THE EXPERIENCES OF CAREGIVERS OF INDIVIDUALS WITH HEAD AND NECK CANCER: A QUALITATIVE STUDY

by

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Doctor of Philosophy (PhD)

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To my beloved son, *Minthant Thanekha*,
the light in my darkest hours,
the calm in every storm,
and the reason I strive to become better each day.
This work is for you –
may it one day inspire you,
as you have always inspired me.

Statement of Originality

This is to certify that to the best of my knowledge, the work contained in this thesis is my own work. It has not been previously submitted to meet requirements for an award at this or any other higher education institution. I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Su Htet Htet Aung

June 2025

Authorship Attribution Statement

Professor Jacqueline Bloomfield and Professor Kate White are my supervisors who guided me throughout my research.

The publication contained within this thesis forms part of the award of Doctor of Philosophy undertaken by Su Htet Htet Aung. The publication embedded in this thesis and the authorship attribution statement of the doctoral candidate are outlined below.

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Su Htet Htet Aung designed this study with co-authors, performed the literature search, co-performed data analysis, drafted the manuscript, and prepared and submitted it for publication.

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Artificial Intelligence

During the preparation of the thesis, I used ‘Grammarly’ for spelling checks and enhancing sentence structure. I confirm that when text was modified by generative AI, I reviewed the content for possible errors, inaccuracies and bias. I take full responsibility for the submitted thesis and have ensured that the work is original and has been used within the parameters outlined in the University of Sydney generative AI guide for researchers.

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More than anything, I want to be a role model for our son, Minthant Thanekha, to show him the value of perseverance, dedication and lifelong learning.

Abstract

Study background

Head and neck cancer (HNC) is a devastating disease. Approximately 20 million people were diagnosed with cancer worldwide in 2022, which is expected to become 35 million by 2050. HNC treatments are often complex, and their associated side effects can result in substantial functional challenges and visible changes for patients. Depending on individual circumstances, recovery from the treatment side effects can last weeks to months or even longer. These patients require considerable care, and caregiving tasks can be challenging for the caregivers. To date, little is known about the experiences of the informal caregivers of individuals with HNC around the world, including Australia, to identify their support needs.

Methods

This study was guided by qualitative interpretive inquiry, enabling the caregiving experience for HNC patients to be explored from the caregivers' perspectives. The research setting was a metropolitan tertiary hospital in New South Wales (NSW), Australia. This institution was selected due to the opportunity to recruit informal caregivers with experience in caring for patients with HNC. Fifteen participants were recruited for this study from 2020 to 2022. Semi-structured individual interviews were conducted via telephone with four males and 11 females, due to the social restrictions imposed by the COVID-19 pandemic. The interviews were audio-recorded, transcribed, and analysed using thematic analysis.

Findings

The overall experiences of caregivers were captured in the overarching theme of '*It is the hardest thing we have ever done*'. This overarching theme consisted of three major themes: '*our lives have changed*', '*caregiver as a coach*' and '*managing familiar and unfamiliar care needs*'. Becoming a caregiver for someone with HNC was a life-changing responsibility, and this transition was emotionally and psychosocially challenging, making caregiving one of the most difficult roles participants had ever assumed. The participants experienced changes in their daily lives as they adjusted to new roles and responsibilities. Those changes included psychosocial impacts, relationship changes and disruptions to their daily routines. The participants acted as coaches in providing care for HNC patients. The caregiving role involved providing emotional, social and financial support; facilitating communication between patients and others; and monitoring patients' symptoms and overall well-being. Many participants in this study gained a sense of purpose in managing familiar and unfamiliar care needs when caring for the person with HNC. They reported that they developed a stronger bond with the person during the difficult times.

Conclusion

By interpreting caregiver accounts, this study uncovers how caregivers of patients with HNC share their caregiving experiences with patients, and how these experiences have transformed their lives. The findings also offer valuable insights for healthcare practice, emphasising the need for ongoing support for caregivers to manage their roles effectively without neglecting their psychosocial and informational needs.

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Abbreviations

CINAHL	Cumulative Index of Nursing and Allied Health Literature
HNC	head and neck cancer
HPV	human papillomavirus
MEDLINE	Medical Literature Analysis and Retrieval
MeSH	Medical Subject Headings
NSW	New South Wales
PEG	percutaneous endoscopic gastrostomy
PET	positron emission tomography
PsycINFO	Psychological Information
UK	United Kingdom
USA	United States of America

Chapter 1: Introduction

This introductory chapter lays the foundation for the PhD thesis by outlining the study's background, providing an overview of the research topic, and situating the study within its broader context. It begins with a discussion of the background, followed by an introduction to head and neck cancer (HNC). The effects of HNC on patients and the role of informal caregivers in their care are also described. Next, the impetus for the study is presented, followed by a statement of the problem. An overview of the subsequent chapters of the thesis is also provided.

1.1 BACKGROUND TO THE STUDY

Cancer continues to be a significant global concern due to its increasing incidence and mortality rates, which are markedly affected by changes in lifestyle and socioeconomic background (Zhang et al., 2024). Cancer is a condition characterised by the unregulated growth of altered cells that undergo evolution through natural selection (Brown et al., 2023). Approximately 20 million people were diagnosed with cancer worldwide in 2022, which is expected to become 35 million by 2050 (Nierengarten, 2024). Cancer remains the leading cause of mortality (Bray et al., 2024). Cancer incidence and mortality vary geographically and between genders. Statistics show that men have a higher cancer incidence and mortality rate than women (Nierengarten, 2024). Prostate cancer ranks as the most prevalent cancer among men in 118 countries, followed by lung cancer in 33, and liver, colorectal and stomach cancer in 11, nine and eight countries, respectively (Bray et al., 2024). Lung cancer is the leading cause of death among men in 89 countries, whereas breast and cervical cancer are the leading causes of cancer mortality among women in 112 and 37 countries, respectively (Bray et al., 2024). The variations of the disease across different regions, the influence of available medical facilities, and various socioeconomic factors have affected the prevalence, mortality rate and effective management of cancer (Bray et al., 2024). At the same time, there have been improvements in cancer screening, diagnosis and treatment, and this has contributed to a higher number of cancer survivors in developed countries (Lopes Cardozo et al., 2021; Nguyen, Vu, et al., 2023; Oh et al., 2023; Selmouni et al., 2024). While prevalence, mortality rates and survival outcomes differ among various types of cancer, the impact on individuals of specific cancer types varies significantly according to their anatomical location and the treatment modalities. This distinction is particularly evident in HNC, which often involves a combination of aggressive treatment modalities, often leading to significant visible and functional impairments (Vermaire et al., 2021; Ward & van As-Brooks, 2024). In HNC, the tumours are located in areas of the body that have important functions, such as communication, swallowing and breathing, leading to not only functional impairments but also visual disfigurement. The extent of these effects may not be seen with other types of cancer (Vermaire et al., 2021; Ward & van As-Brooks, 2024). The next section will present an overview of HNC.

1.2 OVERVIEW OF HEAD AND NECK CANCER

HNC includes malignancies that occur in or on the lips, mouth, pharynx (which includes the nasopharynx, oropharynx and hypopharynx), larynx, salivary glands, paranasal sinuses and skin, or soft tissues and bones of the head and neck (Thome et al., 2018). Approximately 890,000 people are newly diagnosed with HNC annually worldwide (Aupérin, 2020). The incidence of HNC is on the rise and is expected to continue to increase, primarily due to the rise in oropharyngeal cancer (Gormley et al., 2022). In Australia, HNC was the seventh most commonly diagnosed cancer in 2017 (Cancer Australia, 2024). In 2022, there were 5,189 new cases of HNC diagnosed in Australia (3,822 in males, 1,367 in females) (Cancer Australia, 2024). In Australia, HNC mortality has decreased from 4.3 per 100,000 deaths in 2009 to 3.9 per 100,000 in 2019 (National Cancer Control Indicators, 2024). Chances of survival for individuals with HNC have also improved. In 2011–2015, the chances of survival for five years after HNC diagnosis were 74.1% in females and 69.5% in males in Australia (National Cancer Control Indicators, 2025). In New South Wales (NSW), 1,358 new cases of HNC were diagnosed in 2021, and the rate of HNC incidence in NSW has remained the same over the past 10 years (Cancer Institute NSW, 2024) (see Figure 1.1). The five-year survival rate of individuals with HNC in NSW has increased from 52.5% in 1997–2001 to 62.9% in 2012–2016 (Cancer Institute NSW, 2024) (see Figure 1.2). This improvement could be due to an increase in the number of early diagnoses and advances in treatments (Strohl et al., 2022).

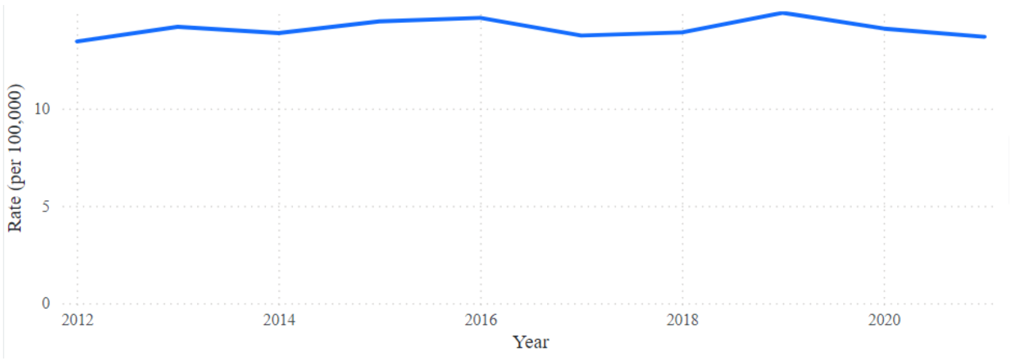

Figure 1.1: Age-standardised HNC incidence rate, NSW, 2012–2021
(Cancer Institute NSW, 2024)

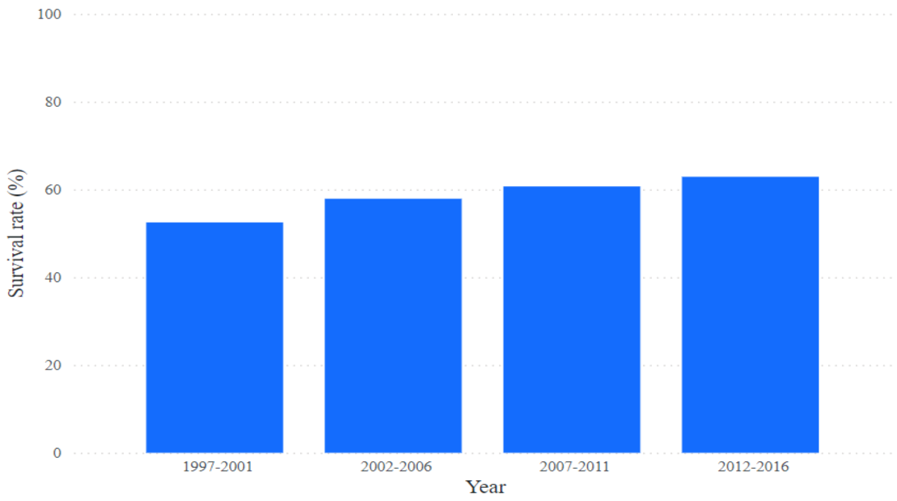

Figure 1.2: Five-year relative HNC survival, NSW, 1997–2016
(Cancer Institute NSW, 2024)

1.2.1 Risk factors of head and neck cancer

Several risk factors have been associated with the development of HNC. Tobacco smoking remains the major risk factor, primarily associated with oropharyngeal cancer (Aupérin, 2020; Di Credico et al., 2019). Smoking cessation can reduce the risk of HNC, and research has shown that former smokers who stopped smoking at least 10 years ago are less likely to be diagnosed with HNC than current smokers (Di Credico et al., 2019). Heavy alcohol intake is another well-known risk factor for HNC, and both heavy alcohol use and smoking are more common in populations with lower health literacy and socioeconomic resources (Chaturvedi et al., 2013; Hsiao et al., 2020).

Other risk factors identified worldwide include chewing betel leaves that contain additives such as slake lime in Southeast Asia; drinking mate in South America; eating large amounts of preserved or salted food in childhood; poor oral hygiene; occupational exposure to substances such as asbestos (Thome et al., 2018). There has been an increase in the number of women and younger adults who are non-smokers or non-drinkers being diagnosed with HNC. It has been identified that this is due to human papillomavirus (HPV) and Epstein–Barr virus (EBV) (Senkomago et al., 2019; Thome et al., 2018). Oral sex is one of the risk factors for positive oral HPV infection (Raju et al., 2024; Strohl et al., 2022). The HPV-16 subtype is most commonly associated with malignancy, and EBV and the herpes simplex virus have been strongly linked with nasopharyngeal carcinoma (Aupérin, 2020; Brockstein & Masters, 2002; Dabouian et al., 2020). Vaping is on the rise in many countries, and e-cigarettes may contribute to the risk of HNC (Ward & van As-Brooks, 2024). Future research is expected to shed more light on the relationship between vaping and HNC risk (Ward & van As-Brooks, 2024). Family history of cancer and genetic changes can also contribute to the development and progression of HNC in a small number of cases (Ward & van As-Brooks, 2024). For example, a rare genetic disease called Fanconi anaemia can increase the chance of developing HNC (Beddok et al., 2020).

1.2.2 Signs and symptoms of head and neck cancer

Depending on the tumour's location and the cancer stage, patients can experience one or more symptoms (Bass et al., 2024). Early signs of HNC are frequently overlooked or disregarded by patients, resulting in delayed diagnosis (Khurshied et al., 2024). Premalignant lesions are often overlooked or taken as minor issues by individuals because the visual presentation of initial symptoms can be nonspecific, such as nonspecific sore throat, mouth sores, loose teeth and/or jaw pain (Bass et al., 2024; González-Moles et al., 2022). Lesions in the oral cavity and pharynx with thick, white or greyish patches called oral leukoplakia are also often observed as precancerous signs in HNC, and these premalignant lesions can transform into malignant lesions (Ramaswamy et al., 2020). Other early symptoms include red and painless patches called erythroplakia, a burning sensation in the mouth, dry mouth or taste changes (Khurshied et al., 2024). Late symptoms can include pain in the affected area, visible masses in the head and neck regions, neck swelling, difficulty swallowing, halitosis, reduced jaw opening, coughing, and a hoarse voice (Cancer Council, 2019; Ward & van As-Brooks, 2024). Currently, there is no screening test or program available to identify early HNC in Australia. However, it is recommended that early symptoms be monitored and that people should receive the HPV vaccination to protect themselves from HPV (Head and Neck Cancer Australia, 2022).

1.2.3 Management of head and neck cancer

Individuals with HNC typically require complex treatment and management from a multidisciplinary team. In HNC, the tumours are located in areas of the body that have important functions, such as communication, swallowing and breathing. Subsequently, this can lead to not only functional impairments but also to visual disfigurement, and both issues contribute to the complexity of HNC management (Sharma et al., 2024). The management of HNC can be extensive and often involves multiple treatment modalities, including surgery, radiation, chemotherapy and immunotherapy (Mody et al., 2021). These treatments aim to preserve bodily functions as much as possible while maximising the chance of survival, which involves a complex process that requires coordinated care from various health experts (Ward & van As-Brooks, 2024).

Treatments are determined based on the patient's comorbidity, the stage and location of the cancer, and post-treatment quality of life (Ward & van As-Brooks, 2024). Accurate staging is essential for treatment planning and patient outcomes. Generally, stages I and II are considered early-stage cancer since the tumour size is less than 4 cm and it has not spread. Therefore, cancer at these stages is usually treated with surgery or radiation alone (Head and Neck Cancer Australia, 2025; Marur & Forastiere, 2016). In advanced cancer (stages III and IV a/b), the tumour size can be larger than 4 cm and spread to other parts of the body (Head and Neck Cancer Australia, 2025). In such cases, treatments may include combinations of chemoradiation with or without induction chemotherapy and surgery (Marur & Forastiere, 2016). The goal of any treatment plan is to remove the tumour and preserve the structures involved in swallowing, speaking and facial expression (Ward & van As-Brooks, 2014). However, these diverse treatments frequently result in side effects that affect patients functionally and visually, necessitating the collaboration of various health specialists with specialised expertise to restore these abilities to the greatest extent possible (Ward & van As-Brooks, 2024). Different treatment options and their related toxicities will now be discussed.

Generally, surgery is considered the first line of treatment for HNC, aiming to remove the tumour completely (Pierik et al., 2021). Less invasive surgical techniques, such as transoral laser microsurgery and transoral robotic surgery, have been introduced alongside traditional open surgery approaches, as these less invasive methods can minimise postoperative complications (Sahovaler et al., 2019). The remaining cancer cells are usually treated with postoperative radiotherapy or chemoradiotherapy (Pierik et al., 2021). If surgery is the treatment of choice, patients may lose parts of their face and may experience postoperative neck–shoulder dysfunction or trismus, visible scarring, and changes in their ability to make facial expressions (Damrose & Doyle, 2019). Due to the anatomy of the tumour and the type of surgery required, deficits in speech and swallowing are both highly prevalent and considerably limiting for this population (Ward & van As-Brooks, 2024). This often results in patients becoming dependent on tracheostomy and/or gastrostomy tubes (Sahovaler et al., 2019). The recovery time for surgery depends on individual circumstances, but it can take weeks to months to recover function. Some side effects may include dysphagia, xerostomia, osteoradionecrosis, facial disfigurement and movement restrictions (Damrose & Doyle, 2019; Sahovaler et al., 2019).

Radiotherapy can serve as an alternative treatment to surgery and is often regarded as a preserving therapy. Intensity-modulated radiation therapy (IMRT) has been used because it allows more effective dose distributions to the targeted tumour while safeguarding surrounding normal structures.

Recently, immunotherapy has been integrated into the management of HNC due to its clinical benefits and improved survival outcomes. Additionally, immunotherapy is used in recurrent and metastatic nasopharyngeal carcinoma.

Individuals with HNC may have more than one tumour, which means they remain at risk of developing further malignancies even after successful initial treatment. Thus, baseline and serial scanning with computed tomography (CT) and/or magnetic resonance imaging (MRI) is recommended to detect any recurrence (Chandra & Li, 2022; Mehanna et al., 2016).

Radiation and chemotherapy can also lead to visible disfigurement and changes in body function. For example, alterations in skin colour and elasticity are often associated with radiation therapy (Thome et al., 2018). Patients often require teeth to be extracted prior to radiation (Moore et al., 2014), resulting in aesthetic and functional changes. Dentures typically cannot be fitted for several months after treatment. Decreased saliva production, difficulty swallowing, changes in taste, and dental issues within the first year of chemoradiotherapy are not uncommon, potentially leading to malnutrition, aspiration, dehydration and poor quality of life (Hunter et al., 2020; Ringash et al., 2018; Vermaire et al., 2021). These treatment-related side effects necessitate further management by health professionals with specialised knowledge and skills.

A multidisciplinary team approach is crucial for meeting the many physical, psychosexual, nutritional and aesthetic requirements of HNC patients. Valuable multidisciplinary team members include oncologists, surgeons, specialist nurses, dietitians, speech pathologists, physiotherapists, occupational therapists, social workers, psychologists, radiation therapists, pathologists, and plastic and reconstructive surgeons, along with other allied healthcare professionals. Multidisciplinary care aims to provide the best treatment for patients and help them achieve optimal quality of life in the long term. In Australia, the care of individuals with HNC is based on the multidisciplinary team approach, and the optimal care pathway for people with head and neck cancer (refer to Appendix A) was developed in 2021. The principles underlying the optimal care pathway prioritise patients and families at the centre of care and encourage healthcare providers to deliver comprehensive and integrated care. Figure 1.3 shows the multidisciplinary model of care in HNC management in Australia.

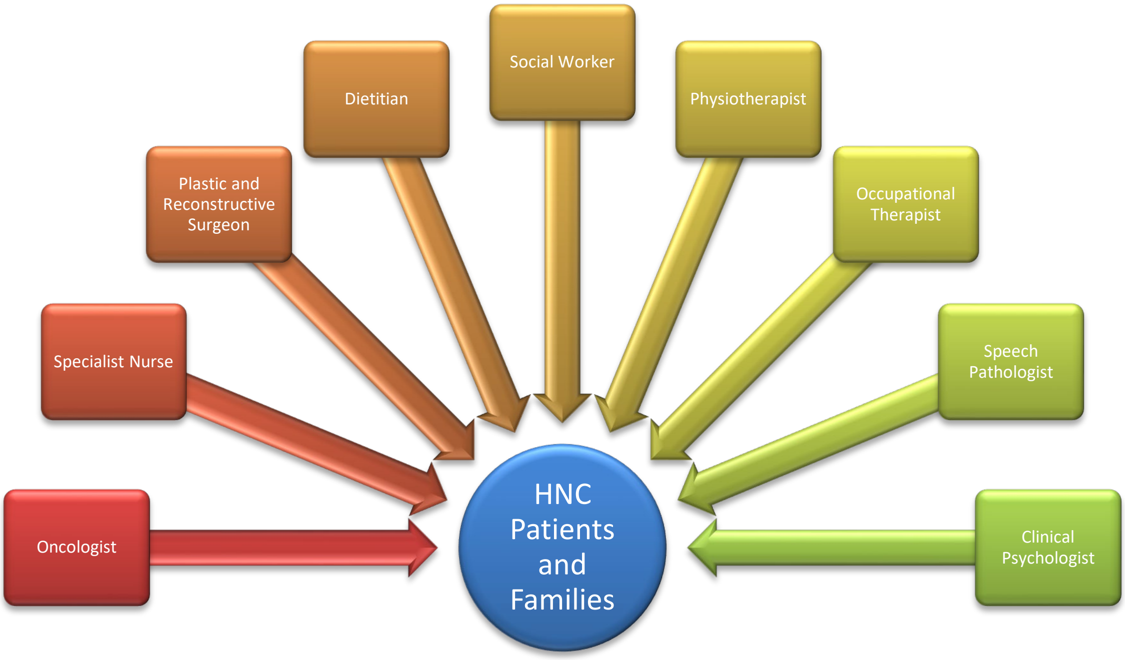

Figure 1.3: Multidisciplinary approach in head and neck cancer management in Australia

The optimal care pathway suggests that patients with signs and symptoms of HNC lasting more than three weeks should be referred to a specialist, ideally within two weeks. Initial investigations, including CT and/or MRI or ultrasound-guided fine-needle aspiration cytology of a node, should be conducted if malignancy is suspected or if a lump persists. Additional diagnostic and staging investigations may include endoscopy, various imaging scans (ultrasound, CT, MRI or positron emission tomography [PET]), and biopsy. Following the HNC diagnosis, a multidisciplinary team discussion occurs, and subsequently, the patient and/or caregiver will be informed of the treatment options and the ongoing care plan.

Reconstructive surgery plays a crucial role in restoring visual and functional structures following radical resections, such as glossectomy or laryngectomy (Lee, Ismail, et al., 2023). When reconstruction is not an option, patients may require nonsurgical interventions such as facial or dental prostheses to improve functional and aesthetic outcomes (Wang et al., 2020). Rehabilitation is also an integral part of HNC care, as patients continue to require collaborative management from various healthcare professionals to enhance treatment outcomes (Ringash et al., 2018). Rehabilitation can last from weeks to months or sometimes even longer, depending on individual circumstances (Sharma et al., 2024).

Within the multidisciplinary team, specialist nurses are essential for delivering holistic care, managing treatment side effects, and addressing patients’ and their families’ physical and psychosocial needs. Specialist nurses assess the patient’s physical and psychosocial status, along with their previous medical and social history, before HNC treatment. They educate the patient and their family about the diagnosis, treatment and possible outcomes, and coordinate patient care with other healthcare professionals (Cook et al., 2019). Holistic assessment of patients and their families is fundamental in HNC management. The role of the specialist nurse is highly valued by the healthcare team in assessing patients' needs and ensuring these needs are met in a timely manner (Kerr et al., 2021). HNC treatments often present ongoing challenges during the treatment and recovery periods (Strohl et al., 2022) Specialist nurses provide valuable support for patients and their families to help them cope with their cancer diagnosis, manage symptoms and pain, prevent and monitor signs of recurrence, and adjust to long-term changes. This includes acquiring disease-related skills such as handling feeding tubes, drainage, dressing, caring for tracheostomies or stomas, and providing palliative care (Kantor & Suzan, 2015; Kerr et al., 2021). Patients may require specialised care from specialist nurses, as they can experience acute symptoms during or immediately after treatment. For example, oral mucositis is common in radiation and chemotherapy, necessitating pain medications, diet modification, and often the placement of a percutaneous endoscopic gastrostomy (PEG) tube for nutrition (Strohl et al., 2022). Upon completing treatment, patients with HNC may be referred to relevant health professionals, community services or support groups for ongoing care as necessary (Ward & van As-Brooks, 2024).

1.3 THE EFFECTS OF HEAD AND NECK CANCER ON PATIENTS

The duration of symptoms and side effects from treatments can vary depending on each person's situation, the occurrence of complications and the healing process. Some individuals undergoing chemotherapy or radiation therapy may experience short-term side effects such as difficulty in eating solid foods due to mucositis. Skin rashes, burning sensations, osteoradionecrosis and dry mouth may also manifest. In some cases, patients experience long-term effects like permanent xerostomia, and severe dental problems such as rampant caries (Kaste et al., 2013).

Beyond these visible changes, HNC and the side effects of the treatments can disrupt the core functions of a person's daily life. The psychosocial impact of the disease on individuals diagnosed with HNC is well known (Fundakowski, 2020). HNC is associated with decreased quality of life and increased psychological distress. Anxiety, depression, and cognitive and behavioural impairments are examples of symptoms associated with psychological distress (Mamatha et al., 2024; Vanumu & Nemade, 2023). Disfigurement is a common side effect of HNC treatment. HNC patients with facial disfigurements are vulnerable to distress, intimacy issues and social isolation (Gibson et al., 2021). Other psychosocial concerns include difficulties adjusting to new roles and responsibilities, social isolation, and problems with employment (Geiss et al., 2024; Lin et al., 2024).

Whether side effects are caused by surgery or radiotherapy, post-treatment symptoms like a dry mouth and difficulty speaking clearly or swallowing safely can impact a patient's self-image and interactions with others. HNC survivors often experience discomfort when going out for a meal or participating in other social activities because they are unable to eat or swallow as they did before. Physical and functional changes, such as weight loss and changes in appearance or speech, contribute to challenges with social activities such as eating, drinking and kissing (Kılıç et al., 2015; Şencan et al., 2020).

1.4 INVOLVEMENT OF INFORMAL CAREGIVERS IN HEAD AND NECK CANCER

The responsibilities of informal caregivers have markedly expanded due to multiple factors. These include the complex process of cancer diagnoses, prolonged side effects of cancer treatments, the transition from inpatient to outpatient care, reduced hospital stays, and the shift of care to home and community settings (Bertucci et al., 2019). An informal caregiver is an unpaid person who assists with the basic and functional needs of someone with cancer, managing a person's finances, arranging for outside services, or visiting regularly. This informal caregiver may be a spouse, a partner, a child, another relative or, in some cases, a friend who may or may not live in the same household as the person with cancer (Deloitte Access Economics, 2020). In 2020, over one in eight Australians (2.8 million people) were estimated to be providing informal care(Deloitte Access Economics, 2020) (Deloitte Access Economics, 2020). It has been estimated that if those informal care hours were replaced with services purchased from formal care providers, the replacement cost of informal care would be $77.9 billion (Deloitte Access Economics, 2020). This highlights the value of informal caregivers within the healthcare system. This thesis focuses on the pivotal role of caregivers and explores their contribution in the context of HNC.

As discussed earlier, HNC treatments are complex. Therefore, patients with HNC typically require care from different health professionals and informal caregivers, particularly following hospital discharge. This is due not only to the nature of the disease and the complexity of treatments, but also to constraints in healthcare resources, shortages of nursing personnel and geographical inequities, which can all contribute to reliance on informal caregivers (Collaço et al., 2024; Stout et al., 2024). In addition, cancer care delivery is being shaped by growing numbers of cancer survivors coupled with an increased cost of primary treatment and follow-up care, heavy reliance on informal caregivers and the transition to value-based care (Alfano et al., 2019). These factors indicate the need for coordinated, comprehensive, personalised care for both cancer survivors and informal caregivers that meets their needs and facilitates the unique role of these informal caregivers.

There has been an increase in the number of survivors who live longer after their cancer diagnosis, due to advances in early detection and treatment. However, five-year survival rates can vary depending on the type of cancer (Miller et al., 2019). This increase in survivorship creates a need to address ongoing health issues for patients and the needs of their informal caregivers. Studies have found that patients who completed their cancer treatment often felt unprepared for what happens next and frequently required considerable support from health professionals and informal caregivers (Leach et al., 2017). Some survivors remain at risk of cancer recurrence and may need further cancer treatment (Ringash et al., 2018).

Informal caregivers play an important role in supporting patients with HNC, providing essential physical care and psychological support throughout the illness trajectory. The role of informal caregiving in alleviating the burden for patients with HNC has been well recognised (Humphris, 2016). Because patients with HNC often require a considerable amount of care and support, the caregiving tasks can be challenging for the caregivers (Precious et al., 2012). The side effects of the treatments can be complex and persist for a long time, requiring long-term care from the informal caregivers (Berkowitz et al., 2018). The physical care that caregivers are often involved in may include tracheostomy care, pain management, wound dressings, management of drainage systems, enteral feeding and dysphagia management (Ringash et al., 2018; Rogers et al., 2017). Informal caregivers also have an important role in managing decision-making and providing emotional care and support (Donovan & Glackin, 2012).

1.5 IMPETUS FOR THE STUDY

My personal interest in this research topic stems from my practical background. As a registered nurse, I have worked in a clinical setting in Singapore for many years. I am not a head and neck specialist nurse, but I have cared for many patients with HNC. I have witnessed how patients and their families experience HNC. I have observed that a diagnosis of HNC creates a major crisis, not only for the patients but also for their families and the primary caregivers. In Singapore, most cancer patients depend entirely on their caregivers for their care needs. I have seen family members who have been emotionally affected by the cancer diagnosis as they tried their best to support the patients. Patients with HNC may require long-term care such as wound care, tube feeding, dysphagia management and nutritional support, even after completing treatment. As these patients require complex care, often involving the input of informal caregivers, I wanted to better understand the experience of these informal caregivers and how they could be best supported to fulfil their tasks effectively and independently. For instance, as a registered nurse, I have provided education to family members of patients with HNC on how to perform wound dressings. During these experiences, I observed that some family members struggle to even look at the wounds due to their extensive and often confronting appearance. Family members often find it difficult to communicate with the patient due to their limited ability to speak after treatment. Most of the patients I cared for were discharged upon completing the active treatment while their informal caregivers received little training and support to maximise the patient's recovery. It remained unclear how these informal caregivers managed the patient at home. It was uncertain if the caregivers felt ready and confident to take on the caregiver role. I was also unsure how these informal caregivers managed their own needs while taking on these responsibilities. Informal caregivers were neglected regarding their psychosocial and physical well-being. They were rarely asked how they could be assisted in taking on the caregiver role without losing their own quality of life. This inspired me to investigate the literature on HNC and to conduct this research.

1.6 STATEMENT OF THE PROBLEM

As discussed earlier, informal caregivers have been recognised as essential partners in cancer care for the past decade due to the complexity of cancer treatment and the increased demand for care provision in the outpatient and home setting (Kent et al., 2016). To date, there is little understanding of the overall experiences and the needs of informal caregivers of patients with HNC, especially in Australia.

1.7 ORGANISATION OF THESIS

Chapter 1 provides an overview of HNC, identifies the impetus for conducting the study, and outlines how the thesis is organised. Following this introductory chapter, Chapter 2 presents a comprehensive review of the existing literature on the experiences of caregivers of someone with HNC and the available interventions for them. It critically examines current research findings, identifies key gaps in knowledge, and outlines how the present study aims to address these gaps. Chapter 3 details the methodological and philosophical underpinnings of the study. It explains how interpretive inquiry methodology was used in this study, guided by hermeneutic theory. The chapter also discusses the suitability of the chosen methodology in addressing the research question. It outlines the detailed procedures followed during the study and describes the strategies employed to ensure trustworthiness throughout the research process. In Chapter 4, the study findings are presented in major themes, with associated subthemes. These themes and subthemes detail the experiences and needs of caregivers of patients with HNC. Chapter 5 summarises the key findings of the study. It also addresses the implications of the study findings for policy, education and practice, as well as the strengths and limitations of the study. It also includes the conclusion of the thesis and provides recommendations for future research.

1.8 List of terms

- **Specialist nurses:** Specialist nurses are nurses with experience and expertise in the care and management of individuals with HNC.
- **Informal caregivers:** An informal caregiver is an unpaid person who assists with the basic and functional needs of an individual with HNC, including managing finances, arranging for outside services or visiting regularly. This informal caregiver may be a spouse, a partner, a child,

another relative or, in some cases, a friend who may or may not live in the same household as the person with HNC.

- **Head and neck cancer (HNC):** HNC includes malignancies that occur in or on the lips, mouth, pharynx (which includes the nasopharynx, oropharynx and hypopharynx), larynx, salivary glands, paranasal sinuses and skin, or soft tissues and bones of the head and neck.

Chapter 2: Literature Review

The previous chapter introduced the study background, an overview of HNC, the effects of HNC treatments, and the role of informal caregivers in HNC. This chapter begins with an integrative review of the literature that examines the current knowledge regarding the experiences and needs of informal caregivers of HNC patients. The findings of this literature review have been published in the journal *Cancer Nursing* (see Appendix B). The second part of this chapter provides a narrative review of the literature relevant to supporting these caregivers in understanding their effectiveness. The chapter outlines the steps taken to locate the literature for the review process. Finally, the chapter identifies existing gaps in knowledge and practice related to the topic, thereby highlighting opportunities for future research. Throughout this chapter, the term ‘caregiver’ will be used to refer to a spouse, child, relative, family member, friend, or any informal caregiver who assumes the role of caregiver for an individual with HNC.

2.1 INTEGRATIVE REVIEW OF THE EXPERIENCES AND NEEDS OF CAREGIVERS OF INDIVIDUALS WITH HEAD AND NECK CANCER

To establish a comprehensive understanding of the current state of knowledge, an integrative review of existing literature focusing on the experiences and needs of caregivers caring for someone with HNC was conducted. Integrative review is a specific review method that summarises various primary research methods to provide a more comprehensive understanding of a particular problem (Whittemore & Knafl, 2005). This approach enabled the synthesis of findings from diverse studies, encompassing both qualitative and quantitative research, to capture the multifaceted nature of caregiving in the context of HNC. This literature review adopted a five-stage approach to the review process, namely (1) identification of the research problem, (2) searching the literature, (3) evaluation of the data, (4) analysis of the data, and (5) presentation of the results (Whittemore & Knafl, 2005). The review process undertaken to facilitate a comprehensive examination of caregivers' experiences and needs is outlined in Table 2.1.

Table 2.1: Integrative review process

Stage	Application
Problem identification	Head and neck cancer (HNC) affects individuals, family members and communities. HNC patients require a considerable amount of care and support, and the tasks of caregiving can be challenging. To date, there is no published literature review related to the experiences of caregivers of patients with HNC. An integrative literature review was conducted to synthesise the findings from published studies to identify the experiences of carers of patients with HNC to increase understanding of caregivers' experiences. It also aimed to reveal knowledge gaps about this topic and, in doing so, identify further areas for research.
Literature search	Literature search was guided by a research question. Electronic databases searched included CINAHL, MEDLINE, PsycINFO and Scopus.
Data evaluation	The relevant Critical Appraisal Skill Programme tool and Mixed Method Appraisal Tool were used.
Data analysis	Thematic analysis was used to develop themes and subthemes.
Presentation	Three central themes running through this literature review were identified in relation to the experiences of caregivers of HNC patients. These were: disruption to daily life, the impact of caregiving, and the availability of information.

2.1.1 Literature review question and aim

This integrative review was guided by the central research question: ‘What are the experiences and needs of caregivers of individuals with head and neck cancer?’ The primary aim was to synthesise existing knowledge on this topic and to identify gaps in the literature that warrant further investigation.

2.1.2 Search methods

A well-defined literature search strategy was used to ensure rigour and to avoid potentially biased searches (Whittemore & Knafl, 2005). With the assistance of a librarian at the University of Sydney and my supervisors, the following databases were searched in April 2018 for this review: Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval (MEDLINE), Psychological Information (PsycINFO) and Scopus. The search terms used were: “head and neck cancer”, “head and neck neoplasms”, caregiver(s), carer(s), family, family member(s), experience(s), need(s) and support(s). Other related terms such as “facial cancer”, “oral cancer”, “laryngeal cancer”, “thyroid cancer” and “tracheal cancer” were also used, particularly in the PsycINFO database, to enhance comprehensiveness of the search.

Medical Subject Headings (MeSH) and free search terms were combined to search for relevant literature. The search was limited to research studies published in peer-reviewed journals from 2008 to 2018. Due to advances in treatments with a reduction in surgery volume, changes in the delivery of radiotherapy, and interventions to improve voice and swallowing function (Argiris et al., 2018), the experiences and support needs of the caregivers of patients with HNC prior to this time period may have been different. The search was also limited to studies published in English. Reference lists from the papers that were identified via electronic database search were also searched to maximise search results. This search strategy is detailed in Table 2.2. An inclusive approach was taken to searching and collecting information, reflecting the diversity of studies that employed quantitative, qualitative and mixed methods study designs.

Table 2.2: Search strategy

Database	Platform	Total search results	Search strategy
CINAHL	EBSCOhost	62	“Head and Neck Neoplasms+” **OR** “head and neck cancer” **AND** Caregivers **OR** caregiver* **OR** carer* **OR** Family+ **OR** “family member*” **AND** Life Experiences+ **OR** experience* **AND** Health Services Needs and Demand+ **OR** Information Needs **OR** need* **OR** Support, Psychosocial+ **OR** Nutritional Support+ **OR** support* Limit: 2008–Current, English
MEDLINE	OvidSP	55	exp “Head and Neck Neoplasms” **OR** “head and neck cancer” **AND** exp Caregivers **OR** caregiver* **OR** carer* **OR** exp Family **OR** “family member*” **AND** experience* **AND** exp “Health Services Needs and Demand” **OR** exp Psychosocial Support Systems **OR** exp Social Support **OR** exp Nutritional Support **OR** exp Financial Support **OR** support* **OR** need* Limit: 2008–Current, English
PsycINFO	OvidSP	29	“head and neck cancer” **OR** “facial cancer” **OR** “oral cancer” **OR** “laryngeal cancer” **OR** “thyroid cancer” **OR** “tracheal cancer” **AND** exp Caregivers **OR** caregiver* **OR** carer* **OR** exp Family **OR** “family member*” **AND** experience* **AND** exp Health Service Needs **OR** exp Psychological Needs **OR** exp Needs **OR** exp Support Groups **OR** exp social Support **OR** need* **OR** support* Limit: 2008–Current, English
Scopus		42	ABS(“head and neck cancer” **OR** “facial cancer” **OR** “oral cancer” **OR** “laryngeal cancer” **OR** “thyroid cancer” **OR** “tracheal cancer”) **AND** ABS(caregiver* **OR** “family member*” **OR** carer*) **AND** ABS(experience*) **AND** ABS(need* **OR** support*) Limit: 2008–Current, English

2.1.3 Search outcome

The original database search located 62 studies in CINAHL, 55 studies in MEDLINE, 29 studies in PsycINFO and 42 studies in Scopus. Six studies were identified through hand-searching, resulting in a total of 194 studies. Firstly, duplicates were removed. Then, titles and abstracts were reviewed based on the inclusion and exclusion criteria outlined in Table 2.3 below.

Table 2.3: Inclusion and exclusion criteria for literature review of experiences and needs of caregivers of individuals with head and neck cancer

Inclusion criteria	Exclusion criteria
Published in English language	Published in language other than English
Relevant primary research study	Articles other than relevant primary research articles (e.g. review papers, editorials, dissertations, conference abstracts, commentaries, discussion papers, irrelevant topics and interventional studies)
Related to caregivers of patients with head and neck cancer only	Related to caregivers of patients with other types of cancer or related to only patients with head and neck cancer
No restrictions on research method	Interventional study

Subsequently, studies were identified based on the relevance of the topic and depth of information related to the review question. Original studies were included regardless of the theoretical approach, data collection process or method of analysis. It is worth noting that few studies studied caregivers exclusively. Some studies, however, focused on both caregivers and patients. Thus, as long as the caregivers' views were being studied, the studies were included. Three researchers independently reviewed the studies identified for relevance. Any discrepancies were resolved through discussion until a consensus was reached. After applying the inclusion and exclusion criteria, a total of 20 studies were included in the literature review.

2.1.4 Quality appraisal

For this review, studies were first categorised into quantitative studies, qualitative studies and mixed methods study designs. The Critical Appraisal Skills Programme (CASP) evaluation checklist for cohort studies was applied to assess the quantitative studies (Critical Appraisal Skills Programme (CASP), 2018a) (Table 2.4), while a critical appraisal of qualitative studies was performed using 10 questions from the CASP qualitative checklist (Critical Appraisal Skills Programme (CASP), 2018b) (Table 2.5). A Mixed Method Appraisal Tool (MMAT) was used for the mixed methods study (Pace et al., 2012) (Table 2.6). These appraisal checklists and tools consist of a series of questions that enable the researcher to acquire a deeper understanding and appreciation of the rigour or trustworthiness of the published studies, which is necessary for making a judgment about their quality for inclusion in the review. The limitation identified in some of the quantitative studies reviewed was inadequate sample size. For example, the study by Longacre et al. (2015) included only 59 caregivers and the study by Hiremath et al. (2017) included only 40 caregivers, which may limit the generalisability of the findings. Notably, in the majority of the qualitative studies, no discussion was provided regarding the relationship between the researcher and participants. Subsequently, the influence of potential bias cannot be determined. Despite these limitations, the overall study strengths outweighed their weaknesses, and the decision was made not to exclude any from the review. This resulted in all 20 studies being included in the review.

Table 2.4: Critical Appraisal Skill Programme (CASP) cohort study checklist

Study	Q1	Q2	Q3	Q4	Q5	Q6a	Q6b	Q7a	Q7b	Q8	Q9	Q10	Q11	Q12
Chen, et al., 2009	Y	Y	Y	Y	Y	X	X	X	X	Y	Y	Y	Y	Y
Longacre, et al., 2015	Y	Y	Y	Y	Y	X	X	X	X	Y	Y	Y	Y	Y
Offerman, et al., 2015	Y	Y	Y	Y	Y	X	X	X	X	Y	Y	Y	Y	Y
Balfe, O'Brien, et al., 2016	Y	Y	Y	Y	Y	Y	X	X	X	Y	Y	Y	Y	Y
Hiremath, et al., 2017	Y	Y	Y	Y	Y	X	X	X	X	Y	Y	Y	Y	Y
Hanly, et al., 2016	Y	Y	Y	Y	Y	X	X	X	X	Y	Y	Y	Y	Y
Hung, et al., 2013	Y	Y	Y	Y	Y	X	X	X	X	Y	Y	Y	Y	Y

Abbreviations: Y, reported; X, not reported

Question 1: Did the study address a clearly focused issue?
Question 2: Did the authors use an appropriate method to answer their question?
Question 3: Was the cohort recruited in an acceptable way?
Question 4: Was the exposure accurately measured to minimise bias?
Question 5: Was the outcome accurately measured to minimise bias?
Question 6a: Have the authors identified all important confounding factors?
Question 6b: Have they taken account of the confounding factors in the design and/or analysis?
Question 7a: Was the follow-up of subjects complete enough?
Question 7b: Was the follow-up of subjects long enough?
Question 8: What are the results of this study?
Question 9: How precise are the results?
Question 10: Do you believe the results?
Question 11: Can the results be applied to the local population?
Question 12: Do the results of this study fit with other available evidence?

Table 2.5: Critical Appraisal Skills Programme (CASP) qualitative research checklist

Study	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**
Kitrungrote, et al., 2008	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Röing, et al., 2008	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Mayre-Chilton, et al., 2011	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Nund, et al., 2014	Y	Y	Y	Y	Y	X	X	Y	Y	Y
Schaller, et al., 2014	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Fronczek, 2015	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Nund, 2015	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Taylor, et al., 2016	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Balfe, Keohane, O'Brien, & Sharp, 2017	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Penner, et al., 2012	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Balfe, Maguire et al., 2016	Y	Y	Y	Y	Y	X	Y	Y	Y	Y
Balfe, Keohane, O'Brien, et al., 2017	Y	Y	Y	Y	Y	X	Y	Y	Y	Y

Abbreviations: X, answer not available; Y, reported

Question 1: Was there a clear statement of the aims of the research?
Question 2: Is a qualitative methodology appropriate?
Question 3: Was the research design appropriate to address the aims of the research?
Question 4: Was the recruitment strategy appropriate to the aims of the research?
Question 5: Was the data collected in a way that addressed the research issue?
Question 6: Has the relationship between researcher and participants been adequately considered?
Question 7: Have ethical issues been considered?
Question 8: Was the data analysis sufficiently rigorous?
Question 9: Is there a clear statement of findings?
Question 10: How valuable is the research?

Table 2.6: Mixed Method Appraisal Tool (MMAT)

Types of mixed methods study components	Methodological quality criteria	Patterson et al., 2013
Screening question (for all types)	Are there clear qualitative and quantitative research questions, or a clear mixed methods question?	Y
	Do the collected data address the research question?	Y
Qualitative	1. Are the sources of qualitative data relevant to address the research question?	Y
	2. Is the process for analysing qualitative data relevant to address the research question?	Y
	3. Is appropriate consideration given to how findings relate to the context?	Y
	4. Is appropriate consideration given to how findings relate to researchers' influence?	Y
Quantitative descriptive	1. Is the sampling strategy relevant to address the quantitative research question?	Y
	2. Is the sample representative of the population under study?	Y
	3. Are measurements appropriate?	Y
	4. Is there an acceptable response rate (60% or above)?	Y
Mixed methods	1. Is the mixed methods research design relevant to address the qualitative and quantitative aspects of the mixed methods question?	Y
	2. Is the integration of qualitative and quantitative data relevant to address the research question?	Y
	3. Is appropriate consideration given to the limitations associated with this integration?	Y

Abbreviations: X, answer not available; Y, reported

The relevant information was extracted and the data were synthesised in response to the review question regarding the experiences and needs of caregivers of patients with HNC. This was done using thematic analysis (Thomas & Harden, 2008). Firstly, studies were categorised according to whether they employed a quantitative, qualitative or mixed methods study design. The findings related to the review questions from each study were then extracted. The extracted data were then read and re-read by my supervisors and myself to familiarise ourselves with it. Each line of the text was coded according to its meaning and content. The codes were compared for differences and similarities and then grouped into categories. The patterns and relationships between the categories were analysed and collated into themes. Each of the codes and categories was checked by myself and my supervisors for consistency of interpretation. Findings were finally summarised under thematic headings that the three researchers agreed on.

2.2 OVERVIEW OF STUDIES IN THE INTEGRATIVE REVIEW

The studies originated from the USA (n=2), the UK (n=8), Australia (n=2), the Netherlands (n=1), Taiwan (n=2) and Sweden (n=2). One study each was also conducted in Thailand, India and Canada. The studies addressed the experiences and the support needs of caregivers of HNC patients, with a variety of research aims and methods. Whereas seven studies used a quantitative approach, 12 studies used a qualitative study design, and one study used mixed methods. Caregivers in the studies were spouses, partners, relatives, family members, children or friends of the patients.

The studies addressed a wide variety of research aims. Three studies looked at the experiences of caregivers in relation to HNC treatments (Kitrungrote et al., 2008; Nund et al., 2015; Röing et al., 2008). Two studies explored the experiences of HNC caregivers in general (Fronczek, 2015; Halkett et al., 2020). Eight studies were related to the experiences of different supports or information needs (Balfe, Keohane, O'Brien, et al., 2017; Balfe, O'Brien, et al., 2016; Hanly et al., 2016; Hung et al., 2013; Longacre et al., 2015; Nund et al., 2014; Schaller et al., 2014; Taylor et al., 2016). Two studies focused on the caregivers' experiences of feeding tubes (Mayre-Chilton et al., 2011; Penner et al., 2012), while one study was particularly interested in the caregivers' experiences of treatment-related commuting (Balfe, Keohane, O'Brien, et al., 2017). Three studies explored quality of life and psychosocial issues (Chen et al., 2009; Hiremath et al., 2017; Patterson et al., 2013).

The focus of 16 of the studies reviewed was solely on caregivers of patients with HNC, whereas four studies included views from both caregivers and patients. Most of the participants in 19 studies were females, with the exception of one study that included more males than female participants (15 females, 127 males) (Hung et al., 2013). A summary of the key characteristics of the included studies is presented in Table 2.7.

Table 2.7: Key characteristics of included studies

Author, year **Country**	**Study aim(s)**	**Methodology/design** **Number of participants** **Gender** **Age group**	**Key findings**
(Kitrungrote et al., 2008) **Thailand**	To describe the experiences of caregivers of spouses with head and neck cancer (HNC) undergoing radiotherapy.	Hermeneutic phenomenology 15 spousal caregivers Gender: 12 females, 3 males Age: 38–67 years	Caregivers wanted to care for and comfort their spouses. Caregivers suffered from uncertainty of their future lives, the caregiving strain (physical, social, emotional and financial), and the difficulties with the new living arrangements. Caregivers readjusted themselves by rearranging their lives and holding onto hope for a cure and hope for a longer life for their ill spouses. Caregivers felt positive about successful caregiving.
(Röing et al., 2008) **Sweden**	To describe oral cancer and its treatment as experienced by patient's spouse.	Phenomenology 7 spousal caregivers Gender: 3 females, 4 males Age: 35–78 years	The spouse made changes in roles and came to adopt a caring and supportive role. Thoughts about caregiver's own body and health were put on hold as their partner's well-being became first priority. Caregivers adapted their lifestyle and eating habits to meet the needs of their partners.
(Mayre-Chilton et al., 2011) **UK**	To understand the views and experiences of gastrostomy tube feeding at home for both HNC patients and their caregivers.	Qualitative study 3 caregivers Gender: 2 females, 1 male Age: 40–70 years * Involved both patients and caregivers	The lack of knowledge and understanding had an evident negative impact on caregivers. They experienced difficulty in intimacy. They expressed the importance of nutritional support by having a gastrotomy tube and became dependent on the tube. They experienced financial and psychological difficulties that had a negative impact on caregiving.

Author, year Country	Study aim(s)	Methodology/design Number of participants Gender Age group	Key findings
(Nund et al., 2014) **Australia**	To report on the experiences of carers of people with dysphagia (non-gastrostomy dependent) following nonsurgical treatment for HNC, and to identify the support needs of this group.	Phenomenology 12 carers Gender: 10 females, 2 males Age: >65 years, n=1; <65 years, n=11	Dysphagia disrupts the caregiver's daily life, especially at mealtime. Carers feel angry, stressed, helpless, guilty over the changes to meal preparation. Carers adapt to patient illness and negotiate a new normal. Carers believed that the information provided needed to be practical and personalised.
(Schaller et al., 2014) **Sweden**	To describe how the relatives experienced the patient's situation, especially with respect to pain, and how the relatives themselves experienced the situation.	Qualitative study 21 relatives Gender: 18 females, 3 males Age: 20–89 years	The relatives described little knowledge of pain and its management. The relatives described the need for support from healthcare professionals.
(Fronczek, 2015) **USA**	To describe and understand the lived experience of family caregivers of patients with HNC.	Phenomenology using van Manen's human science approach 9 family members Gender: 8 females, 1 male Age: 43–76 years	Carers need time to absorb and understand large information (during diagnosis). Some caregivers felt unsure about whom (which healthcare professional) to contact to get the answer relating to the patient's care. The caregivers experienced lifestyle changes related to adjusting to treatment plans and assuming responsibilities. The caregivers experienced sympathy, guilt and fear of recurrence.

Author, year Country	Study aim(s)	Methodology/design Number of participants Gender Age group	Key findings
(Nund et al., 2015) **Australia**	To explore the lived experience of communication changes following chemoradiotherapy treatment for HNC from the perspective of survivors and carers.	Qualitative study 9 caregivers Gender: 8 females, 1 male Age: 45–60 years * Involved both patients and caregivers	Carers faced challenges regarding support for communication. Changes in communication impacted their family and social lives.
(Taylor et al., 2016) **UK**	To explore the different types of information used by laryngeal cancer patients and their carers from diagnosis into the follow-up phase.	Longitudinal qualitative study 17 carers Gender: 14 females, 3 males Age: Not specified * Involved both patients and caregivers	The information received at diagnosis appeared to contribute to an '*illusion of certainty*' that life would return to normal at the end of treatment. However, as patients progressed into follow-up, many were propelled into a '*reality of uncertainty*' due to the 'disconnect' between the expectations both patient and carer developed from information received over the cancer trajectory.
(Balfe, Keohane, O'Brien, et al., 2017) **Ireland**	To investigate the difficulties that caregivers of adult patients experience in accessing or receiving social support from their networks; strategies that caregivers use to overcome and address those difficulties; and caregivers' experiences of receiving social support from official health networks.	Qualitative study 31 caregivers Gender: 24 females, 7 males Age: 60.1 years (mean)	The caregivers reported difficulties obtaining social support from their networks. The caregivers experienced the support from official healthcare networks, but this appeared to be short-term in nature.

Author, year Country	Study aim(s)	Methodology/design Number of participants Gender Age group	Key findings
(Penner et al., 2012) **Canada**	To explicate the lived experience of caring for a dysphagic relative with advanced HNC receiving tube feeding.	Descriptive phenomenology 6 family caregivers Gender: 4 females, 2 males Age: 47–74 years	The caregivers experienced changes in their roles and lives. Caregivers felt anxious about undertaking the responsibility of providing feeding via a tube. Family caregivers also found themselves challenged in managing symptoms such as pain and leakage. The caregivers experienced emotional turmoil and physical exhaustion. The caregivers reported that their social lives had diminished.
(Balfe, Maguire, et al., 2016) **Ireland**	To identify and describe the triggers of emotional distress among long-term caregivers of people with HNC.	Qualitative study 31 caregivers Gender: 24 females, 7 males Age: 60.1 years (mean)	Understandings and fears of illness, lifestyle restrictions and competing demands, facial disfigurement, financial problems, comorbid health problems and witnessing suffering were the key triggers of emotional distress among long-term caregivers.
(Balfe, Keohane, O'Brien, et al., 2017) **Ireland**	To explore the effect that treatment-related commuting has on carers of patients with HNC.	Qualitative study 31 carers Gender: 24 females, 7 males Age: 60.1 years (mean)	Treatment-related commuting had an impact on carers economically and psychologically.
(Chen et al., 2009) **Taiwan**	To examine caregivers' perceived levels of caregiving burden, and to examine the predictive factors for caregivers' caregiving burden with newly diagnosed oral cancer patients during the postoperative period.	Cross-sectional correlational design 122 caregivers Gender: 113 females, 9 males Age: >65 years, n=7; 40–64 years, n=75; <40 years, n=40	The caregivers perceived a moderate caregiving burden and experienced higher levels of financial problems.

Author, year **Country**	**Study aim(s)**	**Methodology/design** **Number of participants** **Gender** **Age group**	**Key findings**
(Longacre et al., 2015) **USA**	To explore HNC caregivers' informational needs related to interacting in the medical setting as a caregiver, and whether greater needs were associated with concerns about managing patient pain or distress, and to explore how caregivers prefer to receive information relevant to providing care, and if informational needs were associated with such preferences.	Cross-sectional study 59 family caregivers Gender: 48 females, 11 males Age: 54.6 years (mean)	The caregivers reported that they would first seek caregiving information from a formal healthcare professional (doctor, nurse or social worker) (76.6%, n=47), while 23.4% reported that they would first go to an informal resource (e.g. Internet, family or friend, non-profit). A high percentage of caregivers reported needing information on how to reduce a patient's pain or distress at diagnosis (66.1%), at treatment start (74.6%) and at treatment end (44.1%).
(Offerman et al., 2015) **Netherlands**	To explore the long-term impact of a total laryngectomy (TL) on the partner and on the relationship between laryngectomees and their partners.	Cross-sectional study 144 partners Gender: 121 females, 23 males Age: 66 years (mean) * Involved both patients and caregivers	Female partners of laryngectomees experienced more depression than male partners and more fear of new treatments than male partners. The partners of laryngectomees experienced a psychosocial impact of the consequences of TL, especially on their social life (35%) and on their sexual relationship (31%).

Author, year Country	Study aim(s)	Methodology/design Number of participants Gender Age group	Key findings
(Balfe, O'Brien, et al., 2016) **Ireland**	To examine the unmet supportive care needs of long-term HNC caregivers, and the factors associated with those needs.	Cross-sectional study 197 HNC caregivers Gender: 150 females, 47 males Age: 57 years (mean)	Managing fears about cancer recurring was the most commonly reported individual need. Loneliness and financial stress were consistently and significantly associated with high levels of unmet need. The overall unmet need scores declined with increasing time since diagnosis. Caregivers identified ‘accessing information about the benefits and side effects of treatments’ as one of their top 10 moderate/severe needs.
(Hiremath et al., 2017) **India**	To assess the burden among caregivers of patients with oral cancer using burden inventory.	Quantitative study 40 caregivers Gender: 26 females, 14 males Age: 21–50 years	Many caregivers experienced significant burden, particularly with respect to their physical and psychological well-being, economic circumstances, and social and personal relationships.
(Patterson et al., 2013) **UK**	To explore the quality of life of informal carers of HNC patients pre treatment and post treatment, and its relationship to patient-reported dysphagia.	Mixed methods 96 caregivers (89 females, 7 males) responded to the questionnaire 8 caregivers (7 females, 1 male) participated in the interview Age: 45–76 years	Some caregivers experienced difficulties with food preparation and had concerns about nutritional content, texture and food preferences of the patient. The caregivers experienced lifestyle changes in the context of eating.

Author, year **Country**	**Study aim(s)**	**Methodology/design** **Number of participants** **Gender** **Age group**	**Key findings**
(Hanly et al., 2016) **Ireland**	To investigate the relationship between unmet supportive care needs and carer burden and happiness, in HNC.	Quantitative study 179 caregivers Gender: 136 females, 43 males Age: 23–85 years	Unmet healthcare service needs were significantly associated with carer burden.
(Hung et al., 2013) **Taiwan**	To examine changes in social support and predictors in caregivers of oral cavity cancer patients over the three months after patients' first discharge.	Prospective longitudinal study 142 caregivers Gender: 15 females, 127 males Age: 31–84 years	Caregivers had mild-to-moderate levels of needs and were satisfied with available social support during the first three months after discharge. The peak for both overall and individual needs of social support was before discharge. Caregivers with longer caregiving time reported greater dissatisfaction during the first three months after discharge.

Three central themes emerged from this literature review regarding the experiences and support needs of caregivers of patients with HNC. These themes were disruption to daily life, the impact of caregiving, and the availability of information and support. Each will now be discussed.

2.3 DISRUPTION TO DAILY LIFE

Disruption to daily life was the first theme identified following analysis of the studies reviewed. Once a patient is diagnosed with HNC, a caregiver's life changes. The caregivers had to take on multiple roles and responsibilities. As the extra duties were additional to their daily life, their normal routines were disrupted. Thus, the caregivers made some adjustments to minimise the changes and to accommodate the needs of someone with HNC.

The caregivers of individuals with HNC experienced disruption to their daily lives as the diagnosis and treatment of HNC created changes in daily routines as well as a shift in roles and responsibilities between the patient and the caregiver. Kitrungrote and colleagues (2008) used a phenomenological approach to study the experiences of caregivers of a spouse with HNC undergoing radiation therapy in Thailand. By interviewing 15 spouses, it was found that the caregivers in the study experienced challenges with new daily adjustments as a result of caregiving (Kitrungrote et al., 2008). These included difficulties with new living arrangements and restrictions on their social life. Similar to Kitrungrote and colleagues (2008), Röing et al. (2008) interviewed seven spousal caregivers to explore how their spouse's treatment for oral cancer affected the caregivers' lives. Experiences reported by the caregivers included disruptions to their meal patterns as they had to make changes in their cooking styles and meal routines to accommodate the needs of the patient. While Kitrungrote et al. (2008) and Röing et al. (2008) took a qualitative approach, Patterson et al. (2013) used a mixed methods study design to explore the quality of life of informal caregivers of a patient with dysphagia. Their findings also revealed that the caregivers experienced disruptions to their normal mealtimes because they modified their diets in response to the swallowing difficulties experienced by those for whom they were caring (Patterson et al., 2013). Disruption in relation to lifestyle and meal patterns were commonly reported in the studies reviewed (Patterson et al., 2013; Penner et al., 2012; Röing et al., 2008). For example, caregivers reported disruptions to activities previously undertaken such as eating in restaurants, attending social functions, travelling together, and going out in public with relatives or friends (Penner et al., 2012).

Disruption to the daily life of the caregivers also involved changes in their roles and duties. As the patient’s ability to perform his or her daily routine became limited, extra roles were expected from caregivers, and they often undertook multiple roles simultaneously. These roles included, for example, taking care of the children, handling daily household chores and maintaining employment commitments while they were taking on the caregiver role (Fronczek, 2015; Penner et al., 2012). For many caregivers, their priorities changed to make sure they could be available to assist and support the needs of HNC patients (Halkett et al., 2020). With such a disruption in daily life, the caregivers experienced uncertainty about their future lives due to difficulties adjusting to those disruptions (Kitrungrote et al., 2008). Many caregivers reported living day by day without planning ahead due to uncertainty of when the cancer would reoccur (Dri et al., 2020).

2.4 THE IMPACT OF CAREGIVING

The second theme identified in the literature explains how the act of caregiving can impact caregivers in multiple domains of their lives: psychological, physical, social and financial. These impacts are interrelated and have the potential to distress the caregivers as much as cancer itself. Several studies reported that caregivers experienced a range of distressing psychological effects such as anger, stress, fear, worry and guilt (Fronczek, 2015; Hiremath et al., 2017; Nund et al., 2014; Penner et al., 2012). For some caregivers, shocking and distressing experiences came from looking at a patient's physical deformity and hearing the patient's struggle with loss of voice (Dri et al., 2020). Balfe, Maguire, et al. (2016) interviewed 31 long-term caregivers (more than one year post diagnosis) to explore the triggers of their emotional distress. Findings indicated that the fear of illness, lifestyle restrictions, competing demands, facial disfigurement of the patient, financial problems, comorbid health problems and witnessing the patient's suffering were the key triggers of emotional distress among long-term caregivers (Balfe, Maguire, et al., 2016). As reported by Nund and colleagues, the caregivers also experienced stress and feelings of helplessness related to meal preparation as they were inadequately prepared to manage a patient with dysphagia (Nund et al., 2015). The caregivers also often felt unprepared and anxious about assisting the patient with a feeding tube (Penner et al., 2012).

Another qualitative study involving six caregivers from Canada reported that emotional distress could result in physical exhaustion (Penner et al., 2012). The effort required by caregivers to take care of someone with HNC often led to the caregiver’s own health becoming neglected (Kitrungrote et al., 2008). This finding had also been described by Röing and colleagues (2008), who found that the caregivers put their health on hold when dealing with their partner’s sickness and treatments, which became their priority.

Studies also reported that difficulties in communication with the patient and changes that occurred during mealtime impacted the social relationship between the caregivers and their patients (Nund et al., 2015; Nund et al., 2014; Penner et al., 2012). Offerman and colleagues conducted a cross-sectional study to explore the long-term impact of a total laryngectomy on the relationship between the laryngectomees and their caregiver partners (Offerman et al., 2015). Their study findings suggested that there was a significant impact on social life and sexual relationships between patients and their partners (Offerman et al., 2015). Another study was conducted by Mayre-Chilton and colleagues in which three caregivers and six patients with HNC were interviewed with the aim of understanding the experiences of gastrostomy tube feeding (Mayre-Chilton et al., 2011). The study found that the caregivers had negative feelings and perceptions towards intimacy and sexuality when the patients required long-term gastrostomy.

Financial hardship was another implication for caregivers that was reported in several studies. That financial burden was related to the medical bills, treatment-related expenses (Chen et al., 2009; Hiremath et al., 2017; Mayre-Chilton et al., 2011) and treatment-related commuting (Balfe, Keohane, O'Brien, et al., 2017). Due to the financial difficulties, in some cases, the caregivers and the patient had to wait for funding to be approved before commencing the treatment (Mayre-Chilton et al., 2011). Financial pressures also caused additional worries and anxiety and limited the caregiver's ability to do the best they could for the patient (Balfe, Keohane, O'Brien, et al., 2017).

2.5 THE AVAILABILITY OF INFORMATION AND SUPPORT

The availability of information and support was the third theme identified in the review. The needs of the HNC caregiver can vary depending on the stage of a patient's illness and the type of treatments received. Several studies reported a lack of information about how to care for someone with HNC. The caregivers described having little knowledge about pain and pain management or the indications for and management of feeding tubes (Mayre-Chilton et al., 2011; Penner et al., 2012; Schaller et al., 2014). This lack of information was also identified by Badr et al. (2016) who conducted a cross-sectional study in Ireland involving 197 HNC caregivers. Findings from this study revealed that the need for information about the benefits and side effects of treatments was not met (Badr et al., 2016).

Studies also reported how the caregivers preferred to receive the information (Fronczek, 2015; Longacre et al., 2015; Nund et al., 2014; Taylor et al., 2016). A phenomenological study of nine family caregivers was undertaken to develop an understanding of their caregiving experiences (Fronczek, 2015). Findings showed that caregivers needed more time to absorb and understand a large amount of information provided at the time of patient diagnosis (Fronczek, 2015). The information needs of carers were also a focus of a study conducted by Longacre and colleagues (2015), which involved a survey of 59 caregivers. It was reported that 76.6% of the caregivers preferred to receive the information from the health professionals, and only 23.4% of the caregivers would go to an informal resource such as the internet or a friend (Longacre et al., 2015). Unlike Longacre's study, Taylor et al. (2016) used a longitudinal qualitative approach to understand the different types of information needed by patients and caregivers from the diagnosis to the follow-up phase. The study identified that there was a need for honest and open discussions with health professionals about the treatment plans and outcomes as the caregivers in the study experienced changes from what had been initially discussed about the patient's treatment outcome (Taylor et al., 2016). It was also important that the information provided was practical, personalised and delivered in lay terms rather than medical terms (Nund et al., 2014).

The caregivers obtained support from healthcare networks, but the caregivers felt that this was only short-term support (Balfe, Keohane, O'Brien, et al., 2017). Some caregivers felt they were not fully supported by either the medical system or by family and friends (Halkett et al., 2020). Interviews with caregivers of patients who developed speech and hearing difficulties as a result of chemotherapy for HNC found that caregivers did not receive sufficient support to deal with difficulties in communication they now experienced (Nund et al., 2015).

The caregivers experienced caregiving burden when the available health services did not meet their needs (Hanly et al., 2016). Several of the studies included in the review highlighted the importance of holistic care and ongoing support for caregivers. There was also a lack of integrated care; relatives described meetings with several specialised health professionals which often resulted in an inconsistent view of the patient's situation (Schaller et al., 2014). Some caregivers expressed receiving inadequate contact with and a lack of information from their nurse and their consultant on how to manage post-treatment complications (Fronczek, 2015; Taylor et al., 2016). Although the above studies indicated negative experiences with various forms of support, caregivers from a study in Taiwan were satisfied with the social support provided during the first three months after the patient's discharge (Hung et al., 2013). In that study, Hung et al. (2013) studied caregivers' satisfaction with the available social support at four timepoints: before discharge, and then one week, one month and three months after discharge. The authors also noted that some caregivers had unmet needs of social support, especially wife caregivers and those caregivers who spent a longer time caring for the patient during the first three months post discharge (Hung et al., 2013).

2.6 NARRATIVE REVIEW OF CURRENT EVIDENCE ON SUPPORTING CAREGIVERS OF INDIVIDUALS WITH HEAD AND NECK CANCER

The earlier integrative review highlighted the need for enhanced support services and interventions targeted towards informal caregivers of HNC individuals with HNC. While a range of supportive interventions has been developed for caregivers of patients with various types of cancer, such as breast, lung and colorectal cancer (Ferrell & Wittenberg, 2017; Griffin et al., 2014; Lee et al., 2021), there remains a notable gap in the literature concerning interventions tailored to the unique challenges faced by HNC caregivers. Despite increasing recognition of the vital role informal caregivers play in cancer care, limited research has focused on evaluating the effectiveness of support strategies specifically for those caring for individuals with HNC. In response to this gap, the current literature review aimed to explore and synthesise existing evidence on the types and effectiveness of supportive interventions available to informal caregivers of HNC patients. A narrative review (Sukhera, 2022) was employed, as it allows for a flexible and comprehensive examination of diverse intervention approaches and outcomes across studies, thereby offering a broader understanding of the current landscape of caregiver support in the context of HNC.

2.6.1 Literature review question and aim

The question that guided this narrative review was ‘What are the supportive interventions for caregivers of individuals with HNC?’. The aim was to identify the current state of knowledge regarding available caregiver support and to understand the effectiveness of this support in achieving caregiver outcomes.

2.6.2 Search methods

A literature search was conducted with the assistance of a librarian at the University of Sydney and my supervisors to retrieve as many studies as possible. The following databases were searched in July 2024: CINAHL, MEDLINE, PsycINFO and Scopus. The search terms used were: “head and neck cancer”, “head and neck neoplasms”, caregiver(s), carer(s), family, family member(s), “support program”, “training support”, intervention, “psychosocial intervention”, “caregiver education”, and “support group” to maximise the discovery of relevant studies. MeSH and free search terms were combined to explore the relevant literature. The search was limited to studies published in English and research studies published in peer-reviewed journals within the past 10 years. The rationale for using this date limit was that, firstly, advancements in HNC treatments have occurred over the past decade (Argiris et al., 2018; Ho & Yao, 2013; Ward & van As-Brooks, 2014) and, secondly, there has been a rise in the use of digital health technologies in cancer care (Badr et al., 2015; Dionne-Odom et al., 2022; Marzorati et al., 2018; Yunis et al., 2024). The COVID-19 pandemic has further promoted the use of digital platforms in the delivery of cancer care (Park et al., 2021; Prasad et al., 2020). Therefore, the findings from this review reflect the current practices in supporting caregivers and recent innovations in the delivery of HNC care. Reference lists from the studies identified via electronic database search were also examined to maximise search results. The database search strategy is detailed in Table 2.8.

Table 2.8: Search strategy

Database	Platform	Total search results	Search strategy
CINAHL	EBSCOhost	34	MH “Head and Neck Neoplasms+” **OR** “head and neck cancer” **OR** “Mouth Neoplasms+” **OR** “Pharyngeal Neoplasms+” **OR** “Nasopharyngeal Neoplasms+” **OR** “Oropharyngeal Neoplasms+” **OR** “Paranasal Sinus Neoplasms” **AND** “Caregivers” **OR** “caregivers or family members or relatives or informal caregivers” **AND** “Caregiver Support” **OR** “Caregiver education” **OR** “caregiver training” **OR** “support programs” **OR** “training support” **OR** “Support Groups+” **OR** “caregiver intervention” **OR** “Psychosocial Intervention” **OR** “educational support” **OR** “Support, Social+” Limit: 2014–Current, English
MEDLINE	OvidSP	454	Exp “Head and Neck Neoplasms” **OR** ((mouth* or oral* or lip* or tongue* or palatal* or gingival* or Salivary gland*) adj3 (cancer* or carcinoma* or neoplas* or tumor* or tumour* or malignan* or oncolog* or metastat*)).mp **OR** ((“head and neck*” or Laryn* or Pharyn* or Oral Cavity or Mouth Cavity) adj3 (cancer* or carcinoma* or neoplas* or tumor* or tumour* or malignan* or oncolog* or metastat*)).mp. **AND** Caregivers **OR** carer* **OR** “informal caregiver*” **OR** “informal carer*” **OR** Spouses or “family member*” **AND** support* **OR** “caregiver education” **OR** “caregiver training” or “caregiver education” or “caregiver program” or “support program” or “Training support” or “social support” or “support group” or intervention or Early Intervention or Educational or internet-based intervention or psychosocial intervention Limit: 2014–Current, English

Database	Platform	Total search results	Search strategy
PsycINFO		54	Exp “Head and Neck Neoplasms” **OR** ((mouth* or oral* or lip* or tongue* or palatal* or gingival* or Salivary gland*) adj3 (cancer* or carcinoma* or neoplas* or tumor* or tumour* or malignan* or oncolog* or metastat*)).mp **OR** ((“head and neck*” or Laryn* or Pharyn* or Oral Cavity or Mouth Cavity) adj3 (cancer* or carcinoma* or neoplas* or tumor* or tumour* or malignan* or oncolog* or metastat*)).mp. **AND** Caregivers **OR** carer* **OR** “informal caregiver*” **OR** “informal carer*” **OR** Spouses **OR** “family member*” **AND** support* **OR** “caregiver education” **OR** “caregiver training” **OR** “caregiver education” **OR** “caregiver program” **OR** “support program” or “Training support” **OR** “social support” **OR** “support group” **OR** intervention **OR** Early Intervention **OR** Educational **OR** internet-based intervention **OR** psychosocial intervention Limit: 2014–Current, English
Scopus		176	TITLE-ABS-KEY (“head and neck cancer”) **OR** “oropharyngeal neoplasm” **OR** “nasopharyngeal neoplasms” **OR** “paranasal sinus neoplasms” **OR** “pharyngeal neoplasms” **OR** laryngeal neoplasms” **AND** TITLE-ABS-KEY (caregivers **OR** carer* **OR** “informal caregiver*” **OR** “informal carer*” **OR** spouses **OR** “family member*” **AND** support* **OR** “caregiver education” **OR** “caregiver program” **OR** “support program” **OR** “training support” **OR** “social support” **OR** “support group” **OR** intervention*) Limit: 2014–Current, English

2.6.3 Search outcome

The original database search located 34 studies in CINAHL, 454 studies in MEDLINE, 54 studies in PsycINFO and 176 studies in Scopus, resulting in a total of 718 studies. Firstly, duplicates were removed, leaving 564 studies. Titles and abstracts were then reviewed based on the inclusion and exclusion criteria (Table 2.9).

Table 2.9: Inclusion and exclusion criteria for literature review of effectiveness of supportive interventions for caregivers

Inclusion eligibility	Exclusion eligibility
Informal caregivers of adult patients with head and neck cancer	Formal caregivers, caregivers of patients with other types of cancer, patients with head and neck cancer
Relevant primary research	Articles other than relevant primary research articles (e.g. review papers, editorials, conference abstracts, commentaries, discussion papers, irrelevant topics and book chapters)
Past 10 years	Studies published before 2014
English	Languages other than English

* In case of dyad-focused supports, only caregiver outcomes were taken into account.

Studies were then retrieved based on topic relevance and depth of information related to the research question. Original studies were included regardless of the methodological approach. Some of the studies focused on both caregivers and patients. If these studies reported the outcome of informal caregivers separately, they were included. The reference lists from the papers identified via electronic search were also searched to maximise search results. After the application of inclusion and exclusion criteria, a total of eight studies were included in the literature review.

2.6.4 Quality appraisal

Studies were critically appraised to evaluate their reliability and relevance to the review question. Studies were evaluated using the Joanna Briggs Institute (JBI) tool for randomised controlled trials (Barker et al., 2023) (Table 2.10) and the JBI tool for quasi-experimental studies (Barker et al., 2024) (Table 2.11). The details of the interventions were assessed to determine the methodological reliability of the research. Some studies had methodological limitations. However, it was decided to include them as they still provided valuable insight into answering the review question, and the strengths of the studies outweighed their weaknesses.

Table 2.10: Methodological quality of randomised controlled trials based on the Joanna Briggs Institute (JBI) Critical Appraisal Checklist

Study	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**	**Q11**	**Q12**	**Q13**
Lee, Huang, et al., 2023	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Nightingale et al., 2022	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gremore et al., 2021	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Mazanec et al., 2019	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y

Abbreviations: Y, yes; N, no; U, unclear

Question 1: Was true randomisation used for assignment of participants to treatment groups?
Question 2: Was allocation to treatment groups concealed?
Question 3: Were treatment groups similar at the baseline?
Question 4: Were participants blind to treatment assignment?
Question 5: Were those delivering treatment blind to treatment assignment?
Question 6: Were treatment groups treated identically other than the intervention of interest?
Question 7: Were outcomes assessors blind to treatment assignment?
Question 8: Were outcomes measured in the same way for treatment groups?
Question 9: Were outcomes measured in a reliable way?
Question 10: Was follow-up complete and, if not, were differences between groups in terms of their follow-up adequately described and analysed?
Question 11: Were participants analysed in the groups to which they were randomised?
Question 12: Was appropriate statistical analysis used?
Question 13: Was the trial design appropriate, and any deviations from the standard randomised controlled trial design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?

Table 2.11: Methodological quality of quasi-experimental studies based on the Joanna Briggs Institute (JBI) Critical Appraisal Checklist

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Wang et al., 2023	Y	N	Y	Y	Y	Y	Y	U	Y
Chesak et al., 2023	Y	N	N	N	Y	Y	Y	U	Y
D'Souza et al., 2017	Y	Y	U	Y	Y	Y	Y	U	Y
Loerzel et al., 2014	Y	Y	N	U	Y	N	Y	U	Y
Steinglass et al., 2011	Y	N	N	N	N	Y	Y	N	U

Abbreviations: Y, yes; N, no; U, unclear

Question 1: Is it clear in the study what is the “cause” and what is the “effect” (i.e. there is no confusion about which variable comes first)?
Question 2: Was there a control group?
Question 3: Were the participants included in any comparisons similar?
Question 4: Were the participants included in any comparisons receiving similar treatment/care other than the exposure or intervention of interest?
Question 5: Were there multiple measurements of the outcome, both pre and post intervention/exposure?
Question 6: Were the outcomes of participants included in any comparisons measured in the same way?
Question 7: Were outcomes measured in a reliable way?
Question 8: Was follow-up completed and, if not, were differences between groups in terms of their follow-up adequately described and analysed?
Question 9: Was appropriate statistical analysis used?

2.6.5 Data synthesis

The narrative synthesis was applied to analyse the findings of individual studies. Narrative synthesis was appropriate for this review as it helped manage heterogeneity and allowed for meaningful comparisons of various interventions. During the analysis process, the researcher searched for relevant data to answer the review question. A data extraction table (see Table 2.12) was created based on the aims of the literature review, capturing the following information in the review matrix: authors, year, country and aim of the study, study design, population and sample size, intervention, and results. The researcher critically analysed the data based on the data extraction table and searched for patterns and themes (Garrard, 2014; Goldman & Schmalz, 2004). The researcher also identified similarities and differences among the studies and gaps in the literature. This process assisted the researcher to understand how the studies addressed the review question.

2.7 OVERVIEW OF STUDIES IN THE NARRATIVE REVIEW

Eight studies were included in the review. The studies originated from the USA (n=6), Canada (n=1) and Taiwan (n=1). Most studies recruited patient–caregiver dyads (n=5), except for three (Chesak et al., 2023; D'Souza et al., 2017; Loerzel et al., 2014). Two studies specified that the caregivers were spouses/partners, while others were either family caregivers or friends. All the studies evaluated the outcomes of supportive interventions. Four studies were randomised controlled trials (Gremore et al., 2021; Lee, Huang, et al., 2023; Mazanec et al., 2019; Nightingale et al., 2022), while the other four studies were quasi-experimental, as they either had a pre–post intervention design or lacked randomisation. The sample size ranged from 12 participants to 100 participants. Five studies evaluated the effectiveness of supportive interventions by measuring different outcomes (D’Souza et al., 2017; Lee, Huang, et al., 2023; Loerzel et al., 2014; Mazanec et al., 2019; Wang et al., 2023), while three aimed to test the feasibility and accessibility of the interventions (Chesak et al., 2023; Gremore et al., 2021; Nightingale et al., 2022). The duration of the interventions varied from five minutes to seven weeks. The duration of outcome measures and follow-ups also varied, ranging from immediately after the intervention to six months.

2.8 TYPES OF INTERVENTIONS

The reviewed studies highlighted various interventions to support caregivers of individuals with HNC, including psychosocial education; caregiving training; and the provision of information on HNC-related risk factors, treatment side effects and HNC caregiving skills. The interventions used in two studies (Loerzel et al., 2014; Wang et al., 2023) focused on improving caregiving skills and knowledge of tracheostomy tubes. The first study by Wang and colleagues consisted of 17 family caregivers and 22 patients with HNC (Wang et al., 2023). The intervention consisted of three pictorial posters that detailed tracheostomy suctioning and cleaning procedural steps. These posters were given to the caregivers by the research nurse during the clinical visit or mailed to the participants. The participants were asked to rate their own confidence level on a scale of 0% to 100%. The study showed that caregivers’ self-confidence levels in tracheostomy care had improved with the use of pictorial posters (Wang et al., 2023). The other intervention consisted of an in-person educational program called T-CARES, in which participants learned how to care for a tracheostomy (Loerzel et al., 2014). Registered nurses and respiratory therapists delivered this program, which consisted of watching an instructional video about tracheostomy care at home, and reading written instructions. Participants also observed how to perform the stoma and tracheostomy care, and they practised and returned demonstrations of this care during the program. The study showed that caregivers' anxiety level was significantly reduced after the T-CARES program (Loerzel et al., 2014). Anxiety levels of caregivers were measured immediately after the program. Therefore, the long-term effect of this program in reducing caregivers' anxiety remains unknown.

The interventions in four studies included the provision of information related to HNC risk factors, side effects of HNC treatments, oral care, pain management and monitoring cancer recurrence (D'Souza et al., 2017; Lee, Huang, et al., 2023; Loerzel et al., 2014; Wang et al., 2023). In a randomised controlled trial, a one-hour-long monthly survivorship care program (SCP) was delivered to patients with advanced HNC and their caregivers; this program was led by a nurse and ran for six months (Lee, Huang, et al., 2023). The nurse also provided the SCP manual, which consisted of information related to HNC risk factors, side effects of treatments, symptom management, oral care and nutritional care. The nurse also provided videos for the participants to watch (Lee, Huang, et al., 2023).

The interventions from six studies consisted of multiple components, providing information and education on improving caregivers' physical and psychosocial well-being (Chesak et al., 2023; D'Souza et al., 2017; Gremore et al., 2021; Lee, Huang, et al., 2023; Mazanec et al., 2019; Nightingale et al., 2022). All the studies used more than one approach in their interventions to achieve the desired outcomes. The study by Wang and colleagues used a pictorial education handout on suctioning and cleaning the tracheostomy as an intervention (Wang et al., 2023).

Four studies included psychosocial education as part of the interventions, such as stress, anxiety and depression management, and improving quality of life (Chesak et al., 2023; D'Souza et al., 2017; Mazanec et al., 2019; Nightingale et al., 2022). One of the interventions aimed to improve the relationship between patients with HNC and their partners (Gremore et al., 2021). This couple-based intervention was designed to improve the individual and relationship function between patients with HNC and their partners. The program involved four cognitive behavioural couple therapy sessions, each of which took 75 minutes. The intervention was delivered face to face with couples, except for one couple who received videoconferencing with the clinical psychologist (Gremore et al., 2021).

2.9 MODE OF DELIVERY

The interventions in the studies reviewed used different modes of delivery to achieve the desired outcomes. Most interventions were delivered face to face, or combined an in-person approach with printed material. The interventions used different approaches to support the caregivers and the patients, including individualised education sessions to meet the caregiver’s needs, group-based education, self-directed learning, counselling and coaching sessions. The informational support in one study was delivered using a technology-driven approach, which included a DVD, an information booklet, an interactive computer booth, and computer animation about HNC diagnosis and treatments (D'Souza et al., 2017). All the studies reviewed used more than one mode to deliver the interventions. In-person interventions were mainly used for education sessions where complex skills were involved, such as tracheostomy care (Loerzel et al., 2014), and in counselling sessions (Gremore et al., 2021; Mazanec et al., 2019). Some interventions used the group approach or patient–caregiver dyad approach to foster peer interaction and share learning (Chesak et al., 2023; Gremore et al., 2021; Loerzel et al., 2014). All the caregivers from the studies reviewed received additional materials such as booklets, DVDs or online modules to learn at their own pace and to ensure that the caregivers receive diverse forms of support.

2.10 MEASUREMENT OF OUTCOMES

The studies reviewed evaluated different outcomes related to caregiver interventions, including psychosocial outcomes, physical outcomes, quality of life, feasibility, caregiving skills and cancer knowledge. Six studies measured psychosocial outcomes including emotional distress, depression, resilience, mental health, self-efficacy, anxiety and relationship satisfaction (D'Souza et al., 2017; Gremore et al., 2021; Lee, Huang, et al., 2023; Loerzel et al., 2014; Mazanec et al., 2019; Nightingale et al., 2022). Two studies measured physical outcomes such as physical health and fatigue (Gremore et al., 2021; Lee, Huang, et al., 2023), while three studies measured the feasibility and acceptability of, and satisfaction with, the interventions developed (Chesak et al., 2023; D'Souza et al., 2017; Nightingale et al., 2022). Quality of life was measured in three studies (Gremore et al., 2021; Mazanec et al., 2019; Nightingale et al., 2022). Two studies measured improvement in caregiving skill competency (Loerzel et al., 2014; Wang et al., 2023), and cancer knowledge was measured in two studies (D'Souza et al., 2017; Lee, Huang, et al., 2023). Various measurement tools were used to assess the outcome, and these measurement tools are detailed in the summary of the included studies (Table 2.12).

Among the included studies, the intervention evaluated by Lee, Huang, et al. (2023) seems more effective than others as the study included a larger sample size (n=100) than other studies. In addition, follow-up measurement was conducted six months after the intervention, and the outcomes were statistically significant (Lee, Huang, et al., 2023).

Table 2.12: Data extraction table

Author, year Country	Study aim	Design	Participants and sample size	Intervention and mode of delivery	Outcome measurements and tool used	Key findings
(Wang et al., 2023) **USA**	To evaluate the effect of the pictorial education handout on self-confidence and self-efficacy of patients an family members in relation to tracheostomy care.	Quasi-experimental	17 family caregivers *22 patients with head and neck cancer (HNC)	Participants received a pictorial education handout on suctioning and cleaning the tracheostomy at home. The research nurse gave the handout during the clinical visit or mailed to the participants in person.	Self-confidence in tracheostomy care, data collected at baseline and post intervention Measurement tool: Individual's subjective assessment of their own confidence based on a sliding scale of 0% to 100%	Self-confidence improved (Cohen D=0.78) after receiving the infographic intervention.
(Lee, Huang, et al., 2023) **Taiwan**	To evaluate the effects of a nurse-led survivorship care program (SCP) on emotional distress, social support, physical health, mental health and resilience in primary caregivers of patients with advanced HNC.	Randomised controlled trial	100 caregivers *100 patients	SCP manual and video were given during the one hour of a monthly clinical visit during the six-month nurse-led SCP.	Emotional distress Social support Mental and physical health Resilience Measurement tools: Distress thermometer (DT), Social Support Scale (SSS), Medical Outcomes Study Short Form SF-12 (MOS SF-12), Resilience Scale All measures were collected at baseline and then one, three and six months (T0, T1, T2 and T3) after participating in the nurse-led SCP or receiving usual care.	Improvement in emotional distress ($p<0.001$), physical health ($p<0.05$), mental health ($p<0.001$) and overall resilience ($p<0.001$), no significant improvement in social support six months after the intervention.

Author, year Country	Study aim	Design	Participants and sample size	Intervention and mode of delivery	Outcome measurements and tool used	Key findings
(Chesak et al., 2023) **USA**	To examine the feasibility, acceptability and preliminary effectiveness of a Stress Management and Resiliency Training (SMART) intervention among family caregivers of individuals with HNC.	Quasi-experimental	16 family caregivers	A 90-minute small-group SMART session involved education about stress responses and principles of compassion, gratitude, mindful presence, kindness and a resilient mindset. Brief, practical exercises for gratitude and mindful presence of one to two minutes each were introduced and practised. After the group session, participants were instructed to use an online course with supplemental instructional videos for ongoing follow-up and skills practice during the eight-week study.	Feasibility Acceptability Effectiveness Measurement tools: Retention of participants in the components of SMART used by participants; satisfaction with SMART; Wilcoxon signed-rank tests	The intervention was acceptable among participants; however, additional work was needed to enhance feasibility. Significant improvements in self-compassion (p=0.03) and anxiety (p=0.02), with positive trends (not statistically significant) for resilience, stress and mindfulness.

Author, year **Country**	**Study aim**	**Design**	**Participants and sample size**	**Intervention and mode of delivery**	**Outcome measurements and tool used**	**Key findings**
(Nightingale et al., 2022) **USA**	To assess the feasibility and acceptability of a self-management intervention (Prepare to Care) offering psychoeducation and stress management skills-building for caregivers of patients receiving radiotherapy (RT) for HNC.	Randomised controlled trial	38 caregivers *Both patients and carers	A multi-modality self-management program designed to improve the quality of life and self-management skills of patients with HNC and their caregivers. Modes of delivery: face-to-face sessions, printed materials and digital resources. Duration: 6–7-week intervention aligned with a patient's RT (i.e. intervention began at the start of RT and was completed at the end of RT).	Feasibility Caregiving self-efficacy Anxiety Quality of life Self-efficacy for engaging in progressive muscle relaxation Measurement tools: Caregiver Inventory (CI), Centre for Epidemiological Studies Depression Scale (CES-D), Patient Reported Outcomes Measurement Information System (PROMIS) Emotional Distress Anxiety Short Form, Caregiver Quality of Life Index – Cancer (CqoLCanc)	The intervention was feasible and generally acceptable to participants. Caregivers reported improvements in their ability to manage the patient's condition and in their well-being. However, there were challenges related to the delivery of digital resources, particularly among older participants.

Author, year **Country**	**Study aim**	**Design**	**Participants and sample size**	**Intervention and mode of delivery**	**Outcome measurements and tool used**	**Key findings**
(Gremore et al., 2021) **USA**	To examine the feasibility and acceptability of a couple-based supportive communication (CSC) intervention delivered during oncology treatment for patients with HNC and their partners.	Randomised controlled trial	20 partners of HNC patients *20 patients	Four, 75-minute sessions of behaviour therapy were conducted primarily face to face with couples while patients were receiving chemotherapy. For one couple, the intervention was delivered via videoconference by the psychologist.	Acceptability Relationship satisfaction Caregiver quality of life Depression Anxiety Fatigue Measurement tools: Client Satisfaction Questionnaire (CSQ), The Centre for Epidemiological Studies – Depression (CES-D), Dyadic Adjustment Scale (DAS), Caregiver Quality of Life Index – Cancer (CQOLC), Patient Reported Outcomes Measurement Information System (PROMIS) Emotional Distress Scale	High levels of satisfaction with the intervention. Relationship satisfaction (D=0.047), anxiety (D=0.87). Patients and partners in CSC group reported improvements in individual and relationship functioning.

Author, year **Country**	**Study aim**	**Design**	**Participants and sample size**	**Intervention and mode of delivery**	**Outcome measurements and tool used**	**Key findings**
(Mazanec et al., 2019) **USA**	To evaluate the effect of the intervention on caregiver self-efficacy, anxiety, depression and health-related quality of life compared to a control group.	Randomised controlled trial	18 caregivers	The intervention consisted of four one-on-one sessions between the caregiver and nurse interventionist during the patient's first, second, fourth and sixth weeks of radiation treatment.	Self-efficacy for caregiving Anxiety Depression Quality of life Measurement tools: Caregiver Inventory (CI), Patient Reported Outcomes Measurement Information System (PROMIS)	Improvements in scores for self-efficacy, global mental health, anxiety and depression.
(D'Souza et al., 2017) **Canada**	To investigate and compare levels of anxiety and depression symptoms, satisfaction with information provision and cancer-related knowledge in partners of patients receiving a Multimode Comprehensive Tailored Information Package (MCTIP).	Quasi-experimental	31 partners	The MCTIP was given to the participants, which contained a booklet about HNC general information, an interactive computer booth, computer animation, a take-home DVD, and a database.	Anxiety Depression Satisfaction with information Cancer knowledge Measurement tools: Hospital Anxiety and Depression Scale (HADS), Satisfaction with Cancer Information Profile (SCIP), Cancer Knowledge Questionnaire	The partners in the Test group experienced significantly lower levels of anxiety (p=0.001) and depression (p=0.003) symptoms and were more satisfied (p=0.002) with cancer information provided than partners in the Control group. Providing tailored information seems to have positive outcomes regarding anxiety, depression and satisfaction in partners of HNC patients.

Author, year **Country**	**Study aim**	**Design**	**Participants and sample size**	**Intervention and mode of delivery**	**Outcome measurements and tool used**	**Key findings**
(Loerzel et al., 2014) **USA**	To evaluate the effects of T-CARES program in reducing caregivers' anxiety and improving skill competency.	Quasi-experimental	12 caregivers	Caregivers participated in an hour-long educational program, T-CARES, on stoma and tracheostomy care. The program involved watching video, observing, practising and returning demonstration of stoma and tracheostomy care. Written information about stoma and tracheostomy care was also given. Mode of delivery: The program was delivered in person.	Anxiety Competency in stoma and tracheostomy care Measurement tools: Pre and post anxiety score using State–Trait Anxiety Inventory (STAI) Participants rated the course on a scale with answer choices of "poor", "average", "good" and "excellent".	A significant reduction in caregiver anxiety (p=0.008) and improvement in stoma and tracheostomy care was noted after participation in the T-CARES program.

2.11 FEASIBILITY AND ACCEPTABILITY OF INTERVENTIONS

Three studies evaluated the feasibility and acceptability of their interventions (Chesak et al., 2023; Gremore et al., 2021; Nightingale et al., 2022). Two studies were randomised controlled trials (Gremore et al., 2021; Nightingale et al., 2022) and one was quasi-experimental (Chesak et al., 2023). The interventions of these studies shared a common goal of addressing the emotional and practical burdens faced by caregivers. The development of the interventions was guided by a theoretical underpinning. For example, the concept of self-efficacy from social cognitive theory was applied to promote the development of skills to manage caregiver emotions and coping, improve communication with the patient and health professionals, and support patient care (Nightingale et al., 2022). Despite differences in structure and delivery, all three interventions demonstrated varying degrees of feasibility, with retention and completion rates highlighting the challenges caregivers face due to their demanding roles. Acceptability was generally high, as evidenced by participant feedback and satisfaction scores (Chesak et al., 2023; Gremore et al., 2021; Nightingale et al., 2022).

Participants valued interventions that normalised their experiences, provided practical skills and offered emotional support (Chesak et al., 2023; Gremore et al., 2021; Nightingale et al., 2022). In the study by Chesak and colleagues (2023), caregivers were invited to attend a 90-minute Stress Management and Resilience Training (SMART) session, which focused on stress responses and principles of compassion, gratitude, mindful presence, kindness and resilience. They practised gratitude and mindful presence exercises. An online course and book, *The Mayo Clinic Guide to Stress-Free Living*, were provided for follow-up and assessment. Telephone calls were made every two weeks to maintain progress (Chesak et al., 2023). The intervention was found acceptable among the participants, but the authors concluded that more work was needed to improve recruitment and retention efforts. Significant improvements in self-compassion (p=0.03) and anxiety (p=0.02) were observed (Chesak et al., 2023). Another intervention delivered by a clinical psychologist focused on behavioural couple therapy using the couple-based supportive communication (CSC) approach (Gremore et al., 2021). During the sessions, couples were encouraged to reflect on their feelings and create conversations to understand their problems. This intervention also involved identifying individual support needs. Ninety-eight per cent of CSC sessions were completed, and couples reported high satisfaction with the intervention. The study indicated that patients and partners in the CSC group reported better improvements in individual and relationship functioning than the control group (Gremore et al., 2021). One key limitation of these studies evaluating interventions for caregivers was the small sample size. Additionally, the studies assessed the feasibility and acceptability of the interventions over a relatively short period (up to six months). Therefore, the results should be interpreted with caution, and further research with larger sample sizes and longer evaluation periods is necessary to confirm the efficacy and sustainability of the interventions.

2.12 THE RESEARCH GAP

Findings from the literature review established that caregivers experience life disruptions and have considerable support needs, especially in the educational and informational domains. The literature review also identified interventions designed to support both patients with HNC and their informal caregivers. These interventions appear to enhance caregivers' well-being and caregiving skills, laying a foundation for advancing nursing practice in the context of HNC care. To further advance this field, future research must address existing gaps, refine intervention designs, and explore innovative delivery modes to support caregivers more effectively.

Caregiving does not happen in isolation but occurs within the context of long-standing family relationships and broader social systems. Social Support Theory (Cohen & Wills, 1985) highlights the buffering role of emotional, informational, and instrumental support in reducing caregiver stress and enhancing psychological resilience. Many existing interventions, however, do not adequately address multidimensional support needs. Furthermore, there is limited evidence on how caregivers of individuals with HNC access, perceive, or benefit from these different support types, especially considering the communication challenges and disfigurement often associated with HNC. Similar to Social Support Theory, Family Systems Theory (Titelman, 1998) conceptualises the family as an interconnected emotional unit, where illness in one member affects the entire system, disrupting established roles, boundaries, and communication patterns. Few intervention studies have adopted a family-centred approach that recognises the bidirectional influence between patients and caregivers or aims to strengthen family functioning as a whole. This gap is especially relevant in HNC care, where caregivers are often spouses or close relatives who experience role changes, shared trauma, and emotional labour over long treatment periods.

To develop a tailored education program and ensure that caregivers are adequately supported, their needs must be identified. This literature review has shown that caregivers are equally as important as the patient in terms of understanding their needs and receiving psychosocial support during and after the patient’s treatment. The needs of those caring for a patient with HNC can vary based on the time since diagnosis, and this must be taken into consideration. Availability of support during the HNC trajectory and the extent of the overall caregiving tasks should also be further explored. These aspects may vary significantly across countries due to differences in healthcare systems and models of care delivery.

The literature review identified a need for ongoing support for caregivers throughout the disease trajectory, as the caregivers experienced the ongoing challenge of continuity of care. However, to date, little is known about the support needs of HNC caregivers in Australia and how those needs can be effectively met. An important step to address this knowledge gap is to understand caregivers’ experiences of caring for individuals with HNC. By exploring caregivers’ perspectives, researchers and healthcare providers can gain valuable insights into the aspects of care that are currently effective and those that require enhancement.

2.13 RESEARCH QUESTION AND AIMS

This doctoral study aligns with the identified research gap and seeks to advance the knowledge. The research question guiding this doctoral study is:

> What are the experiences of HNC caregivers in Australia?

The aims of the study are:

1. To explore the experiences of caregivers providing support for individuals with HNC.
2. To identify areas for improvement in supporting caregivers.

2.14 CONCLUSION

This chapter provided a comprehensive review of the literature on the experiences and needs of caregivers of individuals with HNC and the various interventions aimed at supporting them. The review also identified the research gaps and the research question leading to this research. The following chapter will describe the methodology employed to answer the research question, detailing the research design, data collection methods and analytical approach to ensure a rigorous and meaningful exploration of caregiver experiences.

Chapter 3: Research Design

3.1 INTRODUCTION

This chapter describes the design and methods chosen to answer the research question, which explores the experiences of caregivers of individuals with HNC in Australia. In this chapter, the theoretical background to the study is outlined and a detailed explanation of the methodology used is provided, as well as the methods and procedures involved in the recruitment of the participants, data collection and data analysis. Ethical considerations and issues of rigour are also discussed.

As established in Chapter 2, there has been little published work on the experiences of caregivers of individuals with HNC in Australia. To address this gap, a qualitative research design was chosen to gain a deeper understanding of the experiences of those caring for someone diagnosed with and treated for HNC. Qualitative methods are valuable in nursing research as they provide rich insights into human experiences within societies and cultures (Streubert & Carpenter, 2011). This study was guided by qualitative interpretive inquiry, which allowed for exploration of caregiving from the caregivers' perspective. Throughout this document, the term 'the researcher' will be used to refer to the PhD candidate**.**

3.2 ESTABLISHING THE PHILOSOPHICAL BACKGROUND

3.2.1 Ontological and epistemological perspectives

It is an important step to consider how ontological and epistemological considerations shape the research process and assist in understanding the experiences of caregivers of individuals with HNC. The researcher’s first consideration in this study design was to situate the study within a research paradigm that enables the researcher to gain an in-depth understanding from the caregiver’s perspective (Streubert & Carpenter, 2011). A paradigm defines the viewpoint of the researcher known as ‘bricoleur’ (Denzin & Lincoln, 1998). The aim of understanding and interpreting the caregiver’s experiences of caring for someone with HNC was situated within the interpretive paradigm. The interpretive paradigm is informed by the foundational components of ontology, epistemology and methodology (Carter & Little, 2007). Collectively, they provide a framework for understanding how knowledge is constructed, what is considered valid knowledge and how to understand complex human experiences (Denzin & Lincoln, 1994). How this study fits within the philosophical principles of research under the interpretive paradigm is discussed below.

The ontological and epistemological assumptions of the interpretive paradigm are that there is no single reality; the experiences of individuals are constructed by the context within which that experience occurs, and meaning is derived from the individual’s personal beliefs and experiences (Morehouse, 2012). This principle aligns well with the research question of understanding caregivers’ experiences of caring for someone with HNC and how they interpret those caregiving experiences. This research emphasises the unique and diverse experiences of caregivers of individuals with HNC. Through the interpretive paradigm, new knowledge and understanding of caregivers’ experiences can be generated by exploring their subjective experiences (Morehouse, 2012). Thus, it is transactional and subjectivist, which means the researcher and participant are assumed to be interactively connected, allowing findings to evolve as the study progresses (Denzin & Lincoln, 1998). There is no right or wrong interpretation of reality, as long as there is justification for how this knowledge is claimed in a social setting at a particular time (Smith, 2008).

The concepts of interpretivism historically originated from the German school of thought known as hermeneutics, the Verstehen tradition in sociology, Alfred Schutz's phenomenology, and criticisms of scientism and positivism in the social sciences. In the past, interpretivists claimed that human inquiry was special (Crotty, 1998). Some believed that the natural sciences (*Naturwissenschaften*) were not the same as the mental sciences (*Geisteswissenschaften*) or the cultural sciences (*Kulturwissenschaften*). Initially, the goal was understanding (*Verstehen*) what social events mean. Over time, the goal shifted to scientific explanation (*Erklären*) (Crotty, 1998). As Crotty (1998) states, interpretivists agree that people's real-world experiences and their interpretation are crucial for developing new knowledge. Therefore, finding and interpreting the meanings of the experiences of caregivers of people with HNC through the theoretical lens of interpretivism led to the creation of new knowledge in this study.

Given the complex, value-bound and multifaceted issues surrounding caregiving for someone with HNC, a qualitative interpretive stance serves as a suitable conceptual framework to explore the experiences of caregivers of HNC patients. The specific qualitative approach chosen to guide this study is called interpretive inquiry, a methodology that draws upon the epistemological assumptions of interpretivism and the theoretical perspective of hermeneutics (Smith, 1992). Each of these frameworks will be explored below.

3.2.2 Theoretical perspective of hermeneutics

This doctoral study employed a hermeneutic approach to interpret caregivers' experiences by collecting detailed narratives through qualitative interviews. Hermeneutics signifies a shared understanding among individuals, and language aids in conveying this understanding (Koch, 1999). Hermeneutics can be regarded as a theory for gaining a deep understanding of a text that transcends the author's own comprehension (Crotty, 1998). The interpreter must possess the skill to uncover meaning and hidden intentions in the text. Knowledge is constructed through dialogue or hermeneutic conversation between the text and the researcher (Koch, 1999). A "unique characteristic of hermeneutics is its openly dialogical nature: the returning to the object of inquiry again and again, each time with an increased understanding and a more complete interpretive account" (Packer, 1985, p.1091). It is assumed that

> "meaning is a determinate, objectlike entity waiting to be discovered in a text, a culture, or the mind of a social actor. In this view hermeneutics is a particular exegetical method for identifying and explicating these objective meanings" (Denzin & Lincoln, 1998, p. 227)

Qualitative researchers have strived to provide rich insights into the human experience, perspective and the world they live in for many decades (Koch, 1999). Hermeneutics is derived from the ancient Greek term *Hermeneutike*, which means interpretation (Smith, 2010). This was first used by Plato (427–347 BCE) to translate the mysterious messages that can be understood from Gods to human beings (Smith, 2010). Hermeneutics can be considered as both theory and practice of interpretation (Paterson & Higgs, 2005). Hermeneutics as a social science emerged in the 17th century in the field of biblical scholarship to interpret the meaning of scriptural texts (Crotty, 1998). Since then, hermeneutic philosophy has been developed and evolved by philosophers.

Wilhelm Dilthey (1833–1911) extended the field of hermeneutics beyond the individual to include cultural systems and organisations (Dilthey, 1988). Dilthey was interested in humanities and made a distinction between the natural sciences and human sciences. Dilthey believes that human lived experiences, in German '*Erlebnis*', can be translated through the expression (*Ausdruck*) of these experiences. The expression can be written texts, buildings, poems, behaviours and so on. Although only these various expressions are available to study to understand human lived experiences, the aim is not about these expressions themselves, but to gain an understanding of the lived experiences that led to these expressions. For understanding, Dilthey, like Max Weber (1864–1920), used the word '*Verstehen*', which means a special kind of understanding gained by putting someone in the position of the person who makes the expression to understand why that person makes such an expression. Thus, a good connection between experience and expression can lead to a good interpretation (Smith, 2010).

The hermeneutics of Martin Heidegger (1889–1976) took a philosophical aspect of 'being and time'. Being in the world means that what the human is and what the world is are mutually interdependent, and thus, human experiences cannot be separated from the social world and the context where the human lives. These experiences can vary at different times (Crotty, 1998).

The modern hermeneutics attempt to understand and interpret human experience beyond the interpretation of the biblical text (Schleiermacher, 1977). Friedrich Schleiermacher (1768–1834) took a step in transforming hermeneutics from a technical discipline to a philosophy of understanding. According to Schleiermacher, hermeneutics has two aspects: grammatical and psychological. The grammatical aspect deals with the interpretation of the content of the text, while the psychological aspect attempts to uncover and explain the underlying meaning and assumption of an author (Crotty, 1998). As such, hermeneutics has evolved under the influence of several key philosophers in many decades. Language has become a central role in qualitative research as it shapes the human experience in ways that can be shared with others without losing its meaning (Peck & Mummery, 2018). Therefore, it is important for the researcher to use a relevant theoretical framework that explains the relationship between the individual, the world and the language. This doctoral study takes hermeneutic philosophy as a theoretical framework that allows the researcher to delve into the subjective realities of caregivers, uncovering how they perceive and make sense of their experiences of caring for individuals with HNC.

3.2.3 Interpretive inquiry

Interpretive inquiry was chosen as the qualitative methodology for exploring the experiences of HNC caregivers, from their perspective within their natural environment. This methodology offers advantages when compared to others such as phenomenology and grounded theory. One of the benefits of interpretive inquiry is its emphasis on the understanding of a phenomenon from the perspective of individuals who have experienced it and how they create meaning from that situation (Smith, 2008). Interpretive inquiry enables researchers to explore into the subjective interpretations of caregivers, thereby revealing insights that may not be captured through other methodologies, such as grounded theory, which often focuses on generating theories rather than understanding caregivers' experiences in depth (Burns et al., 2022). Unlike phenomenology, which aims to uncover the lived experiences through a philosophical lens, interpretive inquiry allows for a more flexible engagement in addressing the complexities of caregivers' experiences and generating interpretive insights with direct clinical relevance. Therefore, it is a valuable approach in nursing research and practice.

In interpretive inquiry, data are collected through interviews or observations and analysed inductively to identify recurring patterns. These patterns or themes are contextualised within and incorporated into existing knowledge. Researchers who use interpretive inquiry usually start the inquiry process with a genuine research question in their area of interest (Smith, 1992). It is also recognised that researchers can be influenced by their pre-existing assumptions and preconceptions. Interpretive inquiry requires a theoretical framework to understand the participant and their context. Throughout this research, the researcher engages in the hermeneutic cycle of projection and evaluation, interpreting the data and assessing the initial interpretations (Smith, 2007). Through this process, understandings of caregivers' experiences evolve, new interpretations are uncovered, and new ways of seeing and representing the findings emerge. This unfolding process enables the researcher to understand the research question in a richer and more comprehensive way.

3.2.4 The application of hermeneutic theory in interpretive inquiry

The hermeneutic theory and interpretive inquiry fit well for this study as hermeneutics focuses on the interpretation of lived experiences shaped by individuals' personal, cultural and social contexts (Muganga, 2015). Smith argued that hermeneutics is very applicable in human sciences, especially in healthcare and psychology (Smith, 2007). Interpretive inquiry is primarily derived from the hermeneutic tradition (Denzin & Lincoln, 1998). Using this approach in this study meant that caregivers' experiences were interpreted by engaging with the caregiver through qualitative interviews, to explore deeper meaning and insights of their stories, allowing them to reflect upon what it means to care for someone with HNC.

Hermeneutics guides the process of interpretive inquiry by seeking to understand the meaning of the caregiver's subjective description through consideration of contextual factors that can potentially influence interpretation (Muganga, 2015). In the present study, the researcher considered the importance of context in shaping the caregivers' experiences and the meaning attached to their personal experiences because the caregivers' sociocultural backgrounds, environments and experiences as caregivers can be different (Thorne, 2016). To achieve the hermeneutic way of interpretation, the researcher interpreted the HNC caregivers' responses from the perspective of their culture and context. In addition, the researcher acknowledged her own influences by keeping a reflective journal, and eliminated those understandings to minimise bias during the interpretation. During the process of interpretive inquiry, the interview between the researcher and the caregiver involved a continual dialogue that allowed the researcher to gather information from the caregiver. To seek the true meaning of the caregivers' experiences (Josselson, 2004), the researcher tried to avoid overinterpreting or overgeneralising by having discussions with experienced supervisors with expertise in this methodology.

Hermeneutics also facilitates interpretive inquiry through the phenomenon of language, which is a form of communication between the researcher and the caregiver in order to arrive at an understanding (Schleiermacher, 1977). As such, the researcher can connect the smaller parts, such as words, to arrive at larger wholes, such as sentences or paragraphs, to enhance the accuracy of their understanding. So, the concept of language within the hermeneutics philosophy is a good way of decoding the language used by both the researcher and the participants in an interpretive inquiry. The dialogue or interview process in this study fulfilled the objective of hermeneutics to obtain the caregiver's true experience of caring for someone with HNC. In this study, it is critical to understand the caregivers' experiences and how they interpret those experiences within the context. Therefore, interpretive inquiry was an appropriate methodology to use in this study.

3.3 RESEARCH DESIGN

3.3.1 Research question and research aims

The methodology and methods discussed in this chapter address the research question: 'What are the experiences of caregivers of individuals with head and neck cancer in Australia?'. The research aims are:

1. To explore the experiences of caregivers providing support for individuals with HNC.

2. To identify areas for improvement in supporting caregivers.

3.3.2 Research setting

The research study was conducted in Australia. The research setting was a metropolitan tertiary hospital in NSW. This hospital is a nationally recognised centre of excellence, bringing together the specialty areas of head and neck; ear, nose and throat; and plastic and reconstructive surgery. The service includes surgical, radiation and medical oncology specialists, as well as nursing and allied health professionals who have specialty in this area. This institution was selected due to the opportunity to recruit informal caregivers who have experience caring for patients with HNC.

3.3.3 Participant recruitment

Using interpretive inquiry, the researcher sought to understand caregivers' experiences in caring for someone with HNC. Therefore, purposive sampling was used (Morehouse, 2012) to recruit participants who had experience of caring for someone with HNC and were willing to share their experiences. Selection criteria included:

1. Caregiver of someone with HNC
2. Ability to speak and understand English
3. The person/patient they were caring for was currently receiving treatment or had received treatment within the past 12 months.

3.3.4 Recruitment process

The researcher collaborated with the senior specialist nurse from the study site to identify and recruit potential participants. The senior specialist nurse was encouraged to recruit participants who met the selection criteria and came from diverse backgrounds. During the recruitment process, it became apparent that a significant proportion of treated patients did not have an identified caregiver. Therefore, this must be considered when evaluating the findings of this study. The senior specialist nurse agreed to assist this study by distributing the information and consent forms to participants during their clinical visits. The initial contact with potential participants was made by the senior specialist nurse, with no direct initial communication from the research team, who lacked information about those who had received the information and consent form. Please see Appendix C for the participant information sheet and consent form used for communication. Interested participants reached out to the researchers directly via telephone or email to learn more about the study.

3.3.5 Participant characteristics

Caregiver characteristics

The study attempted to recruit a broader range of participants to enhance gender balance. Fifteen participants were recruited for this study from 2020 to 2022 – four males and 11 females – ranging in age from 31 to 80 years. All the participants were Australians who were living in NSW, except one who was living in Canberra in the Australian Capital Territory. Twelve participants lived in a metropolitan area of NSW, and three lived in a rural area. All lived with the patient at the time of patient diagnosis, except one caregiver who lived 15 minutes drive away from the patient’s house. In terms of relationship to the patient with HNC, two participants were daughters, 11 were spouses, one was the mother, and one was the father. Participants came from different occupational backgrounds. Eleven participants were working, and four participants were retired at the time the patients were diagnosed. However, the employment status of the caregivers changed in some way due to the care demands required by the patients. One participant retired early to care for the patient, and two changed to part-time work to allow the caregiver more time to care. All the caregivers belonged to a middle socioeconomic background.

Patient characteristics

The patients cared for by the participants in this study had been diagnosed with HNC and had received various treatments, leading to physical and functional difficulties. The level of informal care required from the caregiver participants varied, and each participant's experience was unique as they provided both short-term and long-term care. Common side effects of the treatments among the patients included weight loss, pain and difficulty swallowing. Fourteen patients had PEG tubes inserted to maintain nutrition. Along with these treatment-related side effects, some patients faced additional complications. For instance, Michael's wife and Mary's mother underwent extensive surgical procedures, whereas Sofia's husband experienced ulcerated skin, lymphoedema, and oral thrush. He also suffered from septic shock and was hospitalised in the intensive care unit (ICU) following chemotherapy.

3.3.6 Impact of COVID-19 pandemic on the study

This doctoral study commenced in 2018, prior to the COVID-19 pandemic. It was initially planned to provide participants with interview options, either face-to-face individual interviews or focus groups. However, these original plans were affected by the COVID-19 crisis in several ways. The COVID-19 pandemic led to travel and social restrictions, as well as funding limitations, which significantly impacted non-COVID-related research activities (Harper et al., 2020). During the COVID crisis, there was a notable delay in participant recruitment for this study due to fewer opportunities for clinicians at the study site to contact potential participants. Consequently, this study had to be suspended for one year during the COVID-19 crisis. When the study was permitted to recommence, individual interviews conducted via telephone became the only available option as social restrictions persisted due to the COVID-19 crisis. An ethics amendment was made and approval was secured to conduct telephone interviews.

3.3.7 Data collection

Semi-structured, in-depth interviews were conducted as a method of data collection with the aim to understand how informal caregivers perceived the experience of caring for an individual with HNC and what needs or challenges they shared in common. The interviews were a powerful way to create a conversational relationship with the participants to uncover the deeper meaning of their personal experiences of caregiving (van Manen, 2016). In interpretive inquiry, the researcher is the instrument for data collection and analysis (Smith, 1992). Thus, the researcher remained reflexive during the analytic process to minimise biases. The researcher continuously examined her assumptions, values and potential influences on the interpretation of data. This ongoing self-awareness, along with intensive discussions with supervisors, helped to identify and mitigate personal biases, ensuring that the findings were grounded in the participants' perspectives rather than being shaped by the researcher's preconceptions.

The interview questions were developed to align closely with the scope of the research question and the study's aims. To test the interview questions and gain experience, the researcher conducted two mock interviews with her supervisors. These preliminary interviews helped ensure that the questions were framed well. They also prepared the researcher to explore the participants' stories in depth using probes. Any potential issues that could arise during the interviews were handled in advance of the formal interviews after receiving feedback from the supervisors about the pilot interviews. As a novice researcher, she was likely to follow the interview guide too strictly during the mock interviews, and probing was inadequate for an in-depth exploration of participants' feelings and meanings. Therefore, the initial interviews were led by the supervisor to help the participants understand the interview questions and ensure their stories were explored in depth with appropriate probes. Additionally, English is not the researcher's first language, which could have made it hard for participants to understand her accent over the telephone. To overcome this, before the researcher began the interview, she informed the participants that English was not her first language and encouraged them to ask her to repeat the question if it was unclear.

Fifteen individual interviews were conducted via telephone to ensure sufficient depth to allow for thick descriptions or to make a meaningful contribution to the field. During the interviews, the researcher explored the experiences of participants as caregivers, as well as the type of support they received or were offered. The researcher also asked participants to discuss what kind of support might help them perform better as caregivers. If they identified any support need, they were asked how they would like this support to be delivered (see Appendix D).

During the telephone interview, the researcher encouraged open, relaxed conversation through reflective listening and validating statements. The researcher also took notes during each interview and reviewed them immediately after each session. The notes included participants' background information, the duration of the interview, and the key issues discussed. Additionally, the researcher recorded her initial thoughts after each interview. Reflecting on those initial ideas and issues enabled the researcher to adjust the interview questions as needed, enhancing the overall quality and depth of subsequent interviews. The interviews were audio-recorded, each lasting approximately 45 to 60 minutes. Data saturation was considered achieved after 15 interviews, as no new themes, patterns or insights emerged from the data. The final few interviews confirmed the consistency of the previously identified themes, indicating that additional interviews were unlikely to yield novel information. This point of saturation was determined through ongoing, iterative analysis, where data were reviewed and compared across interviews to assess thematic redundancy and depth.

3.3.8 Data analysis

The goal of data analysis in an interpretive inquiry is to make sense of a text or of a lived experience of a human by interpreting its meaning accurately (van Manen, 2016), while the researcher acknowledges the possibility of variation in human activities that are socially and culturally embedded (Morehouse, 2012). To achieve that, thematic analysis of the data suits this research well (Braun & Clarke, 2006; Braun & Clarke, 2019). Thematic analysis provides a systematic and robust framework to code the data, identify the commonalities and differences across the data, and allow the researcher to interpret those patterns or themes related to the phenomenon of interest (Braun & Clarke, 2014).

The researcher used a rigorous and systematic process to analyse the data using the six steps of thematic analysis described by Braun and Clarke (2006) (described in more detail below). All digitally recorded interviews were first transcribed verbatim. Interview transcripts were transferred to a data analysis software called NVivo for coding and data analysis.

The six-step process of data analysis was as follows:

Step 1: Familiarisation with the data

The process of thematic analysis began with transcribing the data, multiple readings of the data and noting down initial ideas (Braun & Clarke, 2006). The researcher listened to the audio-recordings of the interviews and transcribed the data manually into Microsoft Word. Then, the researcher listened to the audio several times while reading the transcription for accuracy to familiarise and immerse herself in the data. The researcher made a summary of each interview and jotted down the early impressions related to caregiver's experiences and key issues shared by the caregivers.

Step 2: Generating initial codes

An inductive approach was taken by coding the transcripts line by line to reduce the large amount of data into smaller pieces of information and also to capture the participants' experiences that were relevant to the research question. A codebook containing the descriptions of the codes was developed using NVivo software. Those initial codes were reviewed by the supervisors for accuracy of the descriptions. After discussion with the supervisors, codes were modified and moved around. An example code of the transcripts is outlined in Table 3.1.

Table 3.1: Example codes with data extracts from the transcripts

Data extract	Code
I didn’t know what she is talking about. I tried to make a bit of jot on a paper but, it is still challenging.	Communication challenge
It’s still a bit of concern. He needs to get scanned every year…I don’t know, still worrying that something’s gonna pop up every time he gets a scan.	Fear of recurrence
It was upsetting for me to see his weight going backwards.	Concern about weight loss
I tried to search and read about treatments on the internet.	Seeking information

Step 3: Searching for themes

The codes with similar content were identified and organised into broader themes. During that stage, the researcher worked closely with the supervisors, with expertise in qualitative research, to analyse and discuss how various codes could be combined into a category to ensure consistency and rigour of data analysis. An example category of similar codes is outlined in Table 3.2. The researcher and the supervisors used a mind map to visualise those categories. To make sense of the data more deeply, the researcher used the inclusion strategy (Morehouse, 2012). In this strategy, the codes were written on cards. Those cards that contained a unit of meaning were placed on a large table and categorised during a meeting with the supervisors. After relevant cards had been grouped together conceptually, themes were identified. Throughout the analysis process, the researcher stayed as close to the data as possible to conceptualise the data by making connections, identifying patterns, and moving or merging the codes around. Those codes that could not fit into any of the themes were managed under the miscellaneous category in case they might be helpful later.

Table 3.2: Example category of similar codes

Codes	Category
Feel unprepared Going through the unknown Seeking information Wanting to meet other carers	Support needs

Step 4: Reviewing themes

After a set of preliminary themes were developed, the researcher reviewed each theme to ensure the findings were true reflections of the participants' experiences. Data analysis at this stage required an iterative process. Through ongoing discussions with supervisors, the researcher reviewed and refined the themes as required. Each code from the initial themes was reviewed by reading the extracted data from the interview transcripts to evaluate whether they formed a consistent pattern with a theme. The researcher modified the codes where necessary as the deeper meaning of participants' experiences became evident. Through intensive discussions with supervisors, the researcher undertook the process of interpreting the data by responding to the question of 'what does it mean?'. In other words, the researcher attempted to gain a deeper sense of what the participants were trying to express through the data collected during the interviews (Braun & Clark, 2021).

Step 5: Defining and naming themes

Step five of data analysis involved defining and refining the themes to ensure each theme captured the meaning of the participants' accounts of their experiences. This involved interpreting the data in a way that discovered underlying patterns, context and broader implications, which offered a better understanding of the participants' experiences. The researcher also identified overarching themes and subthemes for structuring large and complex themes.

Step 6: Producing the report

The final step of writing the findings began once the themes and subthemes were developed. To demonstrate the prevalence of each theme, the researcher provided sufficient exemplars and participants' quotes that captured the essence of the themes. Through writing, reading, discussing, refining and rewriting, an analytic narrative was produced that went beyond mere description and built a strong argument in relation to the research question.

3.4 MAINTAINING TRUSTWORTHINESS

The credibility of interpretive studies focuses on epistemological integrity, representative credibility, analytic logic and interpretive authority (Thorne, 2016). Credibility of this research was ensured by using the following strategies:

- To ensure epistemological integrity, the researcher maintained a reflective journal to consistently review personal assumptions and biases related to the phenomenon. The researcher continuously reflected on those throughout the research process.

- To ensure representative credibility, purposive sampling was employed to demonstrate that, despite variation in sampling, it facilitated the discovery of meaning and understanding.
- The researcher maintained analytic logic by keeping an audit trail.
- The researcher, who came from a non-English-speaking background, maintained interpretive authority. During the initial interviews, a debrief with one of the supervisors was conducted to confirm understanding of the language and clarify any terminology or colloquial language. The researcher also had regular discussions with experienced researchers during the data analysis, which ensured that the interpretation of the researcher was trustworthy and free from any influence of the researcher's own bias or experience.

3.5 REFLEXIVITY OF THE RESEARCHER

As both a researcher and a Registered Nurse, engaging in reflexive thought has been central to this research, particularly within the context of conducting research involving caregivers of individuals living with HNC. Reflexivity, in this study, encompassed a conscious and continual process of self-awareness that shaped and informed all aspects of my research practice (Jootun et al., 2009). It required me to reflect on my own values, assumptions, and positionality, and a constant examination of the evolving relationship between myself, the informal caregivers, and the broader research environment. As a nurse with professional experience in oncology care, I was familiar with the emotional, psychological, and practical challenges faced by caregivers of HNC patients. This insider perspective made me more aware of the issues experienced by caregivers, but it also required me to stay critically self-aware so that my interpretations reflected the caregivers' real experiences, and not my own clinical background or personal biases.

Acknowledging the *reciprocal influence* that exists between the researcher and the participants is imperative to maintain reflexivity (Lamb & Huttlinger, 1989). During the interviews, my nursing background allowed me to establish rapport and trust with participants, enabling them to share their stories openly while I tried to remain vigilant not to let my prior experiences overly shape the framing of questions, the interpretation of data, or the analysis of findings. To achieve that, I asked open-ended questions during the interviews, such as 'how did that feel for you?' or 'can you tell me about your experience?'. As a reflexive researcher, I consciously strove to focus on their narratives while critically examining how my position and assumptions may influence the way those narratives were constructed and interpreted. I also acknowledged and communicated my role as a researcher to participants during the interview, making it clear that their expertise as caregivers was the focus of this study. This was also written in the patient information sheet. This was to minimise the power imbalance that may have influenced caregivers' responses and to promote their voice and autonomy.

My reflexive practice involved critically interrogating my methodological choices, the language I use in the analysis, and the categories I constructed. For example, I reflected on whether my thematic analysis privileged certain voices over others, or whether it accurately represented the diversity and complexity of caregiver experiences.

My reflexivity was also shaped by my own emotional responses during the data collection and analysis process. Listening to the caregivers’ stories about their caregiving challenges, emotional exhaustion, and their struggles to maintain their caregiving role often evoked strong emotional reactions in me, I felt sympathy, sorrow, frustration, and at times, helplessness. These reactions had the potential to influence how I interpreted data. Thus, I maintained a reflexive journal throughout the research process, documenting not only methodological decisions but also my emotional responses and emerging thoughts. In addition, supervisory review of early interview transcripts enabled the identification of my interviewing skills that required modification, as well as the need for me to probe caregivers’ responses adequately. I also had regular meetings with my supervisors, during which I discussed challenges in interpretation and received critical feedback. This iterative process of self-reflection and refinement became a tool for transparency and a mechanism for ensuring that my interviews and the interpretations remained as grounded and rigorous as possible.

3.6 ETHICAL CONSIDERATIONS

Ethical approval was granted by the relevant Human Research Ethics Committee (see Appendix E) and site-specific approval was received from the governance committee (Appendix F).

3.6.1 Consent

Consent forms were read and signed by each participant before interviews were initiated. The participants were given information on the purpose of the study, risks and benefits, and the interview process. The return of a signed consent form indicated their willingness to participate in the research. Participants were assured that their responses would remain confidential.

3.6.2 Autonomy

Included in the consent form was a statement to the participants that participation in the study was voluntary and that if they did not wish to participate or wanted to end their participation in the study, they could withdraw from the study at any time without affecting the relationship with the researcher or the hospital now or in the future. The participants were informed that if they wished, their interview could be removed from the data.

3.6.3 Risk and benefit

Participants were informed of the potential psychological distress or embarrassment that might arise from discussing their experiences as a caregiver. None of the participants in this study expressed psychological distress due to the interview. However, if any participant had shown any signs of distress as they recalled painful incidents or experiences from the past, the researcher would have stopped the interview, showed empathy and given them time to regain composure. They would have then been given the choice of whether to continue or postpone the interview or to withdraw from the study.

3.6.4 Confidentiality and privacy

In the interview transcripts and field notes, participants’ names were replaced with pseudonyms. Other information such as address, date of birth, occupation and institutions (if the participant disclosed them) were replaced with a meaningful descriptive term to maximise the protection of participants’ identities. The original documents and identifiers were stored separately from the edited version. Pseudonyms were used in all transcripts and dissemination of results. No information about a participant or an organisation mentioned in the interview was used in any way that is identifiable. Only fully non-identifiable data were presented when disseminating results.

3.6.5 Cultural sensitivity

The researcher was fully cognisant of the importance of and respect for the unique cultural and religious beliefs, ethnic values and traditional practices possessed by each cultural or ethnic group represented among participants, as well as the variations within groups.

3.7 CONCLUSION

This chapter has discussed the methodology and method employed in answering the research question of the experiences and needs of caregivers of someone with HNC. The findings of this research will be presented in the next chapter.

Chapter 4: Findings

Using interpretive inquiry, participants' interviews were transcribed and analysed using thematic analysis (Braun & Clarke, 2006) to explore the experiences of caregivers of individuals with HNC. This chapter begins with a brief overview of the contextual background of the participants involved in this study. Then, the chapter presents the findings from the analysis of 15 interviews with participants who informally cared for individuals with HNC from the time of diagnosis to the time of the interviews. The caregivers' experiences are discussed under the overarching theme and its three major themes. The findings are further explained under subthemes to provide a deeper understanding of the caregivers' experiences. The participants' quotes are used to illustrate verbatim evidence of participants' experiences. Square brackets '[ ]' are used to add information within the quotes for clarity and grammatical adjustments without altering the original meaning of the interviews. Ellipses '…' are used to indicate that part of the quote has been omitted when the omitted section is irrelevant to the research question. Dashes '–' are used to show an interruption or a pause in the conversation. Pseudonyms have been used to protect the participants' identities in this study. In this chapter, the word 'patient' will be used where necessary to describe the individual with HNC, regardless of their treatment completion status.

4.1 OVERVIEW OF THE CONTEXTUAL BACKGROUND OF PARTICIPANTS

Contextual information is crucial as it shapes the experiences of the participants, influencing their interactions with healthcare services and how they interpret the meaning of caregiving for patients with HNC. During the recruitment process, it was observed that a significant proportion of patients who were receiving treatment did not have an identified informal caregiver. However, the participants in this study were from middle socioeconomic backgrounds. The characteristics of participants were detailed in Chapter 3 (Section 3.3.5). The individuals cared for by the participants in this study had different types of treatments, resulting in various physical and functional difficulties. Therefore, there were differences in the level of care required from the participants during and after treatment completion. Due to the stage of the disease and the complexity of the patient's treatment, the experience of individual participants was unique when they provided short-term and long-term care to the patients. The common treatment side effects experienced by most of the patients included weight loss, pain, swallowing and communication difficulties. All but one of the patients had PEG tubes inserted. In addition to these treatment side effects, some patients experienced other side effects and complications. For example, Michael's wife and Mary's mother underwent extensive surgical procedures, while Sofia's husband experienced ulcerated skin, lymphoedema and oral thrush. He had also developed septic shock and was admitted to the ICU following chemotherapy. All the patients received treatments from a metropolitan tertiary hospital in NSW. This hospital is a nationally recognised centre of excellence, bringing together the specialty areas of head and neck; ear, nose and throat; and plastic and reconstructive surgery.

Caring for individuals with HNC was not easy for caregivers, characterised by uncertainty, life-altering changes and various care responsibilities. The overall findings, captured in the overarching theme **‘It is the hardest thing we have ever done’**, revealed the intense impact of being an informal caregiver of someone with HNC and the challenges this brought. Participants took on the caregiving role with little preparation and experienced different challenges. Despite this, the participants and the patients supported each other, which led to a stronger and closer relationship between them. The unique experiences of these caregivers are further detailed in three major themes: ‘**Our lives have changed**’, which underscores the disruptive and uncertain nature of caregiving; ‘**Caregiver as a coach**’, highlighting the supportive roles that caregivers assumed; and ‘**Managing familiar and unfamiliar care needs**’, which illustrates the broad scope of responsibilities that caregivers had, from routine tasks to specialised medical care. Table 4.1 provides an overview of the three major themes and their subthemes, and their contribution to the overarching theme.

Table 4.1: Overarching theme, major themes and subthemes identified in the analysis

Overarching theme	Major themes	Subthemes
It is the hardest thing we have ever done	Our lives have changed	Experiences of cancer diagnosis
		Cancer never goes away
		Adjusting to the consequences of diagnosis and treatment
	Caregiver as a coach	Fostering resilience in patients
		Bridge to communication
	Managing familiar and unfamiliar care needs	Nutrition as an opportunity to care
		Learning to manage new skills

4.2 IT IS THE HARDEST THING WE HAVE EVER DONE

Caregivers' experience of caring for individuals with HNC was characterised by uncertainty, life changes and different challenges, captured by the overarching theme, 'It is the hardest thing we have ever done'*.* This overarching theme revealed the impact of HNC diagnosis, HNC treatments and treatment side effects on the participants and the individuals they were caring for. For all the participants, the patient's diagnosis came as a shock, and subsequently they found themselves suddenly stepping into the role of caregiver with little prior knowledge about HNC or preparation for caregiving responsibilities.

During the interviews, many of the participants used the words "*we*", "*us*", "*together*", "*it's just hard*", "*we can't*", "*difficult*" and "*challenging*" frequently to reflect the nature of caregiving experiences, and this is evident in many of the participants' quotes presented in this chapter. This sudden transition into a new role provided little preparation time for the participants to manage the complexity of care needs and the emotional toll of caregiving. As Susan described, "*You're never prepared for something you haven't done before. That's the reality. We're aware of the side effects [of the treatments] but, you know, until you're in it.*" The unexpected diagnosis, lack of knowledge about the nature of the disease and its treatments, and the sudden transition into the caregiving role made the caregiving experience very challenging. In this study, patients being cared for by participants in this study required immediate treatment after being diagnosed with HNC. Many patients underwent extensive surgery, adjuvant chemotherapy and/or radiotherapy, depending on the stage and extent of the disease. These treatments impacted various functions, including communication, swallowing and breathing, both in the short term and long term, consequently affecting the patient's overall quality of life. The participants described that one of the hardest parts of the caregiving experience was witnessing the patients coping with HNC. The participants found it challenging to provide emotional support for the patients, as they felt helpless with their limited ability to alleviate patients' symptoms. For example, Penny, the mother of a patient with HNC who underwent surgery and chemotherapy, described her distressing experience. She explained how emotionally upsetting it was to witness her daughter experiencing the physical and emotional side effects of chemotherapy, particularly when she was very sick and depressed. Penny described:

> "It is hard. It is hard to watch what she went through…as far as [I'm] concerned, it was so dreadful after she'd had the chemotherapy because she was so, so sick. She'd get very depressed, and I just didn't know what to do."

Some of the patients had undergone major surgical procedures and required reconstructive procedures. Due to the complexity of surgery and treatment, some patients experienced complications and required longer hospitalisation for additional care and monitoring. Supporting the patients in this situation was described by the participants as distressing and confronting. Emma was the wife of a patient who had a partial glossectomy and mandibulotomy, and later, jaw reconstruction was done using a free flap. Additional to these extensive surgical procedures, her husband also developed a pulmonary embolism during his hospitalisation. This experience added another layer of unpredictability and anxiety for both Emma and her husband. She described:

> "He had the clot in the lung, and they [doctors] straight away put the injection to keep the blood going. It was something from nowhere he got this clot…he was really anxious…It was quite scary, you know? – It was so hard [for the participant] to keep his mind from that [thinking about cancer and worrying about treatments] you know?"

Similar to Penny and Emma, other participants also perceived themselves as ill-prepared to manage unfamiliar caregiving tasks. Michael was the caregiver of his wife. He found it difficult that he could not alleviate the pain and treatment side effects experienced by his wife. He described feeling inadequate in managing his wife's symptoms, which contrasted with his usual ability to cope and solve problems. He described:

> “Four or five weeks into the radio and chemo, we weren’t really coping. I was trying. We weren’t really happy with the pain [management] and, and just horrible thing coming out of [her] mouth, it was horrible for us. It was just very uncomfortable. And it was quite sick for me. I guess [I’m] quite comfortable talking about it. But I was very upset about it. I felt like I was useless, [I] couldn’t help it…feel a bit inadequate because normally, I’ve been able to solve any problem, anything that she ever needed, apart from getting medicine, and I didn’t like to see her in pain.”

While Michael struggled with pain management, Arthur, another participant, expressed his lack of awareness of potential auditory complications associated with the surgery his partner had undergone and the upset this had caused.

> “A big problem with the hearing. If I knew, I might end up getting hearing aids [for her]. But that was something we didn’t expect. I suppose it has been a big disappointment for us…The problems with hearing have been really upsetting. I didn’t know to what extent these head and neck operations could affect [my wife’s] hearing or whether it’s just a bad luck?”

Arthur also described that he had little preparation to take on the caregiver role once his wife was discharged from the hospital.

> “She [his wife] wants to come home. She doesn’t want to stay in the hospital and she wants to stay home…she would have been better cared for if she stayed in the hospital and she would have recovered more quickly. Nevertheless, I made this as she wants to come home. So I become the carer. But in a sense, I felt a little unprepared for it. We need to be a little bit prepared. We need to receive some help as carer about our role. Right?”

Despite these challenges, the participants described these caregiving experiences as a collaborative effort between them and the patient, emphasising that they faced this challenge together. This shared experience emphasised the importance of mutual support and cooperation during the cancer experience, and, eventually, most participants felt that their relationships with the patient became closer. Participants frequently used the words "*team*", "*together*" and "*we*" to describe their experiences.

> "You become less selfish, I suppose. You become more of a team because you need to be together to battle everything…Well! We can't get any closer, yeah, we become closer." (Daniel)

Another participant recalled during the interview his experience of hoping and looking forward to doing more activities with his wife when she fully recovered from cancer. He also described the importance of recovery so that they can "*do things together*", which reflected the value of family bonding and being optimistic about shared experiences ahead.

> "Once a year we [used to] go skiing with the boys. We're looking forward to do more together. But at the moment, we just want to be healthy. So, we can do things together with her when everyone can do." (Michael)

Similarly, Gemma highlighted the importance of mutual support and staying positive while providing care, despite the long recovery process. Gemma has been supporting her husband as a main caregiver for 12 years since his initial diagnosis.

> "We both are quite resilient people. We have been living in this [cancer] journey for so long. Now it's been 12 years, you know. I would always be willing to let new people starting on that [cancer] journey know that it's not all bad and there's still optimism there…he took a long time to recover. But we are optimists. At the end of 2013, we went to Cambodia and Thailand for four weeks. It [HNC] wasn't going to stop us doing things together."

All the participants identified the coordinated efforts required from health professionals and other social networks such as relatives, neighbours and friends. All participants had good support from their family members in caring for the patient, such as preparing meals, regularly visiting, frequently checking in on the participants and patients, and helping them by taking care of the patient so that the caregiver could rest.

> "I'm lucky that I think I had the resources to be able to sit with that and to be able to deal with it [caregiving role] slowly. Like, although the time that my mum was going through her chemotherapy, my sister was around, and she was there to help. That brought up a lot of my family time." (Morgan)

The support provided by family members who worked in the healthcare field was also viewed positively. For example, Michael stated:

> "There is a medical practitioner in the family who is the head of radiology in a hospital. Two sisters of [the patient], one is a radiographer and the other one is a nurse. So, we have sort of various family networks. We know these support networks are there."

Participants also had friends and neighbours who offered help. For example, Emma shared how thankful she was for her friends' support:

> "All my friends are calling and calling me all the time. I'm [her friend] coming and be in the hospital when I was alone. They come in to sit down with me when I was waiting."

For Carolyn, her friend assisted her by taking the patient to medical appointments on the days that she needed to work. She said:

> "I actually work [on] Monday, Tuesday, Wednesday, but at that time, I think I was only working Mondays and Tuesdays. So we either had a friend, my friends took him on the days that I couldn't take him."

Gemma also added: "*We have wonderful neighbours that are always offering to help us should we need help and that is absolutely wonderful.*"

Some participants indicated the important role of health professionals in providing clear explanations, reassurance and support. For example, Carolyn felt reassured when she and her husband received a detailed explanation of his treatment plan from the specialist and were given the contact details of health professionals for support.

> "It was very clear [explanation]. We went to see the doctor and [the doctor] shared the results she [patient] had had from the fine-needle test. She [the doctor] said, you know, based on what I'm seeing here, you'll have a better outcome. And so – we relaxed immediately. I personally relaxed immediately."

Some of the participants found it very reassuring to have the contact details of their health professionals. Michael explained how reassured he felt having these in case of need.

> "We've only used them [call the doctor] once or twice. And they, yeah, it was necessary. It was something we needed to do, or we needed to know. And they knew that we haven't sort of called them every day. It was nice to have those [contact] numbers to know we had that backup."

Similarly, Daniel and Sofia shared their experiences about receiving contact details in case of the need for professional support.

> "We had all the contact numbers that we had any questions and I would encourage you. Here's our email address or phone number. If you have any questions, please do not hesitate to call us." (Daniel)

> "I had phone numbers for the dietitian, phone number for the nurse, also the number for the radiotherapy. So, it was very good that way." (Sofia)

The unique and individualised nature of HNC caregiving experiences will be further detailed below in three major themes: 'Our lives have changed', 'Caregