptable by radiation therapists (Halkett et al., 2016; Merckaert et al., 2015), oncologists (Fallowfield et al., 2002), surgeons (Lebares et al., 2020), and nurses (Darban et al., 2016). Mindfulness-based interventions are the most common and have been found effective for improving mental wellbeing with mixed results in reducing factors associated with burnout (Duarte and Pinto-Gouveia, 2016; Kinnunen et al., 2019; Ofei-Dodoo et al., 2020; Slatyer et al., 2017). Trauma-sensitive trainings for social workers and mental health care providers have shown significant improvements in compassion satisfaction (Butler et al., 2017; Vermilyea, 2014).

There is a lack of research focusing on head and neck cancer specifically, yet supporting HNC patients is particularly challenging for HPs due to their complex needs, can result in decreased work-life balance (Shanafelt et al., 2014), and may also affect mental health and wellbeing (Asai et al., 2007b; Rath et al., 2015).

2. Objective

The objective of this qualitative study was to explore the experiences of HPs who work directly with patients diagnosed with head and neck cancers, with a focus on work-life balance, mental health and wellbeing.

3. Method

3.1. Design

An in-depth cross sectional qualitative design was adopted and semi-structured interviews used. Social constructionist theory informed data analysis (Given, 2008).

3.2. Ethics

The project was approved by the Curtin University Human Research Ethics Committee (HRE 2018-0691), and the ethics committees at participating tertiary hospitals (SCGOPHCG HREC number RGS0000001145).

3.3. Participants

The sample comprised 21 HPs who provide medical and allied health services for people diagnosed with HNC in Australia in 2018/2019. Their disciplines included Radiation Oncologists, Medical Oncologist, Nurses, Social Workers, Psychologist, Counsellors, Dietitians, Speech Pathologist, Radiation Therapists, Oral Medicine Specialist, ENT specialist. Participants were recruited from several settings including cancer centres in tertiary hospital settings, private practice, and not-for-profit cancer support organisations using convenience sampling. All participants who agreed to the study completed their interviews. See Table 1 for demographics.

4. Materials

A semi-structured interview guide was used. Topics included information about their role, pre-treatment processes, providing patient information, managing distressed patients, providing support, communication, team structure, job satisfaction, stress management and career paths. The guide was developed with input from HPs and experienced researchers.

4.1. Procedure

Recruitment of a convenience sample began with the first author explaining the study, her background, and reasons for the study, in person to potential participants at hospital team meetings. A range of HPs from the multidisciplinary team were invited to participate. Written informed consent was gained prior to conducting each interview. 19 interviews were conducted face-to-face, either at the participant's workplace or home, and 2 via Zoom. Participants were alone with the

Table 1
Demographics of health professionals interviewed.

Setting	Hospital	15
	Private Practice	3
	Not for profit org	3
Profession	Radiation Oncologist	5
	Nurse	5
	Social Worker	2
	Dietitian	2
	Psychologist/Counsellor	2
	Speech Pathologist	1
	Medical Oncologist	1
	Oral Medicine Specialist	1
	ENT Specialist	1
	Radiation Therapist	1
Gender	Female	16
	Male	5
Age	Mean 43.39	SD 7.97
Years in Role	Mean 8.44	SD 10.3
Hours Worked per Week	Mean 36.26	SD 16.1

interviewer in private spaces. Interviews lasted from 28 to 67 min (mean = 52 min, SD = 9.41). The HPs were asked questions and prompted to elaborate and provide examples from their work to ensure data was grounded in their realities. No interviews were repeated. All interviews were digitally audio-recorded and transcribed verbatim. Transcripts were not shared with participants.

4.2. Data analysis

Initial analysis was done by the first author and discussed with all authors. It involved reading and rereading of transcripts to understand participants' perspectives. Data was transported into NVivo12 (a qualitative data analysis application) for data management. Following the six steps described by Braun and Clarke (2017), and utilising inductive methodology, Thematic Analysis was conducted. This entailed (1) familiarisation with the data by repeated reading of transcripts, (2) generation of initial codes line-by-line, (3) identification of recurrent themes using collation of similar codes, (4) theme checking throughout single transcripts, followed by the entire dataset, (5) creation of labels and definitions for emergent themes, and (6) utilisation of codes and themes to construct findings related to the research question and tied to the literature reviewed.

4.3. Rigour

Data collection and analysis were conducted concurrently until saturation was reached; saturation was deemed to have occurred when no new information emerged and themes recurred (Strauss, 1998). The first author conducted the majority of interviews and led the data analysis. A reflexive diary was used. The co-authors participated in interpretation of data, with discussion amongst the research team until agreement was reached, contributing to the dependability of the findings (Lincoln, 1985).

5. Results

The following HPs participated: Radiation Oncologists, Medical Oncologist, Nurses, Social Workers, Psychologist, Counsellors, Dietitians, Speech Pathologist, Radiation Therapists, Oral Medicine Specialist, ENT specialist. (See Table 1). In sharing their experiences, HPs offered a range of insights about caring for patients diagnosed with HNC and the impact this work has on them. The key themes that emerged were; Conscientiousness, Empathy, Challenges – (with subthemes of Time & Resource Constraints, Work-Life Imbalance, Patients with Complex Needs, and Lack of Self-Care), Coping, and Burnout or Fade Away.

5.1. Conscientiousness

All HPs described themselves as diligent, and most articulated their approach to work as uncompromising. For many this commitment to doing their job well meant they always put work ahead of other needs,

> ' *… people who are in areas of responsibility are going to continue to absorb more and more work to continue to get the same outcomes for their patients rather than say, "Oh it's five o'clock, my contracted 40 hours a week are finished"'* HP2

They stay until the job is done, no matter the hours, '*we average about 10 to 12 h a day … once or twice a week you'll do an on-call shift so you'll work overnight … '* HP10.

They don't see themselves as the kind of people who take time off, even when their own health is compromised,

> '*There's a lot of talk going around of taking mental health days off and taking days off when you're feeling tired which in theory is nice, but in the medical workforce, I don't think it works well that way and there's still a lot of stigma as to that and if you take too many days off, there's often like a bit of a negative view on you, like you might be lazy or you don't do the teamwork. You feel guilty for taking time off.*' HP10

> ' *… our priority is patient care and not stuffing up for the patient and so our response is different … in addition to one consultant having a heart attack, another consultant has been going down the same path and been investigated*' HP2

Even when HPs take leave they do not get time to switch off,

> ' *…. holidays are always on the back of conferences….we can't go away for two weeks and expect another clinician is going to be able to plan and do what you could do for a patient that you're involved with … I was remotely logging in and outlining for different patients and designing their treatments. We're just not comfortable assigning that responsibility to someone else and often our peers aren't comfortable with that responsibility*.' HP2

Some HPs felt that taking leave added to their workload,

> *'It's difficult too because the hospital doesn't provide enough cover – well, they don't provide any cover at all. So we work doubly hard before we go and then when we come back and I tend to work throughout my holiday as well.'* HP11

5.2. Empathy

Many HPs expressed empathy for their patients, with one defining it as, *'To truly be there for someone in a state of empathy is to let them know that they're not alone, that you're willing to be there with them, but at the same time to have no expectations of them and to have as much unconditional positive regard for them as possible.'* HP1.

Many HPs noted that HNC treatment was more difficult for patients than other forms of cancer treatment,

> '*What you're going to put them through is quite an arduous treatment, probably the most difficult treatment to get through is radiation … The side effects and the morbidity of radiation to head and neck is far worse than any other area.*' HP5

> *'I can feel a little bit more emotional when I'm working with them, because I think it's really tough for them and I can really empathise with how stuck they can feel and how difficult their options are …. it does feel a little bit different to some other cancers which are ones you can't see … '* HP16

> '*Head and neck cancer patients can be complex and emotionally draining because they are so sick or their treatment is so difficult so I guess it doesn't represent easy work … there's nothing straightforward about them usually.*' HP7

> '*There's so much going on with the head and necks that … your heartstrings get pulled a lot more and you can put yourself in their shoes and think that must be terrible, whereas prostates and breasts, it's a bit uncomfortable but at the end of the day, it's not quite as all-encompassing … '* HP13

HPs expressed empathy in a variety of ways. Some talked about crying and the emotional toll of HNC, *'I will cry with clients sometimes …. '* HP16, while others demonstrated an ability to put themselves in patient's shoes and see what matters most to them,

> '*We know the outcome is very poor but they may be very anxious because they're young, they've got a young family, young children, all that sort of thing that they want to live to see the next birthday for their kids*.' HP11

Empathy was seen as part of good, diligent care that gives HPs satisfaction in their role,

> *'Caring for people is actually what I feel is really important.'* HP4

> *'I have quite a big capacity to empathise with clients … and it's a real strength in my work … '* HP16

5.3. Challenges

HPs face numerous challenges in their roles. Challenges described included; Time & Resource Constraints, Work-Life Imbalance, Patients with Complex Needs, and Lack of Self-Care.

5.3.1. Time and resource constraints

Treatment is more time consuming in an HNC case compared with treating other cancers,

> *' … for head and neck, we have to identify and mark out a lot of organs at risk' HP2*

> *'There's so much with head and necks, they're definitely the most engrossing group that we have and they have the most potential to fall in a heap spectacularly'*. HP13

Communication issues can also cause care to take longer than expected, '*sometimes with the trachies and the laryngectomies, if they haven't got a speaking valve in and they can't communicate, it can be very time consuming and very laborious to write everything down'*. HP13.

There's also a greater sense of urgency to treat HNC patients, *'if you see it's a head and neck patient, you know they tend to need more urgent treatment than someone with a low risk cancer.'* HP11.

Along with high needs from the patients, there are not enough trained staff, or constraints on resources at a systemic level, *'the workload is probably the thing that's been pretty stressful in an environment where there's budget constraints … when we also have to do all the other workload, plus fighting for resources all the time, it's been difficult.'* HP11.

5.3.2. Work-life imbalance

The experience of working with HNC patients affected the HPs' personal lives, placing strain on relationships. HPs reported a cost to this dedication in their personal relationships, and their mental health suffered as a result,

> *' … the amount of relationship breakups … in specialist land, is significant. The number of suicides and early deaths … it's there. It certainly exists.'* HP21

> *' … you feel like you spend so much time with people that you don't know, worrying about them that you neglect people that you do know.'* HP2

For HPs who are also parents, the juggling act is complex,

> *'…it's a balance, but I do a lot of my work outside of hours so during hours I spend that time seeing patients …. So after my kids go to bed, 7 to 10 I'm on my computer every night just doing treatment plans and that's not including paperwork or anything like that which is another thing.'* HP3

> *'A colleague of mine can't remember the first year of his child's life.'* HP21

> *' … my approach is very simple; up to 10 o'clock when I put them to bed, they have my undivided attention and after 10, 10 to about 11, 12, I get that work done.'* HP5

These challenges at work take energy, are emotionally draining, and leave little time for other parts of life,

> *'If I have a particularly difficult or hard patient then I do feel like I'm less present at home.'* HP6

> *'I actually shut down. I'm not available for my family.'* HP17

The need to prioritise can feel like a no-win situation, *'If you want to do a good job, you have to be staying very late or you do the bare basics so you can get out on time and have some sort of balance with your life.'* HP19.

5.3.3. Patients with complex needs

Beyond the technicalities of the work, psychosocial factors also add complexity, *'You're dealing with patients' with complex comorbidities, complex social backgrounds and then the actual tumours are always a little bit different.'* HP2.

Treatment for HNC often results in altered appearance, which was distressing for some HPs,

> *'Often people without noses or have a significant part of their face being removed due to surgery … They can look potentially gruesome and to have a really meaningful conversation where you're having face-to-face contact and you're leaning in towards them … that can be quite confronting … the main thing that sticks in my mind about (one case) though was the maggots that were all in his wounds on his face for his final month.'* HP1

One nurse described the challenges of cleaning the sinus cavity when a patient had needed their nose removed *' … gentlemen that have had their nose removed and so they wear this huge white bandages on their nose …. they get very messy … I have to say as a nurse I found it very confronting … We had to get the forceps in there to try and clean it out … It's like a Toblerone of a cavity just going … you get the torch in there and it's just like a cavern … you talk to him using his eyes but you were actually looking at his nose and going in there - and there was no pain or anything, it wasn't painful for him, but you had to really clean it because it got crusty … because you still make mucous, that has got to go somewhere'*. HP13.

Along with disfigurement, some HNC patients had issues related to alcohol use and lacked social support, causing distress for the HPs and communication barriers, *'they might reek of smoke, they might reek of alcohol, they might have been on a bender the night before and they come in and they are really difficult to work with and these patients sometimes they don't turn up for treatment.'* HP12.

5.3.4. Self-care

HPs' personal perspectives, team support, and self -care practices can help them to manage the demands of their role. Self-care is a challenge as HPs put their patients and families ahead of themselves,

> *'I always tell my patients, even head and neck patients, you've got to exercise to make yourself live longer, to reduce the side effects of radiation and chemo and things but I've been wanting to do that myself, I just haven't had time because often I'm home at nine o'clock at night and I start very early the next day.'* HP11

'The exercise or activities to do started diminishing. I was cycling to work for seven years; stopped cycling because you're better off getting an extra 45 min at work rather than do half an hour of cycling to and from work. Cholesterol goes up, weight goes up, big changes'. HP21.

In some teams debriefing is routine '*We do … debrief each other about some of the things … because there's some very sad situations.*' HP7.

However, in most settings the pace of work makes formal debriefing difficult, leaving HPs to use their inner resources, *' …. in a way a bit of denial is how you deal with it, you just kind of have to do the job'* HP10.

HPs who felt they could lean on their team mates felt more resilient to burnout, *'I get tired but I think everyone gets tired but I've got a really good group around me that I could go to and say, "I'm a bit stressed about this or a bit stressed about that."'* HP13.

Some HPs spoke about regular self-care strategies that help them cope,

> *'I might really have a few weeks where I'm really empathising greatly with every client …. I will … make sure that my self-care is still intact … I do things that are completely non-related to work … physical exercise, running, swimming, that sort of thing. That's a form of mindfulness for me … and I find that very refreshing and helpful.'* HP16

> '*I do a lot of self-development work, meditation, yoga, stuff like that, to try and not let it get on top of me.*' HP1

5.4. Coping

Some of the HPs who reported coping well had made conscious decisions to work part-time,

> '*I did find it emotionally quite overwhelming doing this kind of work full-time …. I think it's well-suited to part-time in that you are able to switch off from stories with patients and do your other job, whatever it may be. I don't aspire to coming back into this caseload full-time. If I was to work more days, it would be in another area.*' HP8

> '*I never work full-time hours and I know when I come close to doing that that my risk of burn out increases.*' HP4

Limiting working hours and creating boundaries help some HPs cope with the stress of HNC oncology,

> '*So when I finish my work, I make a real commitment to leave on time. I'm not apologetic for it … otherwise I have this permanent guilt of not being a mum, not being at home.*' HP6

> '*… an active decision to get more sleep, active decision to get more exercise. At work, you practically stop taking on new patients, you actually deflect queries, clinical queries or clinical request; you say, "No, can't do this for you" or "You're going to have to see X, Y and Z to get this done." And in my case, very practically, when I moved to a new job, I made sure I set up new boundaries, one of which is going part-time.*' HP21

Taking time off is another approach, '*I had six months off and at that time I ended up … doing yoga teacher training and getting away from work for a bit.*' HP10.

Planning to retire early is another solution, *'I'm retiring at 50'* HP2.

Experience has led some HPs to practice effective self-care, '*I actually am very good at leaving work behind. It doesn't mean I don't think about patients every now and then but, yeah, no, I'm much better at that. I'm more self-aware and I look after myself a lot better these days.*' HP14.

Another coping strategy is to find other work that allows for a reprieve from the intensity of working with HNC patients,

> '*I've been very saddened by some patients but I've never had burnout, never, because I've changed jobs, I've changed tumour streams, so I'm constantly met with new challenges and that's how I don't get burnout.*' HP18

5.5. Burnout or Fade Away

When self-care strategies and resilience are no longer enough to balance the challenges of their roles, some HPs reported that they experienced symptoms of emotional exhaustion, compassion fatigue, and decreased work satisfaction, which they described as burnout. One HP took a seven month break after experiencing burnout '*I felt like I was emotionally spent. I would go home and I would have a husband and children who wanted me to invest in them as well and I just found it really, really hard.*' HP14

> '*I think you can get fatigued. People fatigue or even empathy fatigue … that kind of cortisol response of go faster, go harder, get the work done and it becomes harder and harder to slow down. Broken sleep, which then messes again with perception. So none of it helps so you choose all the wrong things and then all your helping strategies like exercise, yoga, meditation … they just end up stopping and I'm just on the treadmill. I experienced burnout and that's what it looks like for me.*' HP1

They can have feelings of depersonalisation directed at colleagues or patients,

> '*I didn't think I saw it at the time – I just felt more tired and tired and I felt angrier and angrier and I actually have a sticker – this is my sticker … which I carry around all day; it says 'Must be nice' and it was kind of a little joke, but also it was a reminder to not snap at people on the phone and at one point actually the nursing staff in the clinic pulled me up on it.*' HP10

> '*It's such an elusive thing, burnout, because everyone else sees it before you do. The scariest thing about burnout for me is that you think you're right, that this particular situation or this particular colleague or boss is so wrong that I feel justified in being shitty towards them or whatever.*' HP1

The pressure to continue to work long hours leads to emotional exhaustion, lack of energy and decreased self-care,

> '*I've struggled up and down in the last year with trying to cope with the long hours because you kind of go home and you just flop and you don't really do anything and it doesn't feel very fulfilling.*' HP10

> '*I didn't call it stressful, but I just feel like I can't do this forever, it's burning me out, doing that sort of work.*' HP11

> '*I wake up and I feel really overwhelmed, really tired and probably one of the more noticeable behaviours is I get anxious and I start to eat sugar, sugary sweet stuff.*' HP17

Even those who didn't consider themselves burnt out, suffered from the stress of their role, '*none of us sleep on a Sunday night because we're worried about the Monday.*' HP13.

HPs who previously loved their roles found they wanted to get out, '*I just didn't want to go to work which was a feeling that I had never had before.*' HP19

> '*Emotions got the better of me I guess and sometimes it was difficult to even want to go to work.*' HP12

Burnout and lack of satisfaction at work also negatively impacted colleagues, '*two of our training registrars were feeling too stressed out and quit work very abruptly. They were subsequently unable to be replaced by the hospital which then resulted in a further two registrars burning out and taking time off.*' HP2.

Feeling unsupported at work was a common issue, '*My burnout was more related to frustrations at work and study … not feeling supported and … being held back because the needs of the department come first.*' HP15.

6. Discussion

Our findings demonstrate some issues that are specific to those working in HNC. Participants noted that HNC is more demanding, time consuming, emotionally draining, technically detailed work, than other areas of oncology. Conscientiousness was found to be high, with high levels of commitment, and empathy for patients. The personality trait of conscientiousness has been found to lower risk of burnout in some studies (Geuens et al., 2017), and increase risk in others (Cañadas-De la Fuente et al., 2015). While conscientiousness and commitment did not appear to waver, some participants recognised a tipping point where the demands of the job outweighed their ability to show compassion for patients and the quality of relationships with peers and personal life also decreased. An example is HP10 who described carrying a sticker reminding her to 'be nice' at work. Seminal work by Maslach et al. (Maslach, 2012) refers to this as 'depersonalisation', a kind of protective psychological mechanism for interpersonal stress, which is one element of burnout syndrome. Previous research supports our finding that people who choose to work in oncology are compassionate, empathic professionals who are dedicated to helping people (Najjar et al., 2009). However, as work-related demands increase, compassion tends to decrease, with de-personalisation, emotional exhaustion, and decreased work satisfaction potentially leading to burnout syndrome (Maslach, 2011).

The disfigurement some patients experience can be aesthetically displeasing, causing HPs to distance themselves emotionally from patients' experiences. Witnessing patient's distress, and finding their altered appearance distressing to observe may be understood as an experience of vicarious or secondary trauma. A plausible explanation for avoidance may be the 'specter' of cancer (Breen et al., 2014), or, as reported by HP1, a sense of over-identification with the patient's suffering, leading to compassion fatigue. The distress and discomfort reported by HPs in this study, combined with findings from other research indicating that patients do not raise issues of body image because they anticipate HPs will find it frivolous (Konradsen et al., 2012; Konradsen et al., 2009; Thompson et al., 2020), points to a need for greater HP self-awareness to enable patient empowerment.

The emotional strain, long hours, high caseload, time and resource constraints, complexity of HNC patients, and subsequent work-life imbalance all combine to put HNC HPs at high risk of burn out. In keeping with our findings, high emotional exhaustion was associated with excess workload, inadequate administration time, work invading family life, inability to care for personal health, poor perception of control over professional life, and frequency of irritable behaviour toward loved ones (Contag et al., 2010).

Challenges faced by HPs in HNC are both personal and systemic. Participants described intrusive thoughts about work, worry about patients, sleeplessness, and inability to maintain self-care practices. Our findings reflect earlier work which suggested that personality has a relationship to burnout, absenteeism and turn over (Geuens et al., 2017; Swider and Zimmerman, 2010), in particular more conscientious personality types can be vulnerable to burnout as they will push themselves to complete their work at a high standard. Systemic issues such as understaffing, long hours, lack of supervision, lack of flexibility, funding shortfalls, and management style, were described by participants as stressful, and are out of HPs control. Feeling a lack of agency can contribute to feeling ineffective at work, decreasing job satisfaction (Bridgeman et al., 2018). Personality traits and individual temperament can impact on HPs' ability to process hard stories, tolerate difficult interactions, and take action for self-care (Lamothe et al., 2014). It may be the seemingly positive findings of HPs conscientiousness and empathy contribute to their risk of compassion fatigue and lead to burnout.

Those who managed to navigate the difficulties used coping strategies that were either helpful, or potentially led to them leaving their professional role. Some used exercise, yoga, mindfulness, and social support to help them, while others had excellent support within the workplace. Some elected to work part-time or establish clear boundaries such as leaving on time at the end of the day, as HP6 did. Others found they managed by using short term strategies such as staying late at work, or working on the weekends, working late into the night, and, in the case of HP2, breaking off relationships when the conflict between home and work became too difficult. Our findings support the work of Kleiner and Wallace (Kleiner and Wallace, 2017), who found that oncologists' most at risk of burnout, are those who feel that work encroaches excessively on family or personal time. These findings mirror previous research which showed that contributors to burnout include the necessity to work long hours (Girgis et al., 2009), with the majority of contracted hours spent face to face with patients, and administration and planning done after hours (Kleiner and Wallace, 2017).

When strategies for coping broke down, HPs experienced symptoms of burnout and took action to move away from their role in HNC. They took leave, applied to change roles, or dropped down to part time hours. Some HPs, including HP2, planned to push through and retire early, postponing their interests and personal goals until retirement. This supports findings by Girgis et al. who found half of the oncology workforce reported symptoms of burnout (Girgis et al., 2009). Previous studies (Bhutani et al., 2012; Brenda, 2008; Contag et al., 2010; Gillies et al., 2014) also found high risk of burnout in medical and allied HPs and these findings point to a need for strategies for supporting those who feel distressed and overwhelmed. If HPs are experiencing feelings of burnout such as emotional exhaustion, depersonalisation and lack of job satisfaction, their communications with patients inevitably suffer. Our findings reflect the risk of losing skilled HPs to burnout and highlight the specific demands and challenges of supporting patients diagnosed with HNC.

6.1. *Limitations*

A strength of this study was that recruitment focused on health professionals from a range of professionals. There was heterogeneity in health professionals roles with participants from allied health such as counsellors, dietitians, and speech pathologists, as well as nursing and medical professions. It could be expected that their responsibilities and experiences are quite different; therefore impacting on their experiences of burnout. While differences in burnout risks between professions have previously been explored further understanding of how working with this HNC population for individual professions is limited, Future research could focus on a single discipline working with people with HNC to understand discipline-specific experiences and issues. Most participants were not working full-time which likely influences their perceptions of work-life balance. Additional research with full-time workers is recommended.

6.2. *Practice implications*

The support of HPs within their workplaces is crucial to changing the culture of overwork that leads to burnout and the loss of highly educated, skilful, knowledge workers. It is not enough to expect that HPs engage in self-care strategies outside of work time. Workplace wellbeing initiatives such as communication skills training, trauma-sensitivity training, self-awareness, yoga, and mindfulness-based programs must be supported by leaders and policy makers, and strategies need to be multi-pronged to suit the different work styles and needs of HPs.

7. Conclusion

This study explored the experiences of HPs who work directly with people diagnosed with HNC. We found that the risk of losing qualified, conscientious, empathic HPs from the HNC workforce is significant, and the capacity to serve a growing population of HNC patients is threatened by the challenges facing HPs. While much research has focused on nurses (Brenda, 2008; Houck, 2014; Thomas et al., 2019), and some on the oncology workforce as a whole (Girgis et al., 2009; Najjar et al., 2009), very few studies have explored the experiences of oncology HPs who work with HNC patients. At the systemic level, flexible work and leave arrangements, support for parents, and adequate staffing are all crucial to preventing burnout and loss of talent. At the individual level the development of supports and interventions that will reduce the risk of burnout and improve retention and capacity of HPs in HNC may include trauma-sensitivity training, advanced communication skills training, self-awareness and stress management skills such as mindfulness-based interventions. These findings can be used to inform future training of HNC HPs. There is a need for training that encourages HPs to reflect on their emotional responses to HNC patients and maintain compassion, in order to balance the demands of their work with their personal needs (Krasner et al., 2009; Wacker and Dziobek, 2018). It is vital to the sustainability of HNC oncology services that the highly skilled workforce is retained. Being able to communicate effectively, understand the trauma some patients' experience, and be compassionate to self as well as patients would help HPs in their role and, potentially prevent burnout.

CRediT authorship contribution statement

Chandrika Gibson: Conceptualization, Methodology, Software, Formal analysis, Investigation, Data curation, Funding acquisition, Writing - original draft. **Moira O'Connor:** Supervision, Writing - review & editing. **Rohen White:** Writing - review & editing, Validation, Resources. **Siddhartha Baxi:** Writing - review & editing. **Georgia Halkett:** Supervision, Writing - review & editing.

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Chapter 6: Study 2: Paper 2: Body Image Distress

The objective of this study was to explore the experiences of post-treatment survivors of HNC, with this paper providing an analysis of data relating to the psychosocial impacts of altered appearance. Twenty-one semi-structured interviews were conducted with survivors of HNC who had been diagnosed in the previous six years. Reflexive thematic analysis through a social constructionist lens was used to identify themes. The main themes in this paper were preparation (subthemes: decision-making; and preparation for altered appearance); altered appearance (subthemes: weight loss; face, skin and hair changes; and reconstructive surgery); and consequences (subthemes: reactions from others; and adapting to altered appearance). The study found that preparation for HNC treatment is focused on the practicalities of treatment, and patients feel rushed into treatment, adequately prepared for procedures but inadequately prepared for the aesthetic results of treatment. Findings included the impact of visible weight loss, face, hair and skin changes, and the appearance alterations caused by reconstructive surgeries. Participants reported the trauma of being unrecognisable to loved ones and themselves. Reactions from other people and challenges with adapting to altered appearance contributed to body image distress and psychosocial issues for many people diagnosed with HNC.

Current practice provides information pre-treatment about many aspects of coping; however, the subject of appearance is not routinely addressed. Communication skills training for health professionals that improves their comfort and sensitivity in discussing and conveying compassion around issues of altered appearance, body image and trauma is needed to decrease suffering for survivors, support healthy adaptation to living with altered appearance, and increase patients' satisfaction with healthcare. Screening and referral to psychological support for patients prior to appearance-altering treatment is also recommended. Future research could include development and evaluation of advanced communication skills training which addresses health professionals' understanding of body image and expands their understanding and skills relating to shared decision-making and informed consent.

This study was published as *'I didn't even recognise myself'; Survivors' experiences of altered appearance and body image distress during and after treatment for head and neck cancer* in the journal MDPI Cancers (Impact Factor 6.575) in August 2022 (Gibson et al., 2021). According to Google Scholar data retrieved July 13th, 2022, this article has 2 citations. The open access article was shared on social media and Facebook data shows an organic reach of 580 readers with 33 post engagements.

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Article

'I Didn't Even Recognise Myself': Survivors' Experiences of Altered Appearance and Body Image Distress during and after Treatment for Head and Neck Cancer

Chandrika Gibson [1,*], Moira O'Connor [2], Rohen White [3], Melanie Jackson [4], Siddhartha Baxi [5] and Georgia K. B. Halkett [1]

[1] Curtin School of Nursing, Faculty of Health Sciences, Curtin University, Perth, WA 6845, Australia; g.halkett@curtin.edu.au
[2] WA Cancer Prevention Research Unit (WACPRU), School of Population Health, Faculty of Health Sciences, Curtin University, Perth, WA 6845, Australia; M.OConnor@curtin.edu.au
[3] Department of Radiation Oncology, Sir Charles Gairdner Hospital, Nedlands, WA 6845, Australia; Rohen.White2@health.wa.gov.au
[4] GenesisCare Perth Radiation Oncologist, Wembley, WA 6014, Australia; melanie.jackson@genesiscare.com
[5] GenesisCare Gold Coast Radiation Oncologist, John Flynn Hospital, Tugun, QLD 4224, Australia; siddhartha.baxi@genesiscare.com
* Correspondence: c.gibson1@postgrad.curtin.edu.au; Tel.: +61-0411-954-851

Simple Summary: In interview data collected from 21 people diagnosed with head and neck cancer in the previous six years, participants reported adequate procedural preparation but little or no preparation related to appearance. Body image distress contributed to psychosocial issues for many people, negatively impacting their adaptation to altered appearance. The main themes included; Preparation (sub-themes: Decision-making; and Preparation for Altered Appearance); Altered Appearance (sub-themes: Weight Loss; Face, Skin and Hair Changes; and Reconstructive Surgery); and Consequences (sub-themes Reactions from Others; Adapting to Altered Appearance). Current practice provides information pre-treatment about many aspects of coping; however, the subject of appearance is not routinely addressed. Communication skills training for health professionals that improves their comfort and sensitivity in discussing and conveying compassion around issues of altered appearance, body image, and trauma, is needed to decrease suffering for survivors, support healthy adaptation to living with altered appearance, and increase patient satisfaction with health care.

Abstract: Purpose: Preparation for head and neck cancer treatment is focused on practicalities of treatment. Little or no time is spent prior to treatment discussing aesthetic results of treatment or the psychosocial impact of living with an altered appearance after treatment. The objective of this study was to explore the experiences of survivors of head and neck cancers, with a focus on the psychosocial impact of altered appearance. Methods: A qualitative research approach based on social constructionist theory was used. Twenty-one semi-structured interviews were conducted with survivors of head and neck cancer who had been diagnosed in the previous six years. Thematic analysis was used to identify themes. Results: People diagnosed with HNC reported feeling rushed into treatment, with adequate procedural preparation but little or no preparation related to appearance. The main themes included: Preparation (sub-themes: Decision-making; and Preparation for Altered Appearance); Altered Appearance (sub-themes: Weight Loss; Face, Skin and Hair Changes; and Reconstructive Surgery); and Consequences (sub-themes Reactions from Others; Adapting to Altered Appearance). Conclusions: Body image distress related to altered appearance, contributed to psychosocial issues for many people diagnosed with head and neck cancer. Current practice provides information pre-treatment about many aspects of coping; however, the subject of appearance is not routinely addressed. Communication skills training for health professionals that improves their comfort and sensitivity in discussing and conveying compassion around issues of altered appearance, body image, and trauma, is needed to decrease suffering for survivors, support healthy adaptation to living with altered appearance, and increase their satisfaction with health care.

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Keywords: head and neck cancer; body image; disfigurement; altered appearance; psychological adaptation; cancer survivorship; communication skills; trauma; compassion

1. Introduction

Head and neck cancer (HNC) is a particularly distressing cancer [1,2], with approximately 35% of survivors experiencing adjustment issues, anxiety or depression [3,4]. Individuals diagnosed with HNC not only face a potentially life-threatening diagnosis but must endure treatments that often result in altered appearance. Research on survivors of HNC has shown that altered appearance is a source of psychological distress [1,5]. Changes in appearance and function can be the result of surgery [6] and chemo-radiotherapy [7]. Surgical treatment to the face and neck has been found to create negative changes in auto-perceived body image in 1/3 of survivors with head and neck cancer (n = 36) [8]. In a survey of people with HNC undergoing surgery, 75% reported feeling concerned or embarrassed by bodily changes following treatment [9]. Facial alterations from head and neck disease, and facial transplants have been described as traumatic and, alongside complications affecting functions such as eating and speaking, contribute to feelings of embarrassment and shame, leading to isolation and negative health consequences [6,10–13].

The highly visible head and neck region is closely associated with sense of self, as faces are a primary social communication tool. Temporary and lasting changes to appearance affect self-concept [12] and survivors need to reconstruct their self-concept and body image after treatment [14]. Gili suggests that in altered facial appearance, the face ceases to be the absent background to perception and gives rise to disrupted perceptions, sensations and observations [14]. This sense of altered self -concept makes it harder for survivors to return to their pre-cancer identities, roles and activities [15] resulting in social isolation [16]. Altered appearance can result in body image disturbance in adults who have been treated for HNC where attributes include: self-perception of a change in appearance and displeasure with this perceived change; a decline in an area of function; and psychological distress regarding changes in appearance and/or function [17]. Adjusting to life with an altered appearance is affected by factors including the extent of the altered appearance, the emotional value placed on appearance, cultural and social norms, the survivors' comfort in managing interactions, and support from their closest community [16,18–20]. Reconciling changes in appearance may not resolve spontaneously [4,21] and typically requires supports and interventions.

Psychosocial interventions have proven effective for conditions of altered facial appearance [22] including in HNC [7]. However, almost all of these interventions have been offered reactively post-treatment [23–26]. In a retrospective cohort study of HNC survivors (n = 1992) it was found that a pre-treatment psychoeducational intervention resulted in better oncologic outcomes [27], however, appearance related concerns were not addressed. Rifkin states that '*While there is likely a complex interplay between physical, cultural, and psychosocial factors and successful adaptation to facial disfigurement, a deeper understanding of these factors might help guide development of interventions that facilitate adaptation to facial disfigurement*.' [28]. It should be noted that much of the literature uses the term 'disfigurement'; however, because some survivors of HNC report the term to be stigmatising [14], in this paper we will refer to altered appearance instead.

The aim of this study was to explore the experience of survivors of head and neck cancer, with a focus on the psychosocial impact of altered appearance. This project is part of a larger study conducted to understand the psychosocial education and support needs of people with HNC and the experiences of health professionals who care for them [29].

2. Materials and Methods

2.1. Design

An in-depth qualitative design was adopted using semi-structured interviews. Social constructionist theory underpinned the design and provided a basis for understanding how realities and views of the world are experienced, interpreted and constructed through an individuals' relationships and via a combination of complex interactions with society, and the meanings that individuals attribute to such interactions [30].

2.2. Participants

To be eligible for this study, participants needed to be over 18 years of age, English-speaking, diagnosed with head and neck cancer in the last six years, regardless of HPV status, and treated in Australia. Twenty-one participants were recruited from cancer centres in tertiary hospital settings, private practice, and not-for-profit cancer support organisations. Snowball sampling was used to recruit further participants. See Table 1 for demographics.

Table 1. Participant Demographics.

Age	Min 34, Max 79	Mean 64 years	SD 10.75
Gender	Males 15	Females 6	Other 0
Time since diagnosis	Min 60 days, Max 1827 days	Mean 646 days or ~21.5 months	SD 713.00
Diagnosis	HPV (P16+) 47% 10/21	Non-HPV 33% 7/21	Unknown 19% 4/21
Treatment Received	Surgery 43% 13/21	Radiation therapy 95% 20/21	Chemotherapy 76% 16/21
Race	Caucasian 95% 20/21	Aboriginal 5% 1/21	Other 0
Education Level	Less than school grad 33% 7/21	School Grad 24% 6/21	Beyond Year 12 qualification 38% 8/21

2.3. Procedure

Recruitment of a convenience sample began with the first author explaining the study to HNC health professionals at hospital multidisciplinary team meetings. Health professional (HP) interviews were also conducted [29]. The HPs recruited relevant participants by providing information sheets and requesting their permission to provide contact details to the researcher, who contacted them by email or phone based on their stated preference. Two of the contacted potential participants declined to participate due to poor health. 19 interviews were conducted face-to-face, and two via an online video conferencing platform. No interviews were repeated. Most interviews took place in participants' homes with one at a treatment centre and two online. A partner was present during one interview, otherwise participants were alone with the interviewer. Interviews were 45–75 min (mean = 61 min, SD = 9.40). All interviews were digitally audio-recorded and transcribed verbatim. Transcripts were not returned to participants.

Interviews were conducted by the lead author using a semi-structured interview guide which had been reviewed by HPs and pilot tested by a consumer. Topics included diagnosis, pre-treatment information, treatment experiences, prognosis, unmet needs, emotional well-being and the impact of HNC on roles and relationships. Participants were asked questions and prompted to elaborate and provide examples from their experience to ensure data were grounded in their realities. The interview guide is available as Supplementary Material.

2.4. Data Analysis

Data was entered into NVivo12 (https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home (accessed on 18 June 2021), an application for qualitative data management. Following the six steps described by Braun and Clarke [31], inductive thematic analysis was conducted by the first, second and last authors. This entailed: (1) familiarisation with the data by repeated reading of transcripts, (2) generation of initial codes line-by-line, (3) identification of recurrent themes, (4) theme checking throughout single transcripts, followed by the entire dataset, (5) creation of labels and definitions for emergent themes, and (6) utilisation of codes and themes to construct findings.

2.5. Rigour

Data collection and analysis were conducted concurrently until data saturation was reached and no new information emerged [32]. A reflexive diary, commonly used in social constructionism, was used to provide a consistent and systematic documented account of the process and context, including interviewer's reflections on body image issues. The first author, a PhD candidate and experienced patient educator, undertook sensitive interview training prior to conducting the interviews. The co-authors participated in interpretation of data, with discussion amongst the research team until consensus on themes was reached, contributing to the dependability of the findings [33]. Reporting was informed by the Consolidated Criterion for Reporting Qualitative Research (COREQ) checklist [34]. The COREQ checklist is available as Supplementary Material.

3. Results

Survivors offered a range of insights about their experiences of being diagnosed with HNC, the impact treatments had on their appearance and function, and the social interactions and communications that influenced their social construction of meaning. Their constructions were articulated via these key themes and sub-themes: Preparation (sub-themes: Decision-making; and Preparation for Altered Appearance); Altered Appearance (sub-themes: Weight Loss; Face, Skin and Hair Changes; and Reconstructive Surgery), and Consequences (sub-themes: Reactions from Others; and Adapting to Altered Appearance) (Figure 1).

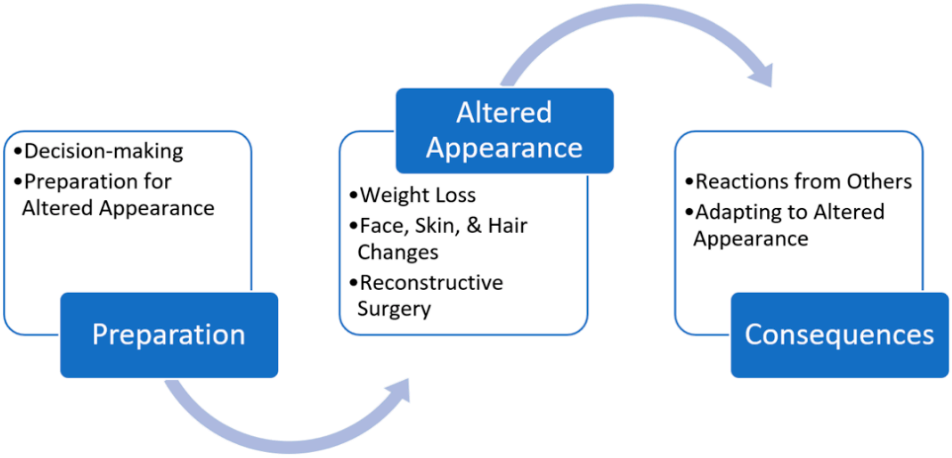

Figure 1. Themes and Sub-themes.

3.1. Preparation

Survivors expressed high levels of satisfaction with pre-treatment preparation in terms of what procedures were expected, and all but one participant felt adequately prepared for treatment. However, they felt unprepared for and traumatised by changes to their appearance, indicating there was inadequate preparation and a lack of informed, shared decision-making. Most survivors described placing trust in their treatment teams, *'I just trust what you are going to do. And that's all there is to it'* PID21. Sub-themes relating to preparation included: Decision-making; and Preparing for Altered Appearance.

3.1.1. Decision-making

Treatment options were presented to patients, however the appearance related consequences were not explicitly discussed. One participant reported that he felt so traumatised following appearance-altering treatment, he regretted his treatment decision. Describing a scenario of cancer recurrence, shaking his head at the idea of undergoing treatment a second time, he said *'I would have to think really hard now if I really wanted to do that again.'* PID16

3.1.2. Preparation for Altered Appearance

Some survivors expressed fear at learning that body parts would be removed to reconstruct the features and organs of their face. Hearing the description of how the surgery would be completed was a shock to most people, for one participant it led to a panic attack:

> *'I heard they were cutting out every part of the upper part of my mouth and they would replace that with parts of my leg, and it was beyond my understanding that they could do that inside my mouth. I felt so confronted and I was starting to shake, and I was getting pins and needles, so my husband just took me for a little walk up the corridor and back, and I had some water. I was dealing with the visceral shock of my mouth being invaded.'* PID13

PID7 initially believed he had a sinus problem requiring cosmetic surgery, but then found it was nasal cancer, requiring complete removal of his nose. This participant expressed that treatment moved quickly and discussed starting radiation therapy unprepared:

> *'There was no preparation, they just said about the treatment and of course I wasn't expecting it to be as uncomfortable as it was the first time.'*

Sometimes treatment didn't go to plan and was more extensive than patients' expected. When asked if HPs had prepared him for the appearance related results of surgery one participant said:

> *'They told me I would lose my teeth, but he did say they were going to save the eye. This eye was not able to be saved though as complications arose.'* PID17

Some survivors asked more questions, but when it came to appearance, most felt it was not worthy of raising and tried to gather information from sources other than the treatment team. For some participants seeking information on the internet was distressing:

> *'I Googled some things that they just said that I was going to have done and you'd only have to look at one picture and you just freak and turn it off.'* PID16

In the absence of more direct communication, survivors were left to deduce what was happening, for example:

> *'I had to meet the prosthodontist for him to take extremely careful views of what my smile looked like at the time-so in other words, get the look of what (participant's name) is before we do this to her.'* PID13

Despite having concerns, the participant still didn't know what to expect in terms of appearance after surgery:

> *'I had no idea whatever about what I was going to look like . . . and I felt vulnerable in anticipation of that.'* PID13

3.2. *Altered Appearance*

Participants felt underprepared for appearance changes that occurred during and after treatment. For some survivors looking in the mirror was a shock:

> *'I didn't even recognise myself. I didn't even know who I was. I looked in the mirror and I didn't even see myself. That's how different I was.'* PID20, while others avoided or delayed looking at the results of surgery, *'it took me about two weeks to actually have a look at where my nose was.'* PID7

It was common to express that aesthetic outcomes were less important than clinical results and yet, some participants were distressed and disappointed with the loss of their pre-HNC appearance:

> *'I often said to them, "Look, I understand there's people that you could be operating on who've got critical cancer and this is really all cosmetic," but I was offered the world and then suddenly it all filters back down to zero.'* PID17

Sub-themes describing aspects of altered appearance included: Weight Loss; Face, Skin and Hair Changes; and Reconstructive Surgery.

3.2.1. Weight Loss

Common side effects related to radiotherapy for HNC are xerostomia (dry mouth), thickened saliva, altered taste and mucositis (painful mucous membranes). These side effects combine to make eating challenging [35]. As a result, many participants described losing weight rapidly:

> *'I've got dry mouth, I've got thick saliva, I've got occasional pain in my throat similar to after the tonsillectomy-type pain, feels like scabs are there . . . I lost maybe 10 kg in a week.'* PID11

Many survivors underwent concurrent chemotherapy which caused nausea and/or vomiting, further contributing to low appetite and under consumption of calories:

> *'They kept giving me injections for nausea . . . but I couldn't eat; I didn't want to eat.'* PID16

Dietitians were frequently involved to provide intervention to manage the side effects of treatment and prescribing high calorie, nutrient dense food and supplements. For some participants it was the first time a health professional had encouraged them to try to put on weight. Some survivors observed that they had been heavy all their lives, frequently cautioned by health professionals against weight gain, so they had mixed feelings about losing weight:

> *'I think (it) is ironic because all my life I've been told to lose weight–but there's this huge focus on keeping your weight up, because if you don't there are all sorts of things that can go wrong like your mask won't fit properly and the treatment won't work as well.'* PID10
>
> Survivors who started with higher body mass, typically lost weight rapidly:
>
> *'I've gone from 120 kilos to 79 kilos. I look like a skin and bone man . . . my face was so withdrawn, I was like a skeleton . . . I have to sit down in the shower now and I'm looking at my legs going, "Jesus Christ, there's nothing there.".'* PID20
>
> While those who were smaller to begin with, became emaciated:
>
> *'I'm only a small build so I looked like something out of a concentration camp.'* PID16

For some the significant weight loss came during the weeks of radiotherapy and chemotherapy:

> *'When I went to treatment I was 60 kilos and when I finished my treatment, I was 38 kilos.'* PID8
>
> For others, major weight loss occurred after completing radiotherapy:

> *'I might have lost two or three kilos during treatment, but the big weight loss was when the mucositis comes in and your membranes are all so sore, you can't swallow, you can't eat, you can't sleep. I lost 20 kgs.'* PID3

3.2.2. Face, Skin, and Hair Changes

Appearance changes related to treatment toxicity were commonly experienced, with participants reporting erythema, lymphoedema, hair loss, and osteoradionecrosis. All but one participant received radiotherapy to treat their HNC, and experienced erythema-inflamed, red and irritated skin. Survivors described the outward appearance of red skin as well as the sensations of discomfort it caused:

> *'It was like somebody taking a blowtorch and just burnt … all my neck and my face.'* PID17

PID14 suffered dry, irritated, itchy skin so uncomfortable he could not tolerate his shirt touching his neck, leading him to self-isolate:

> *'Pretty uncomfortable really. I couldn't go visiting. I went to my daughter's on Tuesday. I was there about half an hour, and I had to come home. I just couldn't talk; I was tired. And I wanted to take my shirt off.'*

Chemo-radiotherapy caused hair loss including facial hair, and many participants observed temporary loss of eyelashes and eyebrows:

> *'I've lost my eyebrows, but they're starting to come back. My eyelashes, I've lost them, but my facial hair now comes back a lot darker.'* PID7

Face shape also changed for some participants such as PID18 who experienced unsightly swelling:

> *'I looked like I had 10 chins and he (doctor) said, "That's just where everything's been attacked and nuked. It'll gradually go down."'* PID18

Radiation treatment has a cumulative effect and side effects often worsen at the end of treatment and after treatment completion. PID4 observed symptoms worsening:

> *'Particularly the last couple of weeks, was quite horrible because it was that cooked and a lot of temperature and a lot of blistering on the neck.'*

While most participants experienced the worst skin changes immediately following treatment, some experienced late effects including osteoradionecrosis:

> *'I got this pretty much straight after the radiation; it started deteriorating my jaw. (It took) five years all up before the jaw actually broke...the jawbone just got so infected and broke and my face was out like a balloon.'* PID16

3.2.3. Reconstructive Surgery

Surgical removal of HNC commonly requires follow up reconstructive surgery for both appearance and function restoration. Participants described aspects of their complex surgeries that caused them distress, such as PID13 who was not informed that she might have leg hair growing inside her mouth:

> *'The fact that the skin that's where my teeth are now, is from my leg, means I get hair there sometimes.'*

Sometimes these free flaps and grafts did not work-for PID17 the promise of a palate took multiple attempts:

> *'(they used) my stomach muscles. That was quite a good palate, it really hung tight actually and then they put a bit of scapula with a bit of bone in, in the muscle … they thought they'd be able to screw teeth into that possibly … that failed after a week so then they went in and put some muscle out of my thigh in there and luckily that took okay.'*

There were commonly delays for those survivors who required follow-up cosmetic surgery:

> *'That's about a two hour operation, but unfortunately, because it's not life-threatening, I have to go on the waiting list.'* PID7

PID16 required multiple surgeries to recreate one side of his face:

> *'They took the jaw from there down to here somewhere and then they took the tibia bone out of my leg and put it in there and then they put a chain, like a bicycle chain-type thing around there for it to heal, but they also had to cut this side of my neck as well to bring all the blood vessels and nerve endings and everything over to this side because radiation had actually killed everything on this side of the face.'*

Altered appearance included the area used to rebuild, where people were left with large scars and functional deficits:

> *'I find it really hard at the moment walking because where they took the bone out of the leg that seems to be more of a problem than the neck and they said that would happen, where they take skin and bone and things is normally the last to heal.'* PID16

3.3. Consequences

Survivors felt acutely aware of the reactions of others to their altered appearance. From interactions with hospital staff, to seeing themselves in the mirror for the first time, and interacting with partners, parents, children and communities, survivors found it challenging to adjust to their new appearance:

> *'People say they don't notice it, but I do and I hate it more than anything.'* PID8

Sub-themes used to describe the consequences of altered appearance included: Reactions from Others; and Living with Altered Appearance.

3.3.1. Reactions from Others

Some survivors found the reactions from others to be one of the most distressing aspects of their HNC experience: *'The lack of education with other people and their insults is something that I had to learn to deal with. '* PID6

> *'I haven't got good self-esteem. To go out, I'm very conscious of people watching me, looking at me. Before you used to look [at] somebody and you'd make eye contact with somebody, that's fine, but now it's eye contact then their contact goes to your face, your neck, and I'm quite aware of it.'* PID16

One participant had become aware of the way people were reacting to her emaciated appearance and decided to say something:

> *'Bad enough people stare at me already because I look like some kind of anorexic walking around . . . I said, "I've just had radiation and chemo for cancer. I actually can't eat anything.'* PID8

Other participants reflected on comments made from others, such as PID6, who also became emaciated, experienced stigmatising comments, and isolated herself so others wouldn't see her:

> *'For a whole year in this house I never went out . . . It all started with a family dinner. When I walked in one of the men said, "Oh my God, (name), you're so skinny. You really need to put on some weight." And that started something for me . . . .I was devastated.'* PID6

For others it was not the reactions from others that hurt, rather the feeling that being unrecognisable to friends was isolating:

> *'I'd have people walk up talking to like me and (partner), family friends walk up and start talking, they were talking to her, and they were sort of looking at me and looking away.*

> *They didn't even know who I was. And then (partner) would go, "Aren't you going to say hello to (participant's name)?" and they were like, "Oh." Nobody knew what to say to me.'* PID20

Family members sometimes did not recognise survivors after treatment:

> *'I didn't see what I looked like, but nobody recognised me–my face was out here and it was green and (daughter) wouldn't believe (partner) when she said, "That's your dad there." "No, that's not Dad." And my mother-in-law came. She took one look and went outside and burst out crying.'* PID17

PID16 thought that his altered appearance was so confronting, it put his marriage under pressure:

> *'You can understand these people that–you've got a married couple whatever and then she'll just go or he'll go because– it's a nightmare for them . . . sometimes my wife would come to the hospital and I'd see her change colour; she'd just go white and have to go outside.'*

A sense of being stared at led to social withdrawal for some survivors. When PID7 first received a prosthetic nose, he tried venturing out:

> *'I went out a couple of times, but I felt uncomfortable because people were really staring at you because it was white, it stood out.'*

Later, his prosthetic nose was altered to look more natural:

> *'I said, "That's really good, but it's too new." So I went back and said "Can you do some more colouring into it and put a bit other stuff in," which he did.'*

This participant observed increased social isolation due to friends and colleagues avoiding seeing him in person:

> *'They'd pick up the phone and ring you, but they don't actually come and see you.'*

3.3.2. Adapting to Altered Appearance

Many survivors who experienced significant altered appearance described a feeling of loss–of the future they had imagined, and of a past version of themselves. For many it was important to their recovery to come to a realisation that ultimately appearance is not what matters, and the richness of their inner lives could not be altered by changing their appearance, for example PID7 who stated: *'I'm still the same person as what I was before the operation.'* Through interactions with others, these constructions helped them adapt to their altered appearance.

PID17 rationalised that he is no longer young and further surgery aimed at cosmetic improvement would be futile:

> *'Intellectually and I think in my heart now I see that it would be ridiculous. I've already had three 12 h-plus operations on this side of my face and, it's not like I'm 25.'*

Others have reassured him:

> *'A lot of people, friends, even women friends, have said, "You're still the same person. It doesn't matter what you look like."'*

PID6 felt that people could see her strength as well as her fragility:

> *'I think people probably see me differently. They thought I was a tough cookie before, but they probably look at me and say that I'm quite a strong person . . . People look at me differently so I feel a bit different, although there is that negative thing of how they feel about me, my weight and how I look, but they also know that I have definitely done it tough and I'm okay still.'*

Returning to social and recreational activities was an important part of recovery for survivors, even when difficult conversations arose:

> *'When I go to my local tavern, people ask me what's happened? I told the bar staff when I had the plastic on and they were, "Bloody hell, you're brave coming out like that." I said, "Well, what do you want me to do?" You can't sit in the house.'* PID7

4. Discussion

This study provides an understanding of the psychosocial trauma of altered appearance, and the construction of the world experienced by people undergoing treatment for HNC. Analysis of the HNC survivors' narratives demonstrates the perceived lack of HP led communication, preparation, screening, and support for people undergoing treatment which is likely to result in altered appearance. All participants reported appearance-related changes, and many experienced lasting changes, which challenged their sense of self due to the social importance of the visible face and neck area. It was through interactions with hospital staff, health professionals, family and strangers that survivors constructed meaning from their experiences. While survivors found ways to adapt, many were re-traumatised by distressing social interactions. These adjustment difficulties are similar to Glassey et al.'s research which found younger women undergoing bilateral prophylactic mastectomies experienced psychological distress related to altered appearance post-surgery. Interestingly, those who had psychological support pre- breast cancer surgery in the study by Glassey et al. adjusted better and reported a more positive body image [36]. This approach of pre-surgery psychological support would be useful for people undergoing surgery for HNC. Every interaction is potentially supportive, so it is important that all health professionals build on their communication skills by undertaking focused training which addresses communication around psychosocial issues of altered appearance and prepares patients to adapt following treatment.

Changes in weight and body composition brought up issues with body image for some survivors. Many participants experienced negative feelings about weight loss which aligns with previous literature, where weight loss is reported to be associated with depression, distress and stigma [37,38]. A novel finding is that some participants were pleased to have lost weight, despite their health professional's advice to maintain body mass. The high degree of focus on dietary intake caused distress for some participants, and there could be a risk of triggering disordered eating. This could be mediated with appropriate screening for body image concerns and eating disorders [38].

Survivors were reticent when requesting information about aesthetic reconstructive surgeries or prostheses as they believed their appearance related concerns may be perceived as superficial. This finding supports earlier work by Fingeret et al. [39] who found that cancer patients were reluctant to raise body image concerns with health professionals. Earlier research found that, rather than being driven by vanity, or even self-consciousness, concerns about altered appearance stemmed from a loss of sense of self, and fear of being stigmatised by others [40]. The interactions between survivors and health professionals typically focused on dysfunction such as pain and inability to eat and did not address altered appearance or body image issues. Furness et al. also found HPs underestimated or neglected psychosocial aspects of rehabilitation following facial surgery for reconstruction due to traumatic injuries or to remove cancer [41]. The clinical implications of lack of preparation for altered appearance include lower patient satisfaction with care, and greater demand for supportive care services post treatment. Some survivors regret having had treatment, potentially disengage from further screening and may decline future treatment if they had a cancer recurrence. This is similar to treatment regret due to altered appearance which has previously been found in women who undergo prophylactic mastectomies [36].

Most participants did not feel prepared for their altered appearance, and their first social interactions with family members sometimes caused further distress due to the reactions of hospital visitors. As they returned to their communities, interactions with friends, family, acquaintances and strangers were frequently experienced as intrusive, insensitive, distressing and added to problems of adaptation. This finding supports the work of Furr et al. [6] who found that problems with altered appearance following face transplantation are rooted in social interactions. Some participants anticipated rejection or disgust due to their changed appearance and would have understood if their partner wanted to leave the relationship. Many others voiced concerns for their loved ones related to their changed appearance. This finding supports work in the field of altered appearance related to orofacial gangrene which found that survivors expected partners to be repulsed [13]. This has implications for psychosexual wellbeing, intimacy, and caregiver support, and there is a need for further research in this area.

Survivors described self-isolation and avoidance of interactions, which reflects Newell's fear-avoidance model of psychosocial difficulties following altered appearance [42]. The tendency to socially withdraw due to altered appearance was also found in a study of partners and survivors who both described changed social and recreational lifestyles, with some survivors withdrawing from social interactions because they did not want to be seen [43]. A number of authors have found that the responses of people close to the survivor have an impact on their adjustment, with negative reactions impeding emotional adaptation [44], and positive social interactions building confidence [15]. Withdrawal from social engagement leads to isolation, loneliness and a loss of confidence, as voiced by our participants and reflected in the literature [15,41].

The effects of radiation treatment on skin were both uncomfortable and unsightly, leading survivors to socially withdraw. Male participants reported feeling sensitive to both how it felt, and how it looked, which contrasts with Rennie et al. who found that men with HNC prioritise function, and distance themselves from concerns about appearance [21]. Our findings align more closely with a study of head and neck and lung cancer survivors, which found stigma was higher for men than women, and highest when altered appearance was greatest [11]. Stigma is generally likely for people with altered appearance regardless of gender [45]; however, it is possibly harder for men to disguise an altered appearance as they tend not to use makeup, scarves or other accessories which could hide the area. Being able to camouflage visible altered appearance has been found to lower distress for female survivors of HNC [46], however, Graboyes et al. point to the inability of cosmetic interventions to effectively address complex psychosocial aspects of body image disturbance [7].

Participants who had reconstructive surgery often required multiple surgeries and described looking very different to their internalised image of themselves, even unrecognisable. Looking in the mirror elicited negative emotional responses, with some survivors avoiding the mirror for weeks after treatment. This has been termed 'mirror trauma' [47] and has been explained as a significant autonomic nervous system shock reaction via the polyvagal response [48]. Earlier research has found similar shock at first sight [41,49], with those who avoid looking in the mirror, likely to experience delayed adaptation [50]. Across a variety of cancer types, a similar theme of concern around future appearance when undergoing reconstructive surgeries can be found. In cancer survivors seeking counselling, regardless of age, sex or cancer type, concern with future appearance was the strongest predictor of counselling enrolment [51]. Our findings point to the need for compassionate, non-judgmental interpersonal interactions to support acceptance of altered appearance. Further research on appearance focused interventions for HNC survivors and those who care for them, including HPs and family carers [52] is needed. Interventions should build on communication skills such as recognizing and responding to emotion, and incorporate health professional reflexivity, self-compassion, and understanding of the impact of cancer treatments which alter appearance.

4.1. Limitations

A strength in this study is that survivors of both HPV and non HPV related HNC were included. Seventy-one percent of participants were male, which is also a strength, as while HNC affects more men than women, health research where participants self-select, often means more female participants are included. The inclusion of an indigenous participant represents 5% of participants compared with 3.3% of the Australian population (ABS

2019). All other participants (95%) were Caucasian. Given the lack of cultural diversity of participants there may be cultural differences that were not explored.

4.2. Practice Implications

Health professionals who prepare people with HNC for treatment need to provide personalised education about altered appearance and could consider screening for distress and referring to pre-surgery psychological support. Where body image distress or appearance related concern is identified by patient disclosure, administering valid and reliable body image screening tools [53–55] prior to treatment could be used to trigger discussion and referral to Psychologists or other supportive care professionals. Regardless of explicit mention of body image or appearance concerns, referrals to psychosocial support should be made routinely prior to treatments expected to alter appearance. All HPs who work with people with HNC could benefit from increased awareness of the psychosocial impact of altered appearance, and training in order to offer focused, trauma-sensitive, compassionate communication prior to and after treatment. Future research could also include peer support groups and family carers, in order to develop interventions that address the social context of survivorship.

5. Conclusions

Body image disturbance and living with altered appearance lead to psychosocial distress for many people diagnosed with head and neck cancer. Current practice provides information pre-treatment about many aspects of treatment, however, the area of appearance is commonly not addressed. Providing greater information, screening, and preparation for altered appearance may influence treatment decisions, and is important for patient satisfaction and empowerment. Feeling unprepared for altered appearance as a result of treatment contributes to the experience of HNC as traumatic. Psychological assessment and support pre-treatment is recommended, especially when treatment is likely to result in altered appearance. Communication skills training for health professionals that improves their comfort and sensitivity in discussing and conveying compassion around issues of altered appearance, body image, and trauma, is needed to decrease suffering for survivors, support healthy adaptation to living with altered appearance, and increase their satisfaction with health care.

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Chapter 7: Study 2: Paper 3: Silenced: Inhibitors and Promoters of Communication

This chapter presents findings relating to loss of voice, drawn from the study exploring experiences of people with HNC.. The objective of this paper was to analyse the data which explored the communication experiences of people diagnosed and treated for HNC—in particular, their communication with health professionals. The paper reports on the detailed analysis of responses relating to communication from 21 participants who participated in semi-structured interviews. Open-ended questions were posed including topics relating to information, education and support needs during and after treatment. The design of this study was underpinned by social constructionism theory as it sought to understand the meanings made by participants.

This paper found that communication between health professionals and patients with HNC was inhibited not only by physical and functional voice changes, but also by issues such as feeling time-pressured and a hierarchical structure in which health professionals are experts and patients feel excluded from decision-making as a result of differences in health literacy and the use of jargon. In contrast, some participants asked for and received person-centred, mindful communication that felt empowering, promoted communication and lowered distress. Four key themes were identified as Voice; Communication; Models of Care; and Compassion. Within each theme, the tension between inhibitors and promoters of communication were explored, providing insight into aspects of communication which people with HNC found lacking, and examples of effective communication which they found helpful.

The findings can be used to inform communication skills training for health professionals, including undergraduate, postgraduate and professional development training. This study adds patients' perspectives to the communication literature and provides clear patient preferences for communication styles. The findings show the complexity of communication between health professionals and people with HNC and identify areas where interventions may prove effective. Further research is required to test tailored communication skills.

This study was published as *Silenced: Patients' experiences of voicelessness in head and neck cancer* in the journal Patient Education and Counselling (Impact factor 3.467) in February 2022 (Gibson et al., 2022). According to Google Scholar data retrieved July 13th, 2022, the article has 29 shares, likes and comments, and 5 tweets. Facebook data indicates an organic reach of 797 people and 48 post engagements.

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Silenced: Patients' experiences of voicelessness in head and neck cancer

Chandrika Gibson[a,*,1], Moira O'Connor[b,2], Rohen White[c,3], Melanie Jackson[d,4], Siddhartha Baxi[e,5], Georgia KB Halkett[a,6]

[a] Curtin School of Nursing, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia
[b] WA Cancer Prevention Research Unit (WACPRU), School of Population Health, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia
[c] Department of Radiation Oncology, Sir Charles Gairdner Hospital, Perth, Western Australia, Australia
[d] Radiation Oncology, Genesis Care, Perth, Western Australia, Australia
[e] Radiation Oncology, Genesis Care, Queensland, Australia

ABSTRACT

Objectives: The objective of this qualitative study was to explore patients' experiences of communicating with health professionals following a diagnosis of head and neck cancer (HNC).

Methods: A qualitative research approach based on social constructionist theory was used. A total of 21 in-depth semi-structured interviews were conducted with people diagnosed with HNC. Thematic analysis was used to identify themes.

Results: The experience of losing the capacity for speech was experienced by survivors of HNC as distressing and traumatic. Voicelessness was not just a loss of physical speech, but a holistic experience of silencing. A number of tensions emerged including patients' experiences of losing their voice and then finding different ways to verbally express themselves; in interactions with health professionals there was a tension between abrupt, hurried communication and a slower, more mindful communication style. Sub-themes around communication style emerged where disparities between levels of health literacy were unaddressed, and patients' experienced a lack of empathy. Another tension experienced was between an old style medical model and the ideal of person-centred care and the biopsychosocial model of health.

Conclusion: Whether HNC patients lose their voice temporarily, have periods of voicelessness, or are able to speak, but feel unheard, the treatment experience is too often one of disempowerment and silencing of their perspectives.

Practice Implications: Health professionals are challenged to find creative communication methods, to practice mindful listening, source speech pathology and adaptive technologies, and to facilitate communication that supports patients in expressing their values, preferences and needs.

1. Introduction

Head and neck cancer (HNC) treatment may include surgery, radiotherapy, chemotherapy, targeted therapy or a combination of treatments [1]. These treatments can cause barriers to verbal communication, including changes to voice quality and reduced speech intelligibility as a result of surgical resection or radiation treatment to tumour sites in the mouth or vocal tract [2]. Depending on tumour site, treatment related variables also may affect communication including xerostomia (dry mouth), hearing loss, and altered dentition [3,4]. A recent review of treatment for HNC found 40 studies describing swallowing-related problems, 24 studies describing voice-related problems, and 7 describing trismus (lockjaw) [5], all of which present physical and functional barriers to communication, and negatively impact verbal communication for people treated for HNC.

Voice and speech changes typically degenerate during the course of treatment for HNC and permanently altered vocal communication and declining voice quality may be experienced by non-laryngeal HNC patients [6] as well as those who have laryngectomies [7–9]. Direct radiotherapy treatment to tumours causes effects to the larynx altering the voice including pitch and volume range [10]; while newer forms of radiotherapy are less damaging, they may continue to affect vocal cord

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* Correspondence to: School of Nursing, Faculty of Health Sciences, Curtin University, GPO Box U1987, Perth, WA 6845, Australia.
E-mail address: c.gibson1@postgrad.curtin.edu.au (C. Gibson).

[1] https://orcid.org/0000-0002-1147-6608
[2] https://orcid.org/0000-0002-7298-5553
[3] https://orcid.org/0000-0002-9646-3653
[4] https://orcid.org/0000-0002-3080-0987
[5] https://orcid.org/0000-0002-6207-1942
[6] https://orcid.org/0000-0003-4065-4044

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function [11,12]. Following chemo-radiotherapy some improvement to voice and speech is typically seen one to two months after treatment, with return or exceeding of pre-treatment function by 12 months post-treatment [13]. Perceptions of changes in voice quality and intelligibility vary between health professionals (HPs) and people with HNC [14]. For example, survivors of HNC report impaired speech following chemo-radiotherapy treatment, in contrast to clinician perceptions of complete intelligibility [15].

Physical and functional barriers to communicative participation often lead to psychological distress. Nund et al. explored the lived experience of $n = 14$ survivors after non-glottic HNC treatment and concluded that communication changes following chemo-radiotherapy have potentially negative psychosocial impacts on HNC survivors and carers [16]. A larger qualitative study ($n = 39$) found that HNC survivors experienced social isolation as a result of difficulties adapting and the increased effort required to communicate [17]. Patients undergoing radiotherapy for HNC are commonly observed by HPs to be emotionally distressed and disempowered [18]; for a sub-population of HNC survivors, their day-to-day communication will change in ways that affect their relationships and sense of self, leading to social isolation and decreased health related quality of life [17,19]. Even short periods of inability to speak are experienced as anxiety provoking [20], leaving patients vulnerable and traumatised.

While physical and functional interventions have proven helpful and continue to evolve with technological advances, the psychosocial impact of short and long-term altered verbal communication is not well understood. This study aimed to explore patients' experiences of communication following a diagnosis of HNC.

2. Methods

2.1. Design

An in-depth qualitative design was adopted and semi-structured interviews used. Social constructionist theory underpinned the design and provided a basis for understanding how realities and views of the world are individual-specific and created through a combination of complex interactions with society, and the meanings that individuals attribute to such interactions [21,22].

2.2. Ethics

The project was approved by the Curtin University Human Research Ethics Committee (HRE2018–0691), and the ethics committees at participating tertiary hospitals (SCGOPHCG HREC number RGS0000001145).

2.3. Participants

The sample comprised 21 adults diagnosed with head and neck cancer in the last six years, and treated in Australia. Participants were recruited from several settings including cancer centres in tertiary hospital settings, private practice, and not-for-profit cancer support organisations, using convenience sampling and snowball sampling. See Table 1 for patient demographics.

Table 1
Patient Demographics.

Age	Min 34, Max 79	Mean 64 years	SD 10.75
Gender	Males 15	Females 6	Other 0
Time since diagnosis	Min 60 days, Max 1827 days	Mean 646 days or ~21.5 months	SD 713.00
Treatment Received	Surgery 43% 13/21	Radiation therapy 95% 20/21	Chemo-radiotherapy 76% 16/21
Race	Caucasian 95% 20/21	Aboriginal5% 1/21	Other 0
Education Level	Less than school grad 33% 7/21	School Grad 28% 6/21	Beyond Year 12 qualification 38% 8/21

2.4. Materials

A semi-structured interview guide was used, that covered diagnosis, pre-treatment information, treatment experiences, prognosis, unmet needs, emotional wellbeing and the impact of HNC on roles and relationships (see Appendix 1). Examples of questions included 'What assisted you in preparation for treatment? How have your relationships been affected by your experience of HNC?' Participants were asked questions and prompted to elaborate with examples from their experience to ensure data were grounded in their realities.

2.5. Procedure

Recruitment of a convenience sample began with the first author explaining the study to HPs at hospital team meetings. The HPs recruited relevant patients by providing information sheets and requesting their permission to provide contact details to the researcher. Nineteen interviews were conducted face-to-face, and two using video-conferencing. Interviews were 45– 75 min (mean= 61 min, SD=9.40). All interviews were digitally audio-recorded and transcribed verbatim.

2.6. Data Analysis

Initial analysis involved reading and rereading of transcripts to understand participants' perspectives. Data was transported into NVivo12 for data management. Following the six steps described by Braun and Clarke [23], inductive Thematic Analysis was conducted. This entailed (1) familiarisation with the data by repeated reading of transcripts, (2) generation of initial codes line-by-line, (3) identification of recurrent themes using collation of similar codes, (4) theme checking throughout single transcripts, followed by the entire dataset, (5) creation of labels and definitions for emergent themes, and (6) utilisation of codes and themes to construct findings related to the research question and tied to the literature reviewed.

2.7. Quality/rigour

Data collection and analysis were conducted concurrently until saturation was reached; saturation was deemed to have occurred when no new information emerged and themes recurred [24]. Repetition in the data informed themes and added to the credibility of qualitative findings. The co-authors participated in analysis and interpretation of data, with discussion amongst the research team until agreement was reached, contributing to the dependability of the findings [25]. As is commonly used in social constructionism, a reflexive diary was kept to provide a systematic account of the context and process. Reporting was informed by the consolidated criterion for reporting qualitative research checklist COREQ [26].

3. Results

The data revealed four themes containing tensions or contrasting experiences which demonstrate patients' perspectives of communicating with HPs and others. Fig. 1 demonstrates the four themes with communication inhibitors and promoters identified; Voice: Voicelessness and Finding a New Voice; Communication: Time-pressured Communication and Mindful Communication; Models of Care: Medical Norms and Person-centred Care; and Compassion: Lack of Empathy and Compassionate Communication. Design of this figure was informed by the framework of communication promoters and inhibitors by Tay et al. [27]. In each theme described, communication inhibitors are identified, followed by examples of promoters of communication, as described by patients.

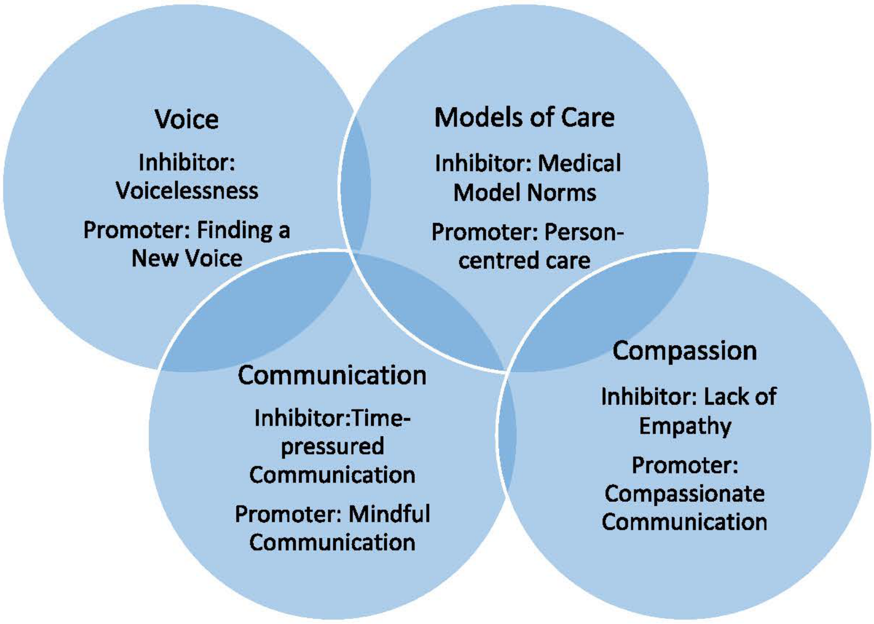

Fig. 1. Inhibitors and Promoters of Communication Experienced by People with HNC.

3.1. *Voice: Voicelessness and Finding a New Voice*

Periods of voicelessness were common during treatment. One patient explained that their cancer was on their vocal cords so they had numerous periods of being unable to speak, 'After every surgery… no talking, no whispering, not even mouthing the words because you can't get that movement of your vocal cords.' PID2.

For patients who had laryngectomies, adaptation was required, 'The only conversation I could have was by writing down. And that was frustrating, it's very difficult to enter a conversation.' PID17.

People found it frustrating being unable to speak, however they found new ways of communicating, often due to support from speech pathologists. Low technology Speech Pathology interventions, such as tongue and jaw exercises delivered with compassion, improved communication,

'A lot of the help that makes you feel okay is when it's normalised. When they say, "You will sound like that; everybody does," and they go, "Try putting your tongue here, putting your tongue there, do these exercises." PID17.

Augmentative and alternative communication (AAC) devices allowed patients to find new ways to communicate, 'I had an app on my phone, text to speech, so I would type something and then press and it would say it, but it was that robot-y kind of voice and I felt so weird.' PID2.

PID17 learnt to use a speech generator, 'the first time you manage to do a Darth Vader, eventually you're well enough to touch it like that and you go, [sounding robotic] "I went like that."'.

3.2. *Communication: Time-pressured and Mindful Communication*

In healthcare settings, participants reported a lack of time to open up a conversation with HPs as communication focused on procedures and moved fast, 'It was just overwhelming. No-one would really tell you what was going to happen…you didn't have time for that. They come in, went out and you didn't have time to even ask a question really.' PID16.

Some patients felt the fast pace was impersonal, 'I think really it's such a production line that they don't have time for any conversation or 98% of conversation is to do with your treatment'. PID9.

However, when a patient was able to ask for things to slow down, communication improved, 'I was like, "Sorry, can you slow down for a sec? I don't quite understand what the situation is." And then they realised at that point and I remember there was a real shift…because they were so frantic…when they saw me sort of say, "Look, I need you to just stop and just give me your attention for a minute," I saw them recognise that and their whole body [stopped]… and they talked me through on a normal level the whole situation to kind of reassure me.' PID2.

A slower pace was also helpful in terms of delivery of pertinent information. 'They're very good at feeding it out to you as the time comes…, they try not to overwhelm you…they give you the information as you need it; they don't give you all the information at once because otherwise you just wouldn't cope.' PID10.

3.3. *Models of Care: Medical Model Norms and Person-centred Care*

The medical model was frequently experienced as overwhelming and unfamiliar. Participants reported that HPs' use of jargon and euphemism was confusing, and contributed to an experience of voicelessness. For example, patients sometimes felt overwhelmed by the sheer number of staff they interacted with, especially when they were not informed of who was responsible for what area of care,

'I class it as a speed dating episode with thousands of doctors it seemed like, but it was probably, I don't know, 14 or something doctors, that would come in the room and probe you and touch you and talk to you and then run out and then another one would come in and we both felt just mortified really because it was such – so quick and so confusing and didn't know what was happening whatsoever.' PID16.

Multiple staff members and handover processes caused concern and confusion, such as this description of potential medication errors, 'The system is not the nurses' fault but it is a total, absolute shambles. I was having three sets of shifts over the 24 h and I'm quite sure that one nurse would give me drugs at the end of their shift, looking at the time, "Oh, I'm finishing at 6 and they're due their drugs at 6 so I'll give them at 10 past 5," or whatever, which wouldn't be a problem. But then the next nurse would come on at 6 and go, "Oh, they haven't had their drugs at 6."' PID9.

Poor intra-staff communication and contradictory communication to patients added to confusion, 'One doctor would come in and they'd say, "Oh, you need this, that and the other," and the next doctor would come in and say, "Oh, no, no, no. You need this, that and that other." And they were just changing me on stuff left, right and centre and I didn't know whether I was coming or going and there'd be something that I thought was working and then they'd change me onto something else which I thought didn't work…I thought, 'Jesus, don't they ever talk to one another, these people?' PID19.

Another patient felt similarly about the information they were given pre- treatment, 'In some cases it actually was contradicting each other. You look at it and go, "What? Why doesn't just one lot of people do this?" PID20.

Disparities in health literacy and language between HPs and patients sometimes led to communication difficulties. Receiving a diagnosis in euphemistic language led patients to seek clarification, '"You've got a mass in the side of your face," and they kept saying mass and I said, "When you say mass, do you mean cancer?"' PID17.

The use of jargon also left patients outside of the conversation about their health, 'I remember they were all frantic and they were talking in like medical language and talking to each other in medical language before they had spoken to me.' PID2.

In contrast, when interactions with HPs were more tailored, offering patients choice, and modelling a calm, measured approach, patients felt more seen and heard. This approach helped reduce patient anxiety, 'The people themselves really helped; they kept everything calm and it was good. At any time, I could stop and get out so it was good.' PID16.

One patient described how a radiation therapist helped to calm them using touch and slow movement, when the mask would trigger claustrophobia and panic, 'They kept one hand on my arm. They were going like this to me (patting his arm slowly) and they just clicked it all down slow because my heart rate would just go through the roof. Because I'm terrified with stuff like that…they just made it all that much better.' PID21.

3.4. Compassion: Lack of Empathy - Compassionate Communication

Participants felt that the HP-patient dynamic had an inherent power imbalance which was sometimes interpreted as a lack of empathy. Patients described their position in the hierarchical relationship, 'They were very old school, you felt much more that I'm the surgeon and you're the patient with them.' PID17.

The power differential between patients and HPs sometimes felt patronising, 'They think they're gods, but they're not gods. they know best so do as you're told. Well, we will – because we have to listen to you, but don't treat us all like dickheads.' PID20.

Weight management and eating were common topics where patients felt misunderstood or that their efforts to communicate about their experiences were ignored, 'They didn't want to listen to me when I kept telling them that I'd put lots of weight on before I started so my normal weight is around 80 kilos, but they just seemed to go back to that, "You were 91 kilos when you started." I couldn't get that out of their heads… I know they want the best, but it seems to me the way they go about it sometimes, they could be a little bit more empathetic.' PID19.

Even when medical feeding had commenced, patients still expressed a communication barrier regarding food. 'Maybe they had trouble understanding me. But they would constantly be bringing me a yogurt or jelly – I couldn't eat them… I was saying, "Take it away. I don't want it." And I was polite. I said, "I can't eat it. I'm on the drip. If I could eat it, I'd take it." PID9.

In contrast, patients appreciated when support staff and HPs showed interest in their life outside treatment, 'You walk in there, "How are you going today?" "Oh, good thanks." And when you finish, "What have you got on today? You doing anything later on? You doing anything on the weekend?" They're really, really good people.' PID14.

HPs offering non-clinical support made a positive difference for inpatients, 'The fact that they would actually occasionally drop in when there was no medical procedure, just to say, "Hi, how're you going?" "What are you up to? " And you could have a conversation with them about different things which was great.' PID17.

Communication which conveyed compassion gave patients a sense of being heard, respected, and related with as an equal. This contributed to a greater satisfaction with treatment, 'I can't praise this place enough. No one talks at you, they talk with you. No one's saying you're doing this wrong; you should do it this way.' PID11.

Having a single HP make a compassionate connection helped patients to cope with treatment, in this case an allied HP stood out, 'they've been very helpful and very understanding and very encouraging'. PID10.

PID17 found non-hierarchical interactions with support staff who demonstrated kindness were helpful and validating, 'The person bringing your meal or the people doing the cleaning acknowledging you…I felt like I was a real person. I felt they were being kind enough to share their energy with me and I felt their energy helped me…that they saw me as a person…rather than again, move over, turn over, thanks, off I go now.'.

4. Discussion

4.1. Discussion

HNC survivors described four key tensions concerning their experience of communication difficulties following treatment. These tensions can be articulated as inhibitors and promoters of communication and include; voicelessness and finding a new voice, time-pressure and mindful communication, lack of empathy and compassionate communication, and medical model norms and patient-centred care. These tensions highlight the limitations of current health systems, which contrast with patients' preference for a more mindful, person-centred, compassionate style of care and communication as ideally informed by the biopsychosocial model of care. Despite extensive literature demonstrating the deficiencies of the classic medical model in which norms may be defined as reductionist [28,29], our findings show that patients still felt reduced and dehumanised within the treatment setting in interactions with care providers. When viewed through a biopsychosocial model lens, biological loss of voice due to treatment was a cause of distress which was exacerbated by the psychosocial impact of feeling unheard. A central, overarching finding was that patients felt voiceless not just because of an inability to speak but also due to feeling a lack of power to 'voice' their concerns.

This study found that during and after treatment HNC patients experienced voicelessness in a number of ways, and their examples expressed the sense that voicelessness was more holistic and complex than the loss of capacity to speak. Our findings support earlier work in critical care where voicelessness was defined as including physiological, psychosocial and technical barriers which limit patients' ability to convey their inner life to others [30]. This experience of voicelessness was distressing, yet there were person-centred communication approaches and supportive care from HPs that helped, and promoted healing and patient empowerment.

The first tension centred on the physical loss of speech which is a known issue in HNC. Patients described periods of silence following surgeries, and some required adaptive technology to verbally communicate. For many patients, there was a permanent change in their voice, and ongoing barriers to speech such as xerostomia as a side effect of treatment. Speech pathology interventions both low tech such as exercises, and high tech such as text to speech apps and voice generators promoted communication, even in the absence of usual voice. While participants noted the unnatural sound of their new voices, the capacity to verbally communicate was highly valued for the way it enabled them to find a new voice. This reflects research that demonstrates the importance of tools that support verbal communication for mental health and wellbeing in HNC [20,31].

The second tension of time-pressure and mindful communication is interesting; time-pressure is a normal part of health care settings, but earlier work has noted the high technology clinical spaces and time-pressures of radiation treatment centres contributed to anxiety and distress for many patients, who described feeling dehumanised [32,33]. The participants in this study articulated this as feeling rushed or 'on a production line' which made communication difficult and limited to procedural necessity. The embodied practice of mindfulness allows for present moment awareness and attention to what is being communicated. It doesn't solve the systemic problems of high workloads and understaffing, yet patients were able to voice their need for HPs to slow down and give them undivided attention. Mindful communication training not only benefits the patient by allowing them time to communicate, it has also been found to decrease HPs' distress and risk of burnout [34,35].

Lack of empathy and compassionate communication were also articulated by participants as contrasting experiences of communication. Empathy has been defined as ability to put oneself in the shoes of another and feel with them, and this is something patients felt was lacking, in particular when a power imbalance was experienced between HP and patient. There was a contrasting experience; when HPs were able to not only feel with them, but also offer a communication style that embodied compassion, patients felt deeply reassured. Compassion has been studied extensively in health settings and is defined as empathy plus meaningful action to decrease suffering [36]. Studies on compassionate communication have centred on palliative care and end of life communication [37–39] where compassion focused interventions have been successful in decreasing HP compassion fatigue and anxiety [40]. It may be hypothesised that less anxious, more compassionate HPs will foster compassionate communication with patients. Further development of targeted interventions is warranted for people experiencing HNC and the HPs who care for them.

Medical model norms were found to inhibit communication, while person-centred care promoted communication. The hierarchical structures of health, the lack of shared language, and an outdated paternalism were experienced as silencing. Berry et al. are among a body of authors who suggest that the power imbalance between clinicians and patients, can be experienced by patients and family members as disempowering [41]. Our findings support earlier work showing that even affluent, educated patients feel compelled to conform to socially sanctioned rules, are reluctant to disagree, and tend to defer to physicians [42,43]. This echoes research which highlighted patients' fear of being labelled as 'difficult' which leads to their passive role in the HP-patient dyad [44]. Participants from a variety of educational and socio-economic backgrounds felt silenced, although some were able to speak up and be heard, effectively recalibrating the power differential.

A plausible explanation for silencing of patients in this unequal power dynamic may be a response to trauma [45], wherein people seek to please those who have power over them, due to a history of trauma or adverse childhood events (ACEs). Cancer diagnosis can be experienced as traumatic [46] and treatment settings may trigger post-traumatic stress symptoms [47]. When communication styles of HPs emphasise the power differential, as described by our participants, this trauma may be exacerbated. Person-centred care is one aspect of trauma-informed care [48], and the benefit of this individualised approach is highlighted by our finding of the impact of non-verbal support and reassurance when patients are on the radiotherapy table.

In this study, communication was inhibited by the use of euphemisms and jargon, and participants expressed their preference for clear, unambiguous language, reflecting work by Nickel et al. who reported that patients are more accepting of adverse events when undergoing surgery if a nodule is labelled as cancer as opposed to a lesion [49]. Using lay language and tailoring communication to meet patients' health literacy has been explored amongst radiation oncologists [50] and radiation therapists [51]. A recent review [52] supports our findings that HNC surgery is a good example of when patient values and perspectives should be sought and patient preference-sensitive decisions must be made.

4.2. Limitations

95% of participants were Caucasian and given that communication is intertwined with cultural norms, there may be cultural preferences and differences that were not explored. 71% of participants were male, reflecting the higher prevalence of HNC amongst men. This may however mean that women's perspectives are underrepresented. Only 38% of participants had a non-school qualification compared with 69% of the general population (Australian Bureau of Statistics 2020) which is likely to contribute to greater information needs amongst participants [53]. While it is a strength that both HPV and non-HPV related diagnoses were included, education levels and therefore information needs may differ between these groups.

4.3. Conclusion

HNC patients experience a loss of agency, which transcends the loss of their physical voice, and they feel voiceless and silenced. As part of their recovery, they sought to find a new voice with which to communicate their needs. There are a number of tensions involved in communication in the patient-HP dyad including voice and speech loss, time pressure, medical settings and their cultural norms, and HP communication styles. Whether people with HNC lose their voice temporarily, have periods of voicelessness, or are able to speak but feel unheard, the treatment experience is too often one of disempowerment and silencing of their perspectives. Promoters of preferred communication include being seen as an individual and receiving care that is tailored to their unique circumstances, which is the essence of person-centred care, a model of care that broadly addresses components of the biopsychosocial model. Patient or person-centred care is a key principle outlined in the updated Head and Neck Cancer Optimal Care Pathways [55], which also prioritise communication in plain language at a level relevant to patients' health literacy [54]. HPs are challenged to find creative communication methods, to practice mindful listening, source speech pathology and adaptive technologies, and to facilitate compassionate communication that supports patients in expressing their values, preferences and needs.

4.4. Practice implications

This study points to the need for interventions such as HP education that increases compassionate communication skills, and leads to pre-treatment consultations that utilise a biopsychosocial model central to person-centred care. Throughout treatment interactions have an emotional and psychological impact on patients, and HPs would benefit from training that gives them time-sensitive skills in communicating with compassion, showing empathy, and delivering information without using medical jargon in order to improve care and enhance the experience of patients.

CRediT authorship contribution statement

Chandrika Gibson: Conceptualization, Methodology, Software, Formal analysis, Investigation, Data curation, Funding acquisition, Writing – original draft. **Moira O'Connor:** Supervision, Formal analysis, Writing – review & editing. **Rohen White:** Writing – review & editing, Validation, Resources. **Melanie Jackson:** Writing – review and editing. **Siddhartha Baxi:** Writing – review & editing. **Georgia Halkett:** Supervision, Formal analysis, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they do not have any conflicts of interest to declare.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2022.02.007.

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Chapter 8: Study 2: Paper 4: Life After Head and Neck Cancer

The objective of the third paper from Study 2 was to explore HNC survivors' experiences of life post-treatment, with a focus on those who navigated pathways to growth including returning to work and other activities. The manuscript titled *"Return to valued activities: Survivors' experiences of adaptation and growth after treatment for head and neck cancer* is in press (December 2022) with the journal *Psycho-Oncology* (Impact factor 3.955).

This paper presents reflective thematic analysis of 21 HNC survivors' stories of post-treatment rehabilitation and recovery, underpinned by social constructionism theory. Semi-structured interviews included questions about role changes, information and support needs. Professionally transcribed interviews were entered into NVivo12 data analysis software, and themes were discussed among the student researcher and supervisors, with input from co-authors once themes were identified. Findings include the ways in which participants navigated the challenges of late and lasting effects, which were managed or modified to varying degrees by their rich internal lives. Returning to previous roles was not always possible, and participants explored how they made meaning from their new circumstances, finding creative pathways back to meaningful activities. Survivors reported internal and external change and development, and these findings are grouped under the themes of Mindfulness; Gratitude; and Adaptation.

This paper has clinical relevance because the findings can be used to inform and tailor health professional communication skills training. Health professionals potentially have a role in fostering adaptation by supporting patients to reflect on their values and find meaning on their path to recovery. Support programs for people with HNC are relevant at the end of treatment, and findings from this study could inform interventions which aim to minimise the psychosocial distress experienced when treatment ends. Development, piloting and evaluation of survivorship interventions, with outcome measures including unmet needs in survivorship, are needed.

Return to valued activities: Survivors' experiences of adaptation and growth after treatment for head and neck cancer

Chandrika Gibson[1*], Moira O'Connor[2], Rohen White[3], Melanie Jackson[4], Siddhartha Baxi[5],

Dianne Sheppard [6,] Georgia KB Halkett[1]

[1] Curtin School of Nursing, Curtin University, Perth, Western Australia

[2] WA Cancer Prevention Research Unit (WACPRU), School of Population Health, Curtin University, Perth, Western Australia

[3] Department of Radiation Oncology, Sir Charles Gairdner Hospital, Perth, Western Australia

[4] Radiation Oncology, Genesis Care, Perth, Western Australia

[5] Radiation Oncology, Genesis Care, Queensland

[6] Monash University Accident Research Centre, Office of the Provost and Senior Vice-President, Monash University, Clayton Campus, Melbourne, Victoria, Australia

***Corresponding author: Chandrika Gibson**

Curtin School of Nursing, Faculty of Health Sciences, Curtin University, Western Australia

GPO Box U1987, Perth WA, 6845

Ph: 0411 954 851 Email: c.gibson1@postgrad.curtin.edu.au

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Conflict of Interest Statement

The authors have no conflict of interest to declare.

8.1 Abstract

Objective: The objective of this paper was to explore the experiences of head and neck cancer (HNC) survivors' who returned to valued activities to understand how they reconstructed their lives following HNC diagnosis and treatment. It is part of a larger study exploring HNC survivors' psychosocial experiences.

Methods: A qualitative research approach based on social constructionist theory was used. A total of 21 in-depth semi-structured interviews were conducted with adults diagnosed with any type of HNC in the previous six years. Reflexive thematic analysis was used to identify themes.

Results: HNC presents a unique trauma following which some survivors navigate paths back to meaningful activities. The experiences of HNC survivors who adapted to life after treatment were described in terms of internal and external change and development, identified by three themes; Mindfulness; Gratitude; and Adaptation.

Conclusion: People diagnosed with HNC frequently experience lasting effects and other survivorship issues, however some survivors were able to return to valued activities and recreate a meaningful lifestyle reflecting the possibility of post-traumatic growth. This study provides insight into the experiences of head and neck cancer survivors who were able to make meaning and find internal and external growth following treatment. These findings can be used to inform advanced communication skills training for oncology health professionals and psychoeducational programs for people diagnosed with head and neck cancer in the future.

Keywords: Head and neck cancer. Cancer survivorship. Return to work. Return to valued activities. Mindfulness. Post-traumatic growth. Psycho-oncology. Cancer. Oncology.

8.2 Background

Head and neck cancer (HNC) includes malignant neoplasms of the lip, oral cavity, pharynx, as well as upper respiratory and intrathoracic organs (*Head and Neck Cancer Treatment Options*, 2020). Survival is improving for some patients with HNC due to evolutions in therapy and shifts in the aetiology of some cancers, such as Human Papilloma Virus (HPV)-associated oropharyngeal carcinoma (Cohen et al., 2016).

The current 5 year survival rate for all HNC types is 71% (*Head and Neck Cancer Treatment Options*, 2020)
which is very close to the 70% survival rate for all cancer types excluding non-melanoma skin cancers (Australian Institute of Health and Welfare, 2021). Researchers estimated that more than 68,000 men and women in the United States would be diagnosed with HNC in 2021 (Siegel et al., 2021). At the end of 2015, there were 4,355 people in Australia who had been diagnosed with HNC that year, 16,891 survivors who had been diagnosed with HNC in the previous 5 years (from 2011 to 2015) and 45,919 survivors who had been diagnosed with HNC in the previous 34 years (from 1982 to 2015) (*Head and Neck Cancer Treatment Options*, 2020). These figures compare with the estimated 151,000 diagnoses, and 49,000 deaths attributed to all cancer types in Australia in 2021, where HNC accounts for 2.5% of deaths (Australian Institute of Health and Welfare, 2021).

HNC has distressing effects due to the nature of treatments and social significance of the highly visible head and neck area (Callahan, 2005). For many patients diagnosis and treatment for HNC is experienced as traumatic and is associated with multiple layers of distress including anxiety, depression, and stigma (Lebel et al., 2013). Alongside follow-up cancer care, survivors also must be responsible for the daily management of often intrusive physical and psychological symptoms, including difficulties with eating and speaking (Saeidzadeh et al., 2021). Issues of survivorship are not limited to the first five years after treatment but may continue for the rest of the person’s life. Psychosocial issues of HNC survivorship include disproportionately high incidences of depression, substance use, and distress related to relationship conflict, social isolation, altered appearance, and damage to self-image, relative to other cancer types (Smith et al., 2017).

Returning to work following diagnosis and treatment of cancer has been explored (Baxi et al., 2016; Keesing et al., 2018; Weaver et al., 2021), in the context of it being an important indicator of recovery. Parsons and Eakin argue in their work on bone cancer survivorship that the definition of work should be conceptually broadened to include three types of work; illness work, identity work, and vocational work (Parsons et al., 2008). For example, illness work may occur when illness is all consuming and vocational work is not possible. Illness work precipitates identity work in that people find their life story or biography, altered in such a way that they feel transformed, hence work does not only encompass vocational work but also internal adaptation work (Parsons et al., 2008). It is rare that survivorship research touches on all of these aspects of recovery and, although some studies have explored returning to valued roles and activities in other cancer types (Keesing et al., 2018), this has not been investigated in survivors of HNC.

The aim of this study was to explore the experiences of HNC survivors who returned to valued activities in order to understand how they reconstructed their lives following HNC diagnosis and treatment. This project is part of a larger study investigating psychosocial experiences of people diagnosed with HNC (Gibson et al., 2021), and the experiences of the health professionals (Gibson et al., 2021) and family caregivers (Halkett et al., 2020; Weaver et al., 2022) who support them.

8.3 Method

8.3.1 Design

An in-depth qualitative design was adopted, and semi-structured interviews used. Social constructionist theory underpinned the design and provided a basis for understanding how realities and views of the world are individual-specific and created through a combination of complex interactions with society, including interactions between participants and researchers, acknowledging the lens of the researcher and the meanings that individuals attribute to such interactions (Given, 2008; Harré, 2002).

8.3.2 Ethics

The project was approved by the Curtin University Human Research Ethics Committee (HRE2018-0691), and the ethics committees at participating tertiary hospitals (SCGOPHCG HREC number RGS0000001145).

8.3.3 Participants

The sample comprised 21 adults diagnosed with head and neck cancer in the last six years, having completed treatment in Australia. Participants were recruited from several settings including cancer centres in tertiary hospitals, private practice, and not-for-profit cancer support organisations using convenience sampling. The mean age of participants was 64 years (SD=10.75 years), and the mean time since diagnosis was 21.5 months (SD=713 days). See Table 1 for patient demographics.

Table 1 Patient Demographics

Age	Min 34, max 79	Mean 64 years	
Gender	Male 15	Female 6	Other 0
Time since diagnosis	Min 60 days, max 1827 days	Mean 646 days	
Diagnosis	HPV (P16+) 47% 10/21	Non-HPV 33% 7/21	Unknown 19% 4/21
Treatment received	Surgery 43% 13/21	Radiation therapy 95% 20/21	Chemotherapy 76% 16/21
Race	Caucasian 95% 20/21	Aboriginal 5% 1/21	Other 0
Education level	Less than school grad 33% 7/21	School grad 24% 6/21	Beyond Year 12 qualification 38% 8/21

8.3.4 Materials

A semi-structured interview guide was used that covered diagnosis, pre-treatment information, treatment experiences, prognosis, unmet needs, emotional wellbeing, and the impact of HNC on roles and relationships. Examples of questions included ‘Did you feel adequately prepared for treatment? What assisted you in preparation for treatment? Have any of your relationships been impacted by your experience of HNC? Did you find any benefits from this experience?’ Participants were prompted to elaborate (e.g ‘Can you share an example?’) to ensure data was grounded in their realities. In this paper we have analysed responses relating to survivorship with a focus on participants who returned to valued activities after treatment for HNC.

8.3.5 Procedure

Convenience sampling was used whereby health professionals engaged in HNC care recruited patients by providing information sheets and with permission providing contact details to the researcher (Gibson et al., 2021). Consenting participants were contacted by the lead author by email or phone, and interviews arranged. Nineteen interviews were conducted face-to-face, and two via a video conferencing platform. Interviews were 45– 75 minutes (mean= 61 minutes, SD=9.40). All interviews were digitally audio-recorded and professionally transcribed verbatim.

8.3.6 Data Analysis

Initial analysis was completed by the first author and discussed with all authors. It involved repeated reading of transcripts to understand participants' perspectives (Pope et al., 2000). Data were transported into NVivo12 for data management. Following the inductive process described by Braun and Clarke (Clarke & Braun, 2017a), reflexive thematic analysis was conducted. This entailed (1) familiarisation with the data by repeated reading of transcripts, (2) generation of initial codes line-by-line, (3) identification of recurrent themes using collation of similar codes, (4) theme checking throughout single transcripts, followed by the entire dataset, (5) creation of labels and definitions for identified themes, and (6) utilisation of codes and themes to construct findings related to the research question and tied to the literature reviewed.

8.3.7 Rigour

Data collection and reflexive thematic analysis were conducted concurrently with repeated readings and reflective practice (Byrne, 2021; Strauss, 1998). NVivo12 software enabled coding of large amounts of data, facilitating both depth and richness of analysis. Repetition in the data informed themes and added to the credibility of qualitative findings. The majority of interviews were conducted by the first author, who reflected on their health science training, role in supportive cancer care, possible bias due to prior contact with some participants, and personal experiences with facial surgery. The co-authors participated in analysis and interpretation of data, with discussion amongst the research team until consensus was reached, contributing to the dependability of the findings (Lincoln, 1985). A reflexive diary, commonly used in social constructionism, provided a systematic account of the context and process. Reporting was informed by the consolidated criterion for reporting qualitative research checklist COREQ (Tong et al., 2007).

8.4 Results

HNC survivors who were able to navigate pathways back to valued activities experienced internal and external change and development, described by three organising concepts or themes:

1. **Mindfulness** – a state of nonjudgmental awareness which includes turning towards suffering that allows integration of experiences into new self-concept.
2. **Gratitude** – appreciation and savouring of what matters – family, relationships, inner life; and
3. **Adaptation** – finding a way to restore interrupted sense of self through work, sport, and hobbies even if they are somewhat altered.

8.4.1 Theme: Mindfulness

In response to the unique trauma of HNC diagnosis and treatment, and in the absence of formal instruction in mindfulness, several survivors found a self-reflective state of moment-to-moment non-judgemental awareness which encompassed acceptance and equanimity,

> *I … learnt this little safe spot which is in the moment*. PID5

PID11 describing getting through treatment by using single-pointed attention,

> *Just concentrate on concentrating on what's actually happening, not everything at once.* PID11

Slowing down and choosing to respond to life rather than react was an important realisation,

> *It's taught me to slow right down… it has changed my perspective on life and… it's just made me stop and think before I make comment or do anything.* PID16

During recovery, a few participants felt that they had become more equanimous and able to accept the experience of HNC,

> *It's that you…have this peace that things are going to happen with or without you and whatever you want or don't want to happen is still going to happen.* PID5.

Managing one's own mindset and looking within was a significant component in accepting the HNC experience,

> *…a lot of people say you need support… but frame of mind is more – you've got to get yourself in order…Nothing's ever going to make you better or make things change unless you can come to terms with what's happening.* PID21

8.4.2 Theme: Gratitude

Having navigated HNC diagnosis and treatment put the rest of life in perspective, promoting gratitude for life including people and the natural environment, which one survivor equated to spirituality,

> *It's not an experience that you would put your hand up for but…it kind of spiritualises you in a way.* PID17

Following treatment, participants expressed a renewed appreciation for all aspects of life. When asked if anything good had come from the experience of their cancer diagnosis, one survivor said,

> *Being alive. Waking up every morning.* PID3

Feeling that the HNC experience had shifted any complacency was also a common perspective,

> *Given my life a bit of a shake-up… every day is important.* PID21

Gratitude for life included finding a sense of connection with nature,

> *I feel more connected to trees and flowers and people and animals and creatures in that…everything's trying to make its way through life, you know.* PID17

A renewed appreciation and commitment to prioritising relationships was expressed by a number of survivors,

> *We've definitely…planned to do more things together. Like… make time to have more holidays instead of just work all the time.* PID19

Family relationships took on greater meaning.

> *Your bond does get stronger with your family… you're more appreciative of it.* PID21

8.4.3 Theme: Adaptation

Survivors returned to activities that they valued pre-treatment, including work, hobbies, community and sporting activities, however they commonly returned with an altered perspective internally, and required an adapted approach externally. In some situations their changed physical capacities or reoriented priorities led them to find creative solutions to allow participation.

> *I think to re-engage…with what you did before you had cancer is important.* PID17

Several participants found their workplaces were accommodating of their needs after treatment. For this survivor work was very important and they set a goal to get back to work, which was delayed by a second diagnosis,

> *I got back…and was doing three or four hours a day here. Work was good for me and then in August they said, "We've found some more over this side."* PID5

For a few participants financial necessity motivated their return to work, while for others there were non-monetary aspects of working that were meaningful, such as social connections,

> *I want to get back as quick as I can. Not because of money but…I run the social club you see.* PID14

Rather than returning to work in the same role as pre-treatment, a number of survivors felt motivated to change careers or undertake further training.

> *I totally shifted. That's what made me decide to be a yoga teacher, was that experience…that made me really realise I'm not going to waste what time I have left on this planet doing something that is really stressful and it's causing me all this stress.* PID2

Selling a business to free up resources to travel was a life decision demonstrating adaptation brought on by HNC,

> *I'm at the stage – well, we both are, in our life, that everything's changed, all priorities have changed… We were talking about just selling everything and getting a mobile home…Things that used to be important to me aren't really anymore.* PID16

Re-engaging with communities and activities they had previously valued was important to survivors. Returning to these activities sometimes presented challenges due to physical limitations post-treatment, and survivors adapted by changing their expectations and finding new outlets. Some activities proved to be too strenuous following treatment, but they found ways to adapt or replace their hobby,

> *Actually, I've given up golf now…I now bowl…It's a bit of exercise.* PID3

Returning to the level of cycling enjoyed pre-treatment was a gradual process for this participant,

> *Not as intense as I was before but gradually getting there… It's coming back. Each week it gets a bit better.* PID4

Supporting other HNC patients and survivors was important to some participants and led them to connect with the cancer community,

> *It brought my strength back to the fore…I have gotten to meet so many amazing people and I've sort of gone into a new community of people that I may never have met without it.* PID13

8.5 Discussion

Our findings demonstrate that some HNC survivors experience internal changes such as increasing mindfulness, greater appreciation of life, and gratitude for relationships, expressed externally in the form of career changes and creative approaches to returning to hobbies and other meaningful activities. The three key themes of Mindfulness, Gratitude, and Adaptation are interrelated concepts, whereby mindfulness, whether learnt formally or discovered independently, opened up greater psychological space, making room for emotions to be observed, and facilitating a shift towards a perspective of acceptance, gratitude, and renewed connection with life priorities and values. This is similar to qualitative research by Calver et al., who found that HNC survivors (n=12) developed an implicit relationship with the changes they experienced, and those who engaged in an acceptance process experienced decreased anger, sadness and frustration (Calver et al., 2019). It also reflects earlier work on coping after HNC, including Lang et al. who found that people with HNC undertook continuous meaning-making (Lang et al., 2013), Harding who found positive psychological change in some HNC survivors (Harding, 2018), and Roing et al. who explored the making of new meanings of being in the world after treatment for oral cancer (Roing et al., 2009). This study provides a new perspective of HNC as a unique trauma and shows how some survivors are able to adapt.

Participants in this study became more mindful and aware of their inner life including their outward responses and reactions. This increased mindfulness may have arisen from previous exposure to meditative techniques for some participants, however in most cases, it was described in the context of a personal realisation that arose out of internal effort to manage HNC related distress. Through mindful self-awareness, our participants found the capacity to accept the experiences of treatment and lasting impacts of HNC. This finding fits with Monitor and Acceptance Theory (Lindsay & Creswell, 2019), which posits that acceptance and attention monitoring are the two main components of mindfulness. Acceptance involves an active process of taking a nonjudgmental and compassionate stance toward internal experiences of the illness such as appraisals, emotional responses, and bodily sensations, thereby reducing the struggle with the realities of the illness (Secinti et al., 2019), which may lead to reduced emotional reactivity and reappraisal of cancer-related stressors (Lindsay & Creswell, 2019). Similarly, Mindfulness-to-Meaning Theory (Garland et al., 2015) suggests that acceptance, as a part of mindfulness, is critical to facilitating positive reappraisal which, in turn, improves psychological and existential outcomes (e.g., a sense of meaning in life). Experiential acceptance as described by our participants, is the opposite to experiential avoidance, and recent work (Simione et al., 2021) suggests it is acceptance more than attention monitoring, which improves psychological wellbeing. Experiential acceptance of cancer may lead to growth in self-compassion, courage, and value-based living, which are theoretically linked to increased psychological flexibility and better psychological well-being (Delprato, 1998).

Our findings show that people recovering after treatment for HNC are able to find benefits, and extract meaning from their experience in creative ways. Similar to our theme of Gratitude, Costa et al. (Costa et al., 2014) identified survivors who felt grateful to be alive, and linked their survival to a sense of meaning or spiritual purpose. Other authors have similarly reported that benefit finding provided greater resilience from the negative effects of stigma and promoted psychological growth in cancer survivors (Threader & McCormack, 2016b). This is highly relevant to HNC survivors, as internalised stigma has been widely demonstrated in this population (Lebel et al., 2013) and mindfulness-based interventions may reduce distress as they have been shown to do in other stigmatised populations, e.g. people living with HIV/AIDS (Gonzalez et al., 2016).

Work was important to many participants who cited financial, social and identity related reasons for wanting to return to work. However, for several participants, work had become less important and prioritising lifestyle and relationships drove decisions to change careers or retire. These factors have been investigated in the literature on returning to work after different cancer types, including in HNC survivors (Baxi et al., 2016). We found that the mindful self-awareness participants discovered, fostered a deepened capacity for meaning-making and greater engagement with life, and for some survivors, prompted previously unfelt empathetic understanding and altruism for others with cancer, also aligning with positive psychology research on shaping a purposeful life (Garland et al., 2015).

These examples of personal growth and positive adaptation after HNC can be conceptualised as post-traumatic growth (PTG), a term which describes the process by which trauma is processed and integrated (Tedeschi & Calhoun, 2004). As our participants demonstrated, PTG may lead to social growth in the form of new ways of knowing and being. All aspects of the inner and outer growth articulated by participants in our study align with findings from previous qualitative studies examining PTG across cancer types (Menger et al., 2021). Studies of HNC survivors' PTG have yielded mixed results, from low incidence of PTG (Holtmaat et al., 2017) to moderate – high levels of PTG (Sharp et al., 2018). Sharp et al. (Sharp et al., 2018) found that some subgroups (women, younger survivors, those with social support, and those who experience cancer-related financial stress) demonstrate greater growth. In a cross-sequential study where data was collected over five years, Harding (Harding, 2018) found positive psychological change – a synonym for PTG (Tedeschi et al., 2014) became greater over time, peaking at 18 months post-treatment, and was highest in people with lower stage tumours and those treated with surgery only. Among distressed HNC survivors, higher PTG was associated with lower tumour stage, absence of an anxiety disorder, absence of alcohol dependence, and better social functioning (Holtmaat et al., 2017). Moreover, greater PTG is associated with higher health related quality of life (Liu et al., 2020), and increased health behaviours (Lim, 2018), suggesting strategies to encourage and support PTG in HNC survivors may yield benefits. Tedeschi and Calhoun argue that traumatic events (such as cancer and its treatment) are, in themselves, insufficient to cause PTG. Instead, an individual must reflect on their experiences and seek to find meaning in them, i.e., growth arises from adaptation to the trauma and rebuilding one's sense of the world (Menger et al., 2021), much as participants did in this study. While work in other cancer types has shown promise for promoting healthy adaptation and fostering growth (Ochoa Arnedo et al., 2019), future research to determine the optimal timing, content and delivery of interventions which aim to facilitate personal growth is warranted for head and neck cancer survivors.

8.5.1 Limitations

Only 38% of participants had a post-school qualification compared with 69% of the general population (Australian Bureau of Statistics 2020) which may contribute to less representation of middle and higher earning survivors (Matsuyama et al., 2011). While it is a strength that both HPV and non-HPV related diagnoses were included, education levels and lifestyle choices may differ between these groups. Interview data represents a single, heterogenous time point and does not show changes over time. Participants' date of diagnosis is known and time since diagnosis is recorded in the demographics table, however time since end of treatment is unknown. Psycho-social outcomes for these participants are unknown.

8.5.2 Clinical implications

Findings from this study can be used to guide nursing, psychology, allied health and medical education curriculum content to identify and develop core competencies for caring for individuals with HNC. Implications for practice include the benefit to people with HNC of health professionals being trained in advanced communication skills, and the offering of positive psychology interventions at the end of treatment, with the aim of facilitating positive adaptation to life after HNC. In practice, this may include psycho-education for HNC survivors addressing returning to work and other activities, mindfulness-based interventions aimed at fostering psychological attitudes of acceptance and gratitude, identifying patient/survivor values and programs promoting the possibility of PTG.

8.6 Conclusion

HNC survivors are able to experience PTG as part of their recovery, and returning to valued activities such as work, sport, hobbies, and community involvement all foster growth; however, there are many survivorship-related obstacles such as fatigue, altered physical capacity and altered appearance, which require a flexible approach to find creative pathways back to meaning and purpose. Health professionals who support HNC patients are well placed to facilitate brief interventions such as emotional co-regulation or suggest longer interventions and services such as counselling and psychoeducation designed to support survivors to be equipped to meet the challenges of recovery. Fostering this personal growth makes it possible for survivors of HNC to not only recover but grow from the trauma associated with diagnosis and treatment.

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Chapter 9: Integrated Discussion

9.1 Introduction

9.1.1 Aim

The overall purpose of this PhD was to explore the psychosocial education and support needs of people diagnosed with HNC, and the health professionals who care for them. The research questions were:

a) What are the psychosocial experiences of patients with head and neck cancer?
b) What are the experiences of health professionals who work with head and neck cancer patients?

Initial analyses of the interview data collected resulted in a number of manuscripts that focused on different aspects of the experiences of health professionals and patients.

The aims of the individual analyses conducted were:

1. Study 1: Paper 1 (Chapter 5): To explore the experiences of health professionals working directly with people with HNC in Australia.
2. Study 2: Paper 2 (Chapter 6): To explore the psychosocial effect of altered appearance on people treated for HNC.
3. Study 2: Paper 3 (Chapter 7): To explore inhibitors and promoters of communication between health professionals and people with HNC.
4. Study 2: Paper 4 (Chapter 8): To explore issues of survivorship experienced after treatment for HNC.

This chapter includes a summary of the findings of each of the two studies, the first of which focused on the experiences of health professionals who care for people with HNC, while the second focused on the experiences of people diagnosed with HNC and is presented in three papers. Findings from all papers are discussed through the lens of social constructionism and in the context of the relationship of the findings with the existing literature.

9.2 Experiences of health professionals working with people diagnosed with head and neck cancer: Risk of health professional burnout

In study 1, the objective was to explore the experiences of health professionals working directly with people diagnosed with HNC. Semi-structured interviews were conducted with 21 health professionals, and questions centred on work–life balance, mental health and wellbeing. Thematic analysis through a social constructionist lens showed that health professionals who work with HNC patients and survivors are conscientious and empathic people who face numerous challenges in delivering high-quality treatment and support services, including time and resource constraints, difficulty maintaining self-care as they navigate between the demands of their professional and personal lives, and communication issues with patients who have complex needs.

Feeling empathetic made it difficult to leave the distress of patients at work:

> *I can feel a little bit more emotional when I'm working with them, because I think it's really tough for them and I can really empathise with how stuck they can feel and how difficult their options are … it does feel a little bit different to some other cancers which are ones you can't see …* HP16

The lifestyle and socioeconomic issues associated with greater risk of HNC created complexity in the relationship between health professionals and patients. For example, one health professional described HNC patients in this way:

> *they might reek of smoke, they might reek of alcohol, they might have been on a bender the night before and they come in and they are really difficult to work with and these patients sometimes they don't turn up for treatment.* HP12

These challenges contribute to their experience of burnout, which has three characteristics: overwhelming exhaustion, feelings of cynicism and detachment from the job, and a sense of ineffectiveness and lack of accomplishment (Sprang et al., 2007).

Health professionals gave examples of their own experiences of burnout and highlighted the lack of human resources to counter the loss of staff:

> *Two of our training registrars were feeling too stressed out and quit work very abruptly. They were subsequently unable to be replaced by the hospital which then resulted in a further two registrars burning out and taking time off.* HP2

Health professionals felt the impact of their work-related distress on their own health:

> *… our priority is patient care and not stuffing up for the patient and so our response is different … in addition to one consultant having a heart attack, another consultant has been going down the same path and been investigated.* HP2

The effect on health professionals can be distressing both personally and professionally:

> *… the amount of relationship breakups … in specialist land, is significant. The number of suicides and early deaths … it's there. It certainly exists.* HP21

In conclusion, the findings pointed to the need for training and cultures that support the retention of this highly skilled workforce. The oncology workforce has been found to have high levels of burnout; however, limited research has focused on the HNC workforce specifically. The development of interventions that will reduce the risk of burnout and improve the retention and capacity of health professionals may include advanced communication skills training, trauma-sensitivity training, and self-compassion and stress management skills.

9.3 Patient experiences of head and neck cancer

Study 2 is presented as three papers focused on different aspects of the data analysis. Papers 2–4 focused on the experiences of people diagnosed with HNC during and post-treatment, including the psychosocial effect of altered appearance, inhibitors and promoters of communication with health professionals, and experiences of survivorship after treatment completion. Interviews were conducted with 21 patients. Reflexive thematic analysis was conducted and highlighted overarching themes relating to preparation, communication and unmet needs. Further analysis was conducted to unpack these themes into pre-treatment decision-making; preparation for altered appearance; weight loss; face, skin and hair changes; reconstructive surgery; reactions from others; adapting to altered appearance; tensions between hurried communication and mindful communication; disparities in health literacy; biomedical norms in tension with biopsychosocial needs; and returning to meaningful activities, with interrelated themes of mindfulness, appreciation and adaptation.

9.3.1 Body image distress in people treated for head and neck cancer

Study 2 explored the experiences of HNC survivors, with the first paper presenting a focus on the psychosocial effect of altered appearance. The findings indicated that preparation for HNC treatment is focused on the practicalities of treatment, and patients feel rushed into treatment and adequately prepared for procedures but inadequately prepared for the aesthetic changes resulting from treatment. Body image distress related to altered appearance contributed to psychosocial issues for many people diagnosed with HNC. The intrusive nature of treatments—in particular, surgical excision and reconstruction—was traumatic for many participants who recounted their shock and anxiety:

> *I heard they were cutting out every part of the upper part of my mouth and they would replace that with parts of my leg, and it was beyond my understanding that they could do that inside my mouth. I felt so confronted and I was starting to shake, and I was getting pins and needles, so my husband just took me for a little walk up the corridor and back, and I had some water. I was dealing with the visceral shock of my mouth being invaded.* PID13

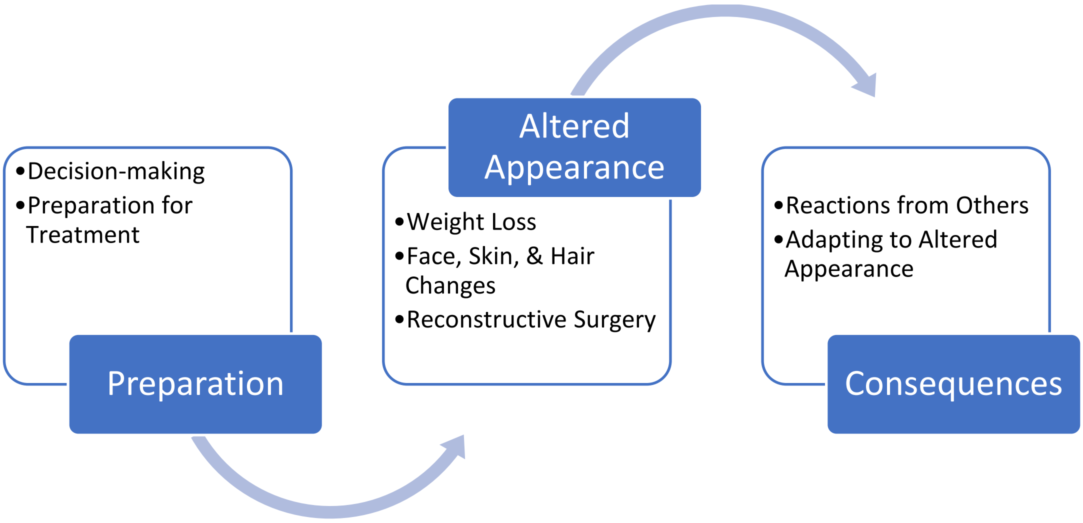

Figure 9.1. Study 2 themes and subthemes.

Current preparation for patients having surgery for HNC consists of providing information pre-treatment about procedures and many aspects of coping; however, the subject of appearance is not routinely addressed. This study concluded by highlighting that due to the complex unmet needs expressed by participants, communication skills training for health professionals that improves their comfort and sensitivity in discussing and conveying compassion around issues of altered appearance, body image and trauma is needed to decrease suffering for survivors, support healthy adaptation to living with altered appearance, and increase patient satisfaction with healthcare.

9.3.2 Communication inhibitors and promoters

The second paper of study 2 focused on communication between health professionals and patients with HNC, and included contrasting experiences of inhibited communication and aspects of communication that promoted understanding between people with HNC and their health professional care providers. These tensions were grouped under themes of voice, models of care, communication and compassion, with each theme demonstrating factors that promoted connection and those that inhibited effective communication.

The main findings of this study were that communication between health professionals and HNC patients was inhibited by issues such as health professionals feeling time-pressured and a hierarchical structure whereby health professionals are experts and patients feel excluded from decision-making as a result of differences in health literacy and the use of jargon.

In contrast, some participants asked for and received person-centred, mindful communication, which felt empowering, promoted communication and lowered distress. Illustrating the experience, one participant was able to articulate what was required:

> *I was like, "Sorry, can you slow down for a sec? I don't quite understand what the situation is." And then they realised at that point and I remember there was a real shift…because they were so frantic…when they saw me sort of say, "Look, I need you to just stop and just give me your attention for a minute," I saw them recognise that and their whole body [stopped]… and they talked me through on a normal level the whole situation to kind of reassure me.* PID2

The experience of losing the capacity for speech was experienced by survivors of HNC as distressing and traumatic. Voicelessness was not just a loss of physical speech, but a holistic experience of silencing. A number of tensions emerged, including patients' experiences of losing their voice and then finding different ways to verbally express themselves. In interactions with health professionals, there was a tension between abrupt, hurried communication and a slower, more mindful communication style. Subthemes around communication style emerged whereby disparities between levels of health literacy were unaddressed, and patients experienced a lack of empathy. Another tension experienced was between an old-style medical model and the ideal of person-centred care and the biopsychosocial model of health. Whether HNC patients lose their voice temporarily, have periods of voicelessness or are able to speak but feel unheard, the treatment experience is too often one of disempowerment and silencing of their perspectives. Health professionals are challenged to find creative communication methods, practice mindful listening, source speech pathology and adaptive technologies, and facilitate communication that supports patients in expressing their values, preferences and needs.

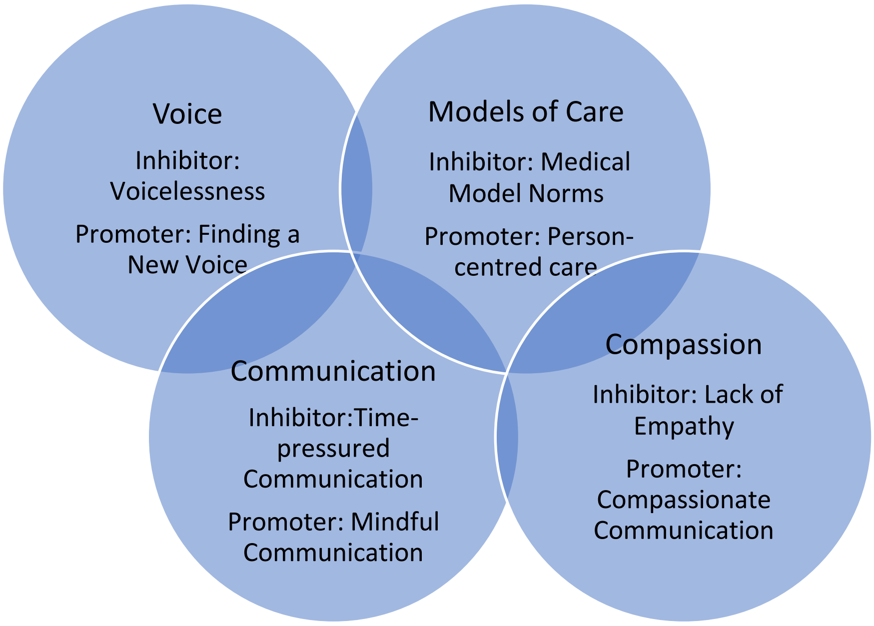

Figure 9.2. Study 3 themes: inhibitors and promoters of communication experienced by people with HNC.

9.3.3 Return to meaningful activities

The third paper of Study 2 explored HNC survivors' experiences of post-treatment survivorship, including their inner lives and returning to work and other activities. HNC survivors experienced inner and outer change and development, described by three themes: mindfulness, appreciation and adaptation. Participants discovered mindfulness by necessity, such as this example:

> *I sort of just learnt this little safe spot which is in the moment … if I'm sort of sitting here thinking about right here, right now about breathing, how I'm feeling in my hunger and my thirst, like what is it right now—that was a pretty safe little place for me and when I worked that out … I found that was easier to deal with and that's sort of pretty much where I live now. I do live really quite in the moment …That was probably the most powerful realisation I had, about that it's safe right in the moment because everything's fine …And that was one of the things to go, well, you're not dead yet and it's like if you take another breath, you're probably not going to die in the next minute either so just hang there.* PID5

Some HNC survivors were able to integrate the trauma of their HNC experience and find their way back to a meaningful, purposeful life with greater compassion for themselves and others. Through mindful reflection, which led to acknowledging and accepting the trauma of biographical disruption, altered appearance and disempowerment, some people found an increased connection with their inner life, a greater appreciation of life in general, including nature and relationships, and hope for the future, which was expressed externally in career changes and creative pathways back to meaningful activities such as sport, volunteering and hobbies. People diagnosed with HNC frequently experience lasting effects and other survivorship issues; however, some survivors are able to recreate a meaningful lifestyle and experience post-traumatic growth. Health professionals can play a role in promoting and supporting post-traumatic growth after HNC by demonstrating compassion for the suffering of HNC, supporting survivors to reflect on what matters most and encouraging a return to meaningful activities.

HNC survivors experienced internal and external change and development, articulated by three themes: mindfulness—a state of nonjudgmental awareness that includes turning towards suffering that allows integration of experiences into new self-concept; gratitude—recognition of mortality and savouring what matters (family, relationships, inner life); and adaptation—finding a way to restore an interrupted sense of self through work, sport and hobbies, even if they are somewhat altered.

9.4 Overall discussion

This section discusses the different forms of trauma experienced by health professionals and people diagnosed with HNC, including vicarious trauma, body image distress and mirror trauma, health system–related trauma and the possibility of post-traumatic growth. The findings of the studies collectively point to these shared but unique types of trauma as areas requiring further research and which are potentially modifiable through targeted psycho-educational and communication skills–based interventions. Types of trauma, trauma-informed healthcare and communication skills training are discussed with reference to existing literature and clinical guidelines for best practice. A social constructionist lens is applied throughout, and the process of reflexive thematic analysis, including the researcher's lens is noted.

9.4.1 Trauma

Taking all the study findings into account revealed the overarching motif of trauma for health professionals and people diagnosed with HNC. For health professionals, there is a need for personal and systemic approaches to manage stress and prevent burnout, while for patients, psychological preparation for treatment is needed along with compassionate communication from health professionals. Survivors of HNC demonstrated some of the possible pathways back to meaningful activities and the potential for post-traumatic growth. These findings have multiple implications in terms of clinical practice, education, leadership, policy and future research. We found that health professional trauma and patient trauma in people treated for HNC were interrelated, and that personal and professional growth could be facilitated by similar pathways, including cultivating and expressing compassion for oneself and others, as shown in Figure 9.4.

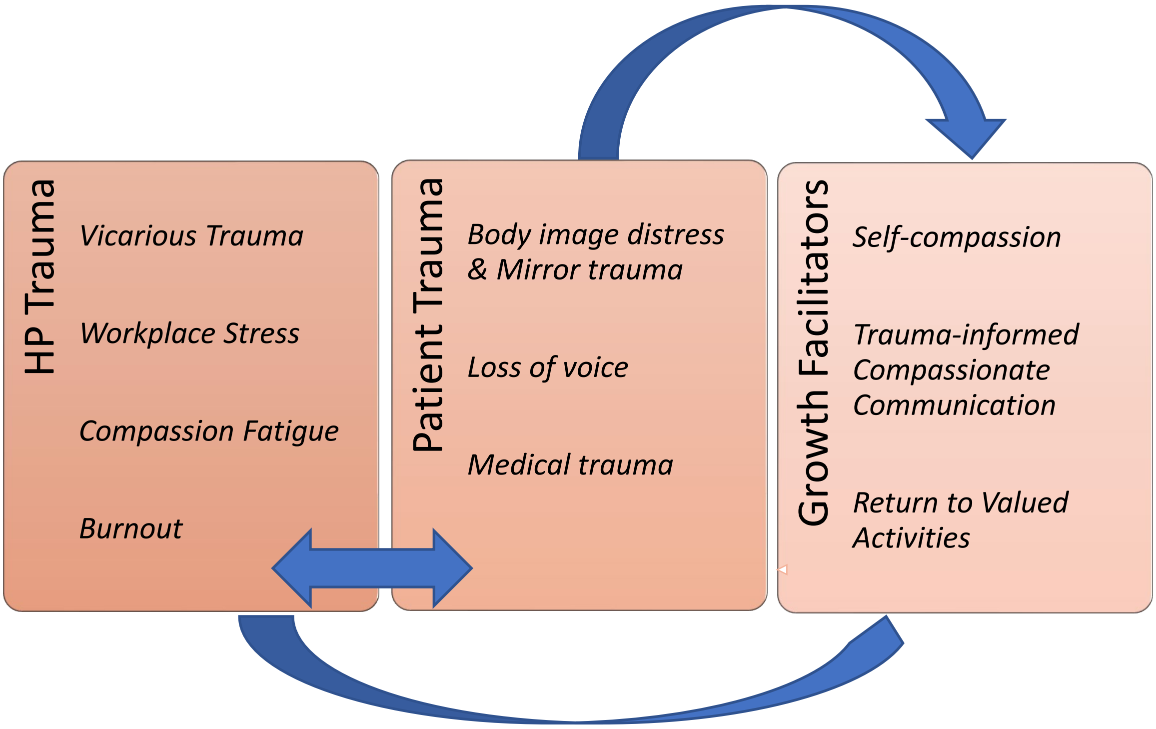

Figure 9.4. Overarching themes of the study: HP Trauma; Patient Trauma; Growth Facilitators

HNC is challenging and potentially traumatic for both health professionals and patients; however, personal growth is possible when communication is trauma-sensitive, person-centred and compassionate. While the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) does not include cancer as a source of trauma, the experiences described in this study fit the definition of trauma as "distress resulting from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being" (p. 271) (American Psychiatric Association & American Psychiatric Association, 2013). Physiological and psychological responses to trauma are well documented (Payne et al., 2015; van der Kolk et al., 2005), debilitating and demonstrably present in participants in this study, for health professionals and people diagnosed with, and treated for, HNC.

Regardless of whether people have historical trauma, treatment settings are likely to trigger trauma responses from many people as a result of co-constructed meanings about hospitals, oncologists, radiation and chemotherapy, as well as the anxiety and fear provoked by cancer itself. Our findings demonstrate that treatment for HNC can be traumatic in a number of ways. Study 1 found that vicarious trauma and subsequent compassion fatigue lead to a loss of skilled oncology health professionals (Gibson et al., 2021). Study 2 found that the shock of altered appearance was experienced as mirror trauma (Gibson et al., 2021). Study 3 showed that the trauma of physiological loss of voice and psychosocial silencing is associated with communication barriers during and post-treatment (Gibson et al., 2022).This is reflective of a growing body of literature supporting the need for trauma-informed healthcare generally (Gerber, 2019; Schimmels & Cunningham, 2021), although there is a paucity of HNC-specific research.

9.4.2 Vicarious trauma, compassion fatigue and burnout in health professionals

Health professionals in this study reported experiencing work-related distress, including vicarious or secondary trauma from repeated exposure to the suffering of patients. The secondary trauma associated with healthcare settings is well documented (Butler et al., 2017; Canfield, 2005; Gieseler et al., 2018), and while the vast majority of research on vicarious trauma has been in oncology nursing (Wu et al., 2016), it is particularly relevant in HNC, where some of the interviewed health professionals described that the complexity and challenges of working with people with HNC include technical complexity and psychosocial issues such as substance misuse, altered appearance, stigma and socioeconomic issues. Our findings reflect earlier work by Breen et al. (Breen et al., 2014), who described the “spectre of cancer” and found that oncology health professionals reported secondary or vicarious trauma, which had serious repercussions for their wellbeing and blunted their emotional responses to patients, compromising the care they provided.

Our health professional participants reported having low tolerance for interactions with peers outside work, and either ending personal relationships or taking their dysregulated emotional states home to their families. This demonstrates the holistic effect of vicarious trauma, which is exacerbated by workplace stressors such as understaffing and limited resources. We found that health professionals were planning to retire early, change tumour streams or leave their role, which was characterised as ‘fading away’ from their profession, with or without a self-perceived burnout experience (Gibson et al., 2021). This reflects previous research, which found that health professionals experiencing daily work–family conflict had increased symptoms of burnout and intention of leaving the profession (Maglalang et al., 2021).

Our findings also showed that health professionals working with people with HNC experience symptoms of burnout and frequently choose to work in different areas with people diagnosed with other tumour types, or to reduce their working hours to reduce exposure to suffering and vicarious trauma. This supports the understanding of compassion fatigue, which has been found to be prevalent in oncology health professionals as a result of grief, a sense of failure when patients die, and prolonged and repeated exposure to suffering (Laor-Maayany et al., 2019). The term “compassion fatigue” and its relationship to burnout is contested (Henson, 2020), largely because of differing definitions of empathy and compassion (Singer & Klimecki, 2014). Our finding that health professionals are highly empathetic and frequently emotionally exhausted aligns with the work of Matthieu Ricard (Klimecki et al., 2014) and others who suggest that identifying with the suffering of others (i.e. empathy) is unsustainable. Regardless of the definitions used for empathic distress (Klimecki et al., 2014), compassion fatigue and burnout, our findings add to the understanding of the syndrome known as burnout, which is widely recognised as a multifactorial problem for health professionals, especially those who witness trauma (Asai et al., 2007a; Canfield, 2005).

Our findings showed that the altered appearance of people during and post-treatment for HNC is highly distressing, with some health professionals expressing aversion to looking at these patients (Gibson et al., 2021). Participants’ experiences of accumulated distress when witnessing case after case of HNC—in particular, the altered appearance of patients—reflects the literature on vicarious trauma as a cause of burnout in health professionals (McCormack & Adams, 2016). Adapting to the distress caused by their work was challenging for health professionals in this study, and the need to create interpersonal distance from patients was experienced as dehumanising (Gibson et al., 2022). It is possible that depersonalisation is a symptom of burnout as well as a coping style, which some authors suggest may be worsened when health professionals have their own body image issues or value appearance highly (Cho et al., 2018a).

9.4.3 Body image distress and mirror trauma for people treated for head and neck cancer

For people with HNC, trauma is inherent in the experience of diagnosis, treatment and life after treatment. It is both life-threatening and threatening to the sense of self because the disease and treatment disrupt the highly visible face, which is central to communication as the social engagement centre (Porges, 2021). This paper explored the extent of body image distress experienced by HNC survivors and their struggle to adapt to altered appearance and the social stigma that comes with visible difference. Participants experienced a rupture in their life story reflective of Bury's theory of biographical disruption (Bury, 1982). The results of treatment led to a diminished sense of self, whereby altered appearance challenged their pre-treatment identity, hence the title quote, "I didn't even recognise myself" (Gibson et al., 2021). Fisher and O'Connor reported similar findings: mothers diagnosed with breast cancer struggled to integrate their pre-treatment identity with their roles as mothers and survivors (Fisher & O'Connor, 2012).

Our findings indicated that HNC patients perceived a lack of health professional–led communication and felt unprepared for the appearance-altering impact of treatment because most communication was focused on procedural details and disease eradication. Participants described the first sight of themselves in a mirror as shocking, reflecting the literature on "mirror trauma" (Freysteinson, 2020). In a nurse education repeated measures mixed-methods study (n=48) on assisting people who had an amputation, an overarching theme from the qualitative analysis was that the nurse participants perceived assisting patients in viewing their changed bodies in mirrors as an act of compassion (Freysteinson et al., 2021). When participants interacted with health professionals, were reunited with loved ones after treatment and returned to public settings, they frequently reported feeling stigmatised and re-traumatised by social interactions, leading to social isolation. This reflects work from more than 20 years ago, which found that nurses and other health professionals play a role in preparing patients with altered appearance to manage social encounters and minimise body image distress (Price, 2000).

Our findings showed that the experience of altered appearance and adaptation to a changed body image continue to cause psychosocial distress post-treatment. This reflects a similar qualitative study by Costa et al. (Costa et al., 2014), which found that HNC patients' individual experiences are complex, challenging and have multiple psychosocial effects. We found that recovery involves a process of repairing and rebuilding self-concept. This supports earlier literature that showed that patients experience a significant psychological burden after HNC surgery and must undergo a process of body image reintegration, which entails reorganising their perception of self into a unity that is once again acceptable (M. Fingeret et al., 2014; Furr et al., 2007). A recent literature review examined the psychosocial role of body image in the quality of life of people with HNC (Covrig et al., 2021) and highlighted the continuing knowledge gap regarding the longitudinal course of body image distress in patients with HNC, particularly in long-term survivors. Our study (Gibson et al., 2021) goes some way towards filling this gap.

Reflexive journalling, a common practice in social constructionism, was significant during the writing up of this paper, and during analysis of both studies' data relating to appearance, as the researcher experienced appearance altering facial surgery during data collection. The role of the researcher's own appearance, and their emotional responses to people with HNC who had appearance altering experiences has been summarised in the reflective piece 'Seer and seen: Becoming insider-ish in research' (Gibson, 2020).

9.4.4 Stigma and re-traumatisation of people with head and neck cancer

Participants in this study described trauma responses, including one who had a panic attack, others who expressed anger, and many who became silent and meek, as evidenced in study 3 (Gibson et al., 2022). For the cohort of HNC patients for whom lifestyle contributes to risk of disease, the likelihood of adverse childhood events (ACEs) and trauma, including post-traumatic stress disorder, is greater than for the general population (Smith et al., 2017). ACEs contribute to higher incidence of chronic illness, including substance use and misuse, as well as cancer (Hays-Grudo et al., 2021). Our findings demonstrated that, for some patients, the perceived attitudes of health professionals added to their shame and stigma (Gibson et al., 2022), thereby adding insights to earlier work showing that patients experienced increased psychological distress as a result of shame and stigma around lifestyle-related causes of HNCs such as HPV, alcohol consumption and smoking (Lebel & Devins, 2008; Smith et al., 2017; Threader & McCormack, 2016a). Other common psychosocial concerns centred on fear of negative evaluation. This is a central feature of social anxiety and can lead to increased feelings of social isolation (Clarke et al., 2011).

There is a counter-cultural aspect to the extreme weight loss distress experienced by participants, because leanness and lower body weight are largely celebrated and desired. While a small number of participants were initially happy about their weight loss, it later became a source of negative body image and social stigma. The negative effect of these social interactions led to patients feeling judged, having awkward conversations or needing to confront strangers. This led to self-isolation to avoid further stigmatisation and added to their loss of sense of self and loss of meaningful interactions and engagement with communities. This contrasts with a multitude of studies that found that stigma, including self-stigma, affected people living in bodies judged to be overweight or obese (Pearl et al., 2017; Puhl et al., 2015). A recent systematic review found that health professionals also hold strong bias against overweight and obese bodies (Lawrence et al., 2021), potentially adding to the confusion felt by people with HNC when they lose weight rapidly.

9.4.5 The medical model contributes to trauma for both patients and health professionals

In study 3, people with HNC reported feeling dehumanised, voiceless and silenced both literally and figuratively. The hierarchical, paternalistic nature of the biomedical model created distress for patients, with disparities in health literacy adding to a sense of health professionals being distant, cold, superior and condescending (Gibson et al., 2022). This is reflective of a body of research in oncology showing that patients' psychosocial needs are unmet (Zebrack et al., 2014) and shared decision-making is not routinely practiced (Sandman & Munthe, 2009) because of factors such as communication barriers (Steenbergen et al., 2022).

For health professionals who care for people with HNC, our findings showed that high workloads, unsupportive management, lack of work–life balance, inadequate leave arrangements and vicarious trauma contribute to compassion fatigue and the syndrome of burnout (Gibson et al., 2021). This reflects research in emergency nurses' wellbeing, which found that the secondary stress of health professionals is exacerbated by high workloads, lack of control over work, feeling inadequately rewarded, and challenging interpersonal relationships with inadequate conflict resolution in a culture that is competitive rather than compassionate (Hooper et al., 2010). Similarly, our work reflects the findings of Kreitzer et al. (2020), who highlighted the experiences of social workers experiencing compassion fatigue and found that institutional barriers to healthy workplace environments included cutbacks in services and time constraints (Kreitzer et al., 2020).

Health professionals in our study expressed how the constraints of the medical model contributed to distress because their personal values as empathetic and conscientious caregivers were sometimes challenged by the need to meet complex patient needs with limited resources (Gibson et al., 2021). The medical model traditionally emphasises outcomes over person-centred care, and it has often been criticised for reducing people to pathophysiology (Getz et al., 2011; Rocca & Anjum, 2020). Our findings support recent qualitative work that found that personal distress in trauma therapists was linked to medical model norms (McCormack & Adams, 2016). The challenges faced by health professionals in HNC care are both personal and systemic. Therefore, it is not enough to suggest that health professionals need support to increase their personal stress resilience, cultural change is required. As a recent exploration of palliative care professionals found, professional quality of life and compassionate care are related to health professionals' wellbeing, and when health professionals take care of themselves, this leads to more compassionate care for patients as well as healthier, happier professionals (Galiana et al., 2022).

9.5 Healing from trauma is possible: Growth facilitators for people with head and neck cancer and the health professionals who care for them

People with HNC described their recovery after completing treatment and the importance of mindfulness, gratitude for their lives and returning to meaningful activities that supported healthy adaptation and post-traumatic growth (Gibson et al. in press December 2022). Despite the psychosocial challenges of HNC, including biographical disruption (Bury, 1982), mirror trauma (Freysteinson, 2020) and the loss of their voice, participants were frequently able to recover from HNC, experiencing acceptance and personal growth, and finding wisdom from their experiences. Facilitators of their post-traumatic growth included the discovery of mindfulness—in particular, acceptance without judgment—and cultivating appreciation of meaningful things in life, such as relationships, which fostered adaptation to the changes wrought by diagnosis and treatment. This is supported by previous research showing that experiential acceptance of cancer may lead to growth in self-compassion, courage and value-based living, which are theoretically linked to increased psychological flexibility and better psychological wellbeing (Delprato, 1998). A recent systematic review of post-traumatic growth in frontline workers suggests that health professionals face similar possibilities to find growth through suffering (Henson et al., 2021).

The findings showed that health professionals who care for people with HNC are empathic, conscientious care providers who experience vicarious or secondary trauma and are at high risk of burnout and leaving the workforce (Gibson et al., 2021). There is a large body of literature describing the symptoms, prevalence and factors associated with the related concepts of compassion fatigue (Boyle, 2015; Figley, 1995), secondary traumatic stress or vicarious trauma (Canfield, 2005), and burnout in health professionals across disciplines including nursing (Hegney et al., 2014), social work (Butler et al., 2017), palliative care (Asai et al., 2007a) and oncology (Blanchard et al., 2010). While the problem of burnout has been clearly described over a number of decades, interventions that aim to improve compassion satisfaction and professional quality of life have been more recent. Health professionals in our study described that their personal resilience activities included regular yoga as well as mindfulness in various forms, including meditation and exercise (Gibson et al., 2021). These approaches are reflected in interventions that are designed to reduce compassion fatigue in health professionals, the majority of whom focused on stress reduction using yoga (Gregory, 2015) and mindfulness (Brooker et al., 2012; Cocker & Joss, 2016; Horner et al., 2014).

Mindfulness and similar contemplative practices, including yoga, help health professionals manage their stress levels and support people with HNC to cope with the trauma of treatment and the ongoing issues of survivorship (Gibson et al., 2022; Gibson et al., 2021). Most intervention studies aimed at lowering patients' distress are not specific to people with HNC, with the exception of Pollard et al., whose pilot study found that individualised mindfulness-based stress reduction lowered anxiety (Pollard et al., 2017). While it is clear that mindfulness-based interventions can be effective in populations affected by cancer (Cillessen et al., 2019; Oberoi et al., 2020), there have been mixed results, including that adherence to home practice is challenging (Baydoun et al., 2021) and that mindfulness without appropriate support can have negative outcomes for highly distressed cancer patients during treatment (Reynolds et al., 2017). Mindfulness is a powerful tool for emotional regulation for patients and health professionals (Taylor et al., 2020). However, it cannot be used in a mechanistic, reductionist manner as a universal elixir; rather, it needs to be embedded in the health system and contextualised for individual situations (Liu et al., 2018; Taylor et al., 2020).

9.5.1 Healing the healers: Interventions to prevent or recover from health professional burnout

Burnout symptoms, vicarious trauma and compassion fatigue were prevalent among the participants; however, a number of health professional participants reported finding increased resilience through mindfulness and yoga. Some had undertaken mindfulness training, while others found their own ways to manage stress, including exercise, which was described as a form of mindful practice (Gibson et al., 2021). This finding is reflected in the large number of mindfulness-based interventions that have been developed and tested to prevent the syndrome of burnout and reduce compassion fatigue related to vicarious trauma. There are overall positive findings from the majority of these studies, showing that burnout and compassion fatigue can be addressed with mindfulness-based skills programs delivered to groups, including obstetrician–gynaecologist trainees (Babbar et al., 2019), medical students (Hathaisaard et al., 2022), nurses (Hilcove et al., 2021; Slatyer et al., 2017), nurse researchers (Kavurmaci et al., 2021) and health professionals generally (Ofei-Dodoo et al., 2020). Hegel et al. found that present-centred awareness and attention was associated with lower disengagement, lower emotional exhaustion, higher compassion satisfaction, lower secondary traumatic stress and lower compassion fatigue (Hegel et al., 2021). Further research is needed to identify which types of mindfulness training and specific elements of practice are most effective. A commonly cited obstacle to mindfulness-based practices is time constraints; thus, it is important that brief interventions are studied more extensively.

Participating health professionals reported feeling highly empathetic towards people with HNC (Gibson et al., 2021), and while this appears to be a positive quality, it has been established that empathy worsens burnout (Flarity et al., 2013; Klimecki et al., 2014), while compassion-based interventions are likely to be preventative (Conversano et al., 2020; Pérula-De Torres et al., 2019). Existing models and approaches to resilience training are promising, such as an inter-professional compassion fatigue resiliency programs (Pfaff et al., 2017), trauma-informed training for social workers (Berceli & Napoli, 2006), and multiple mindfulness, compassion, self-compassion and loving kindness meditation interventions in healthcare workers (Boellinghaus et al., 2012; Cameron et al., 2015; Conversano et al., 2020). Mindfulness-based compassion training tailored to health professionals involved in palliative care used Gilbert's (Gilbert, 2017) evolutionary, motivational model of compassion towards others, from others and towards self, leading to decreased anxiety, lower compassion fatigue and less emotional exhaustion (Watts et al., 2021). A comprehensive intervention aimed at actively treating compassion fatigue in emergency nurses through a multifaceted program involved guided imagery, education about compassion fatigue, and recognising and actively preventing and treating compassion fatigue in themselves and others (Flarity et al., 2013). Others have called for a career-long resilience model to help physicians cope with the emotional, social and physical effects of care provision (Cordova et al., 2020). Our vision expands beyond physician training to include a comprehensive, health system–wide cultural shift towards trauma-informed practice and a compassionate care culture for everyone.

9.5.2 Health professional communication skills to reduce distress for people with head and neck cancer, and the health professionals who care for them

People with HNC reported a mixture of communication styles from health professionals; some facilitated communication, while others shut down communication and became a barrier to expressing patient needs (Gibson et al., 2022). Health professionals also shared their challenges in communication—in particular, when their stress levels affected their ability to emotionally connect (Gibson et al., 2021). Participants with HNC expressed a preference for person-centred, tailored communication, and a longing to be recognised as multidimensional humans beyond their diagnosis (Gibson et al., 2022). This reflects the ideals of a biopsychosocial formulation, which includes person-centred communication featuring lay language that is non-judgmentally tailored to individuals and foregrounds patient values and patient preference sensitive decisions (Bolton, 2019).

The findings highlight the ongoing need for communication skills training for health professionals. This need has been established in previous research (De Vries et al., 2014) and has been used in oncology to improve patient education and support (Longacre et al., 2015). A systematic review of communication skills training programs found that they improve health professionals' communication skills in terms of conducting psychological assessments and interviews, and they improve their attitude towards communicating with patients and their confidence in their ability to communicate effectively with patients (Gysels et al., 2004). Communication skills training has been found to have a positive effect on communication between health professionals and patients (Butow et al., 2008; Kissane et al., 2012) and can lead to integration of effective communication skills into clinical practice (Back et al., 2007). Eliciting and responding to emotional cues has been useful for oncologists in improving empathy (Patel et al., 2019), reducing patient distress (Halkett et al., 2018) and communicating bad news (Back et al., 2007; Williams-Reade et al., 2018). Two recent systematic reviews showed that training that focuses on responding to the emotions and needs of patients improves the quality of their communication and may improve patient outcomes (De Vries et al., 2014; Moore et al., 2013).This reflects the REDE model of Healthcare Communication (Windover et al., 2014), which explicitly places relationship and rapport as a primary need for effective communication.

Participants expressed a desire for slower, more mindful and emotionally attuned communication episodes (Gibson et al., 2022). Communication skills training programs that use roleplay to develop skills and observe patient interactions to provide feedback should be available to health professionals at every level of practice, as per the American Cancer Society Guidelines and work in medical student education (Gilligan et al., 2021; Gilligan et al., 2018). People diagnosed with HNC valued interactions with health professionals who were able to communicate more mindfully, and who showed an interest in getting to know them as a whole person (Gibson et al., 2022). While it may seem counter-intuitive for time-pressured health professionals to slow their communication down, it has been shown that brief compassionate communication can improve patient satisfaction and decrease the need for future consultations, as found in a study on 40 seconds of compassion (Fogarty et al., 1999).

For patients who were able to ask for what they needed from health professionals, an experience of compassionate communication built trust and mediated the trauma of diagnosis and treatment (Gibson et al., 2022). Our findings reflect the work of Henson, who found that adaptation following a traumatic experience is supported by empathic others whose unconditional acceptance helps people co-create a felt sense of safety (Henson et al., 2021). The ways our participants described helpful interactions with health professionals included non-verbal communication (Gibson et al., 2022). This reflects the work of Quillman, who stated that conceptualising and responding to patients through the lenses of the body, personality and intersubjective field enables health professionals to respond to implicit communication from traumatised patients by providing emotional co-regulation (Quillman, 2012). Similarly, Cameron et al. (Cameron et al., 2015) suggested that emotional resonance is an internal emotional response of the physician, evoked by recognition of the patient’s suffering. The emotion felt by the physician may be distinct from the emotional experience of the patient, and communication skills training can reduce distress for both the health professional and the patient. Evaluation of a communication skills training program aimed at radiation therapists (RT-Prepare CST) found that providing routine communication skills training and emotional cues training enhanced the ability of health professionals to care for patients holistically and equipped them with skills to be included within a psychosocial model of care (Arnold et al., 2021).

9.5.3 Preparation and information for people with head and neck cancer

We found that people diagnosed with HNC reported feeling rushed into treatment and received adequate procedural preparation but little or no preparation related to appearance (Gibson et al., 2021). Visible difference was associated with distressing social interactions (Gibson et al., 2021), thus aligning our work with the first category of stigma defined by Goffman (1974) (Goffman, 1974). Our findings are further supported by a recently published study on patient-reported aesthetic and psychosocial outcomes after microvascular reconstruction for HNC, which found that a lack of aesthetic satisfaction with treatment results correlated with impaired appearance–related psychosocial functioning (Zebolsky et al., 2021).

For people undergoing treatment for HNC, a highly distressing aspect of their care was the lack of psychological support for altered appearance, with the shock of seeing themselves for the first time after treatment causing disruption to self-concept (Gibson et al., 2021). This finding is similar to earlier work with amputees, which referred to observing the results of surgery as ‘mirror trauma’ (Freysteinson, 2020). Health professional education with a focus on mirror trauma has been found to enhance nurses’ frequency of offering mirrors and supporting patients in mirror viewing after visible disfigurement resulting from trauma or surgery. Education provides nurses with the necessary skills to assist patients in adapting to an altered body image (Freysteinson et al., 2021), and this approach deserves deeper investigation for people undergoing treatment for HNC.

Time-pressured communication and the inherent power imbalance between health professionals and patients prevented people with HNC from asking for more information about their aesthetic expectations prior to treatment (Gibson et al., 2022). In contrast, studies have shown that psychological preparation for prophylactic bilateral mastectomy improved the psychological wellbeing and satisfaction with intimacy of women who had a psychological consultation prior to surgery, and they reported higher positive body image than those who had no support (Glassey et al., 2018). Perceived body image distress has been found to be modified by preoperative expectations in HNC (Ellis et al., 2019), and communication about this important aspect of treatment outcomes needs to be prioritised in routine preparation. Further research needs to be conducted and may include communication skills training not only for health professionals, but also for newly diagnosed patients, who may be empowered by greater health literacy and a shared language with health professionals.

9.5.4 Trauma-informed organisations

Our findings showed a need for the culture of organisations to better recognise and value the needs of health professionals, who are highly conscientious and empathic, yet lose their ability to be fully present at work because of the intense time and resource scarcity of many workplaces (Gibson et al., 2021). We found a high risk of burnout leading to the loss of highly educated, skilful health professionals from the HNC workforce. Trauma-informed training has been found to lower this risk of burnout (Vermilyea, 2014), and this is particularly relevant given that beyond the vicarious trauma of the workplace, every incident of personal trauma renders health professionals more susceptible to secondary traumatic stress (Kartsonaki et al., 2022). This reflects a body of work on trauma-informed organisations (Gerber, 2019) and workplace structures, whereby outcomes are measured using a quadruple bottom line: (1) improving individuals’ experience of care; (2) improving the health of populations; (3) reducing the per capita cost of healthcare; and (4) improving the experience of providing care (Sikka et al., 2015). The principles of trauma-informed care are safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment and choice; and cultural, historical and gender issues (Gerber, 2019). The first principle of safety requires that health professionals feel safe at work in order to provide emotional regulation in their communication with patients, and this requires cultural change.

We found that HNC treatment settings were experienced by patients as impersonal (Gibson et al., 2022), and for health professionals they were frequently time-constrained, emotionally charged environments where providing psychosocial care for patients was a secondary concern (Gibson et al., 2021). The National Safety and Quality Health Service Standards (Care., 2014) aim to protect the public from harm and to improve the quality of health service provision. Of the eight standards, three are most relevant to this study; Partnering with Consumers, Comprehensive Care and Communicating for Safety. These same principles could be applied to interactions between people with HNC and the health professionals who care for them. Leadership and support from management are needed to set a cultural tone, provide trauma-informed policies for staff at all levels, and circumvent the risk that health professionals perceive that their communication training has been ineffective and their ability to manage strong emotions deficient (Chan et al., 2019). A safe workplace in a healthcare setting includes ensuring the psychological and social safety of people receiving treatment, those providing care, and support staff across all levels of the organisation.

9.6 Strengths and limitations of the thesis

A strength of this study was that the recruitment of health professionals extended across Australia and focused on health professionals from a range of speciality areas. There was heterogeneity in health professionals' roles, with participants from allied health such as counsellors, dietitians and speech pathologists, as well as the nursing and medical professions. It could be expected that their responsibilities and experiences are quite different, leading to different risks and experiences of burnout. While differences in burnout risks between professions have previously been explored, there is limited understanding of how working with this HNC population is experienced by individual professions. Future research could focus on a single discipline working with people with HNC to understand discipline-specific experiences and issues. Most participants were not working full time, which likely influenced their perceptions of work–life balance. Additional research with full-time workers is recommended.

Patient participants were also recruited from across the country. Seventy-one per cent of patient participants were male, which is also a strength, because while HNC affects more men than women, health research where participants self-select often means that more female participants are included. The inclusion of an Indigenous participant represented 5% of participants compared with 3.3% of the Australian population (ABS 2019). All other participants (95%) were Caucasian. Given the lack of cultural diversity of participants, there may be cultural differences that were not able to be explored.

Only 38% of patient participants had a post-school qualification compared with 69% of the general population (Australian Bureau of Statistics 2020), which may contribute to less representation of middle- and higher-earning survivors (Matsuyama et al., 2011). While it is a strength that both HPV- and non-HPV-related diagnoses were included, education levels and lifestyle choices may differ between these groups.

Another strength was that the semi-structured interviews produced a large quantity of rich and deep data from which to draw out findings, as per the four studies. Data collection involved the transcription of recorded interviews, and deep and repeated analysis of data was conducted concurrently until saturation was reached. While the concept of saturation has become contested, the researchers agreed that data saturation was deemed to have occurred when no new information emerged and themes recurred (Strauss, 1998). Thematic analysis was conducted following Braun and Clarke's six-step process (Clarke & Braun, 2017b), and repeated analysis and reflexive practice reflected updated interpretations of this rigorous approach (Braun et al., 2022).

9.7 Study implications

We found that health professionals caring for people with HNC experience compassion fatigue, and the symptoms of burnout lead them to decrease their work and potentially leave the HNC workforce altogether (Gibson et al., 2021). People with HNC experience many types of psychosocial distress, including body image distress (Gibson et al., 2021) and the literal and metaphorical challenges of voicelessness (Gibson et al., 2022), yet they find meaningful pathways to recovery and growth following treatment (Gibson et al. in press December 2022). These findings have implications for health professionals, patients and organisations.

The findings can be used to guide nursing, allied health and medical curriculum content, as well as clinical education and professional development, to develop core competencies for caring for individuals with HNC. Practice implications include developing and evaluating HNC-specific communication skills training for health professionals that aim to equip them with inner resources, as well as practical skills to minimise the effect of vicarious trauma, prepare patients for the possibility of body image distress, and embed the skills of mindful self-compassion and compassionate communication, which are likely to benefit both health professionals and their patients with HNC. Using brief mindfulness- and compassion-based techniques, health professionals can be trained to convey compassion both verbally and non-verbally, and to practice mindful self-care and self-compassion with the primary aim of decreasing compassion fatigue and subsequent risk of burnout.

This study provides insights into the experiences of HNC survivors who are able to make meaning and find inner and outer growth following treatment. These findings can be used to inform the provision of information and support prior to treatment, supportive interventions during treatment, and psychoeducational courses for people completing treatment for HNC in the future. Pre-treatment support could include existing information about HNC treatment and expand to include psychological preparation for altered appearance and loss of voice. Patient and carer self-compassion interventions could be trialled prior to treatment, and post-treatment survivorship programs could be developed for HNC patients to foster mindful self-reflection, aiming to build capacity for healthy psychosocial adaptation and post-traumatic growth.

Trauma sensitivity training that is appropriate for all levels of the multidisciplinary health team could include an understanding of types of trauma, including vicarious trauma and how it may present in employees, clinicians, patients and carers. There are implications for organisational structures and leadership whereby trauma-informed leaders set new cultural norms, recognising that health professionals cannot provide compassionate care when they are distressed by time and resource scarcities. Policy implications could include increased staff support such as employee assistance programs, adequate staffing, ability to purchase leave, flexible rosters, increased choice and ongoing advanced communication skills training. It is acknowledged that cultural change takes time, and all of these proposed interventions require committed leadership and adequate allocation of time and resources for health professionals to learn and implement new skills.

Future research implications include the development and evaluation of advanced communication skills training for HNC health professionals, including eliciting and responding to emotional cues, non-verbal communication, health professional resilience, education on differences between empathy and compassion, self-care derived from mindful self-compassion, and trauma-sensitive compassionate communication skills. Communication skills training aimed at decreasing compassion fatigue, burnout and psychopathologies (e.g., anxiety and depression) in health professionals could also consider brief rapport-building skills, prevention of patient distress, improved satisfaction with care, decreased risk of burnout and retention of the skilled oncology workforce.

Research that focuses on patient-reported outcomes could develop and evaluate brief interventions at time points including pre-treatment, during treatment and post-treatment, with input from all stakeholders, including people diagnosed with HNC and those in post-treatment survivorship. Further studies could develop and evaluate early interventions for body image distress, including testing screening tools and psycho-educational programs informed by mindful self-compassion practices. Communication skills training could also involve pre-treatment education for patients, focusing on increasing health literacy, demystifying terminology, and identifying and communicating needs. Mindfulness-based interventions could be adapted for people diagnosed with HNC, with aims including lowering distress during treatment and facilitating adaptation to life after treatment.

Organisational change interventions are also recommended. They could start with focus groups in order to develop resources that are suited to the existing workplace culture. Trauma-informed organisations are becoming more prevalent, partially as a result of the pandemic, and they may aim to implement the 4 R’s approach created by the Substance Abuse and Mental Health Services Administration (SAMHSA) ("SAMHSA’s Concept of Trauma and Guidance for a Trauma-Informed Approach ", 2014). Learning outcomes that could be measured following staff training include: realising the widespread effect of trauma and understanding potential paths for recovery; recognising the signs and symptoms of trauma in clients, families, staff and others involved with the system; responding by fully integrating knowledge about trauma into policies, procedures and practices; and actively resisting re-traumatisation.

9.8 Conclusion

HNC is a traumatic experience for people with a diagnosis and for the health professionals who care for them. For health professionals, vicarious trauma and the stressors of under-resourced work settings lead to personal and professional distress, and frequently result in highly educated and skilled health professionals leaving their roles or decreasing their hours. For people diagnosed with HNC, trauma arises from the disease and its treatment, especially when it results in altered appearance, voicelessness and the sense of being dehumanised within the medical model. What alleviates distress and promotes growth appears to be similar for people with HNC and the health professionals who care for them. Compassion is central in preventing unnecessary distress and healing from trauma, and all participants in this study expressed, in various ways, a preference for compassionate communication delivered in a trauma-informed environment. To create a treatment experience that minimises psychosocial distress and facilitates personal and professional growth, the health system requires trauma-informed cultural change embedded at every level in order to become more compassionate, including organisational policies, executive leadership, workplace culture for all staff, health professional education, patient information and support, research, and practice.

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Appendix B: Patient Information Sheet and Interview Schedule

Determining the support and education needs of patients diagnosed with head and neck cancer and their carers

Investigators: Georgia Halkett, Moira O’Connor, Chandrika Gibson, Raelee Golding, Rohen White and Melanie Jackson.

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Information Sheet for People diagnosed with Head and Neck Cancer

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don’t wish to take part, you don’t have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

This research is the intellectual property of PhD students from Curtin University as listed above.

You will be given a copy of this Participant Information and Consent Form to keep.

Ethics Approval

Curtin Human Research Ethics Committee (HREC) and Sir Charles Gairdner and Osborne Park Health Care Group HREC have approved this study (Curtin HREC number HRE2018-XXXX SCGOPHCG HREC number XXXXXXXX). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Curtin University Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au. Or the SCGOPHCG HREC on (08) 6457 2999 or email hrec.scgh@health.wa.gov.au.

Research contact person:

Name	Chandrika Gibson
Position	Student Investigator
Telephone	0411 954 851
Email	c.gibson1@student.curtin.edu.au

Nature and Purpose of the Study

You are invited to participate in our study which aims to determine the support and education needs of patients diagnosed with head and neck cancer and their carers. During the interview we will explore your experience of receiving a head and neck cancer diagnosis, your perspectives about preparing for treatment and your education and support needs from the time of diagnosis.

What the Study Will Involve

If you agree to participate, you will be asked to participate in a 45 minute to 1 hour interview, either face-to-face or via telephone, with a researcher to talk about your experience of being diagnosed and treated for head and neck cancer. The interview will be digitally recorded so that it can be transcribed for analysis by the research team. At the beginning of the interview you will be asked complete a consent form and a few personal details such as age, education level and employment status. All of your details will remain confidential and will only be known by the researcher.

Benefits

While you may not benefit from participating in the research, the information you provide regarding your experience may assist in developing education interventions for patients and health professionals in the future. You may also benefit from the opportunity to speak about your experience knowing the information you are sharing will be used to improve the quality of care for those living with head and neck cancer.

Discomforts and Risks

No harm is expected to come from your involvement in this study. The interviews may contain questions that are personal such as age and your experience with the healthcare system. You may find discussing your experience distressing. If for any reason you do find any of the questions upsetting you may choose not to answer the question. You can choose to withdraw from the study without having to give a reason until one week post interview. The research team will provide you with contacts for no cost, low cost and web-based support services for you to follow up if needed.

Voluntary Participation and Withdrawal from Study

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project until one week post interview when the data becomes de-identifiable.

Data Management

All digital audio files and transcribed interviews will be stored on the secure research drive at Curtin University, consistent with Curtin University's Research Data and Primary Materials Policy. Each interview will be transcribed immediately and identifying information will be removed at this time. A twelve digit reference number will then be used to identify each interview participant and only the researchers will have access to this information. All records from the interviews will be securely held for a period of seven years and subsequently destroyed.

Privacy, Confidentiality and Disclosure information

At all times your confidentiality and privacy will be maintained and no information that might identify you will be used in any report, presentation or publication resulting from the research. Thank you for taking the time to read this information sheet. If you have any questions please do not hesitate to contact Associate Professor Georgia Halkett (08 9266 1762) or g.halkett@curtin.edu.au.

Determining the support and education needs of patients diagnosed with head and neck cancer and their carers

Investigators: Georgia Halkett, Moira O’Connor, Chandrika Gibson, Raelee Golding, Rohen White and Melanie Jackson.

Consent Form for interview

ID Number _________

Thank you for agreeing to participate in a semi structured interview on **“Determining the support and education needs of patients diagnosed with head and neck cancer and their carers”**

Declaration by Participant

1. I am over 18 years of age.
2. I agree voluntarily to take part in the study “Determining the support and education needs of patients diagnosed with head and neck cancer and their carers”
3. I have been given a copy of the Information Sheet and Consent Form, have read and fully understood the purpose and aims of this study, and what is required from me if I participate.
4. I understand I may keep a copy of the Consent Form.
5. I agreed to have the interview digitally recorded.
6. I have had the opportunity to ask questions and I am satisfied with the responses I have received.
7. I understand that I am free to withdraw from the study until one week post-interview and that this withdrawal will not have any repercussions.
8. I agree that the research data collected can be published in peer reviewed journals and reports unrestrictedly as long as my identity is kept confidential and is not be disclosed at any time.
9. I agree that the findings or results from the study can be shared with staff and other key stakeholder groups at the completion of this research.

Signature by Participant

Name ___________________________

Date ___________________________

Signature by Researcher

Name ___________________________

Date ___________________________

Interview Guide for People Diagnosed with Head and Neck Cancer (HNC)

Introduction

1. We are interested in understanding your experience of being diagnosed with HNC. Perhaps we could start with your account of your experiences with HNC so far?
2. Can you tell me about the treatments you have received so far?

Information Needs

3. Overall, what sort of information have you found most useful? Why was this?
4. Can you identify what information has helped you to reduce your fears and/or concerns during consultations? What sort of information was most useful initially?
5. So far, who has provided you with information?

Info re Diagnosis

6. What information have you been provided with about HNC?
7. How prepared do you feel for what is likely to happen in the future? What information has helped?

Info re Treatment

8. What information has been provided about treatment so far? Was this information helpful? Why/why not? How has it been useful?
9. At the moment, how well informed do you feel about your treatment?
10. Are you concerned about anything?

Questions relating to treatment (ask for each treatment received)

11. Did you feel adequately prepared for …. treatment?
12. What assisted you in preparing for treatment?
13. Who provided you with information?
14. Did you feel anxious or worried about receiving treatment?
15. What aspects concerned you?
16. Was it like you expected?

Info on Prognosis

17. Can you tell me about your prognosis?
18. What information about your prognosis has been provided? Was this information helpful? Why/why not?
19. How much of this information do/did you understand?
20. Was it discussed openly and in a sensitive way? Explain
21. Do you feel that you were told the right amount of information about prognosis? Too much?
22. Did you feel the timing of this information was appropriate?

In general

23. What type of information have you needed during this time?
24. Are there things happening to you that you feel you don't understand?
25. Have you accessed the information that doctors have provided to you? What information has been useful?
26. Have you independently accessed additional information? What about? Where? When? Why?
27. Which information sources have you found most useful/beneficial? Why? – written, video, verbal.
28. How do you feel about accessing information from the internet? Have you accessed the internet to gain information about radiation therapy?

29. Would you have preferred information to have been provided in a different way or using a different type of media? e.g. videos, education sessions etc.
30. When was information provided to you? Did you feel the timing was appropriate? Would you have preferred to receive information earlier/later?
31. Do you have any unmet information needs? What are they?
32. Have you had to ask for any information at a particular time? What sort?
33. What sort of information do you need now?

We are going to talk about your feelings and experiences now, so please remember that if any questions make you feel uncomfortable you can simply opt not to answer and we will move on to another topic.

Emotional and Practical support needs

34. How did you feel when you were first diagnosed?
35. Do you feel that you have assumed the role of patient? If yes, when did you take on the role?
36. Did being diagnosed with HNC change any of the other roles you play? e.g. Partner, employee, employer, recreation
37. Can you identify who has provided you with support since your diagnosis?
38. Do you feel like you are getting the support you need?
39. Have your support needs changed over time? Can you tell me more about when you did or didn't need various forms of support?
40. Do you feel like you can get additional support for yourself if/when you need it? Can you identify additional support needs you may have in the future?
41. Have you accessed support from other sources outside of the hospital? If so, what? Did you find these sources helpful? Why/why not?
42. Have you needed any practical or physical supports in the home? If so, what? Have you required financial assistance during this period? Has this need been adequately met?
43. Do you feel that the currently available patient support resources are adequate? If not,
    a) How could they be improved?

    b) What additional resources/supports do you think would be useful?

Self –Care and Psychological Wellbeing

44. Are there any practices that you have undertaken since learning of your condition that assist you in feeling good about yourself?
45. Has your physical appearance been altered by the disease and/or treatments? If so, what has that been like for you?
46. Have any of your relationships been impacted by your experience of HNC?
47. If you could rate your level of distress on a scale with one being very low and ten being very high, what number would you assign to your experience so far?
48. Have there been any positives to come out of your experience so far?

Thank you

Similar questions will be used at each of the different time points during the study.

Appendix C: Health Professional Information Sheet and Interview Schedule

Determining the support and education needs of patients diagnosed with head and neck cancer and their carers

Investigators: Georgia Halkett, Moira O'Connor, Chandrika Gibson, Raelee Golding, Rohen White, Melanie Jackson, Colin Tang and Joshua Dass .

Information Sheet for Healthcare Professionals Nature and Purpose of the Study

You are invited to participate in our study which aims to determine the support and education needs of patients diagnosed with head and neck cancer and their carers. We are keen to gain your perspective on their needs and explore your experiences in caring for them. We are particularly interested in exploring your experiences in communicating with these patients and carers.

What the Study Will Involve

If you agree to participate, you will be asked to participate in a 45 minute interview with a researcher to talk about your experiences. The interview will be digitally recorded and transcribed for analysis. At the beginning of the interview you will be asked complete a consent form and personal details such as age, training, and your experience with head and neck cancer patients. All of your details will remain confidential and will only be known by the researcher.

Benefits

While you may not benefit from participating in the research, your ideas will inform our understanding of patients' and carers' needs and the development of interventions to address these needs. You may benefit from the opportunity to speak about your work experience knowing the information you are sharing will be used to improve the quality of care for patients living with head and neck cancer.

Discomforts and Risks

No harm is expected to come from your involvement in this study. The interviews may contain questions that are personal such as age and your experience with the healthcare system. If for any reason you find these upsetting you may choose not to answer the question. If for any reason you choose to withdraw from the study you are free to do so. You do not need to give a reason for your decision.

Voluntary Participation and Withdrawal from Study

Participation in this study is entirely voluntary, completely confidential and is in no way linked to your employment. If you decide to take part and later change your mind, you are free to withdraw from the project prior to data analysis and publication of the results. There are no repercussions if you decide to withdraw from the study for whatever reason.

Data Management

All digital audio files and transcribed interviews will be stored on the secure research drive at Curtin University, consistent with Curtin University's Research Data and Primary Materials Policy. Each interview will be transcribed immediately and identifying information will be removed at this time. A reference number will then be used to identify each interview participant and only the researchers will have access to this information. All records from the interviews will be securely held for a period of seven years and subsequently destroyed.

Privacy, Confidentiality and Disclosure information

At all times your confidentiality and privacy will be maintained and no information that might identify you will be used in any report, presentation or publication resulting from the research. Thank you for taking the time to read this information sheet. If you have any questions please do not hesitate to contact Dr Georgia Halkett on (08) 92661762 or g.halkett@curtin.edu.au

Ethics Approval

Curtin Human Research Ethics Committee (HREC) and Sir Charles Gairdner and Osborne Park Health Care Group HREC have approved this study (Curtin HRE2018-0439 , SCGH HREC RGS0000001145). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Curtin University Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au. Or the SCGOPHCG HREC on (08) 6457 2999 or email hrec.scgh@health.wa.gov.au.

Curtin University

Determining the support and education needs of patients diagnosed with head and neck cancer and their carers

Consent Form for Health Professionals

ID Number ____________

Declaration by Participant

1. I am over 18 years of age.
2. I agree voluntarily to take part in the study "**Determining the support and education needs of patients diagnosed with head and neck cancer and their carers**"
3. I have been given a copy of the Information Sheet and Consent Form, have read and fully understood the purpose and aims of this study, and what is required from me if I participate.
4. I understand I may keep a copy of the Consent Form.
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8. I agree that the research data collected can be published in peer reviewed journals and reports unrestrictedly as long as my identity is kept confidential and is not be disclosed at any time.
9. I agree that the findings or results from the study can be shared with staff and other key stakeholder groups at the completion of this research.

Signature by Participant	Signature by Researcher
Name ____________________________	Name __________________
Date ____________________________	Date ___________________

Interview Guide for Health Professionals Working with People with Head and Neck Cancer (HNC)

Introduction

1. We are interested in understanding how you find working with people with HNC. Perhaps we could start with your account of your experiences with HNC patients so far?
2. Can you tell me about your role?

Pre-treatment

3. Do you meet with patients prior to their treatment starting? If so, how many times? How long are the meetings?
4. Can you talk me through the usual pre-treatment process you go through?
5. Are there any barriers to effective communication with patients pre-treatment?
6. Do you feel satisfied with the interactions you have with patients pre-treatment?

Providing Patient Information

7. What information do you provide to patients?
8. What sort of information have you found most useful? Why was this?
9. Are there any gaps in the information/resources you offer patients?
10. What unmet information needs do you perceive patients have as they progress from diagnosis to treatment?

Providing Patient Support

11. What support needs do patients with head and neck cancer have at each time point?
12. What support do you provide to patients? Is this support practical or emotional?
13. Do you feel adequately equipped to offer emotional support?
14. What do you do if a patient expresses distress?
15. Would you like to access further training to manage distressed patients?
16. What do you feel could make the experience of being treated for HNC less distressing for patients and carers?

Health Professional Support

17. Do you feel supported by your colleagues/team?
18. Is there a formal or structured peer support system in place?
19. Do you have a mentor or receive supervision?
20. Do you informally support your peers?

Communication During Treatment

21. Can you tell me about your relationship with patients undergoing treatment?
22. How much time do you typically spend with each patient?
23. Do you feel satisfied that the patient understands you?
24. Do you feel that you can understand the patients' needs, concerns etc?
25. What situations or circumstances make communication more challenging?
26. How could communication between yourself and the patients be improved?

In general

27. Do you enjoy your job? If so, what aspects do you enjoy most?
28. Is there anything you'd like to change about your job?
29. Do you find your role stressful? If so, what would make it less stressful?
30. Do you feel that you can switch off and relax when you leave work? What do you do to unwind?
31. How many hours a week do you work?

32. Have you ever experienced ‘burnout’ (a feeling of exhaustion due to overwork)?
33. Would you recommend people starting out in your profession work with HNC patients? Why? Why not?

Thank you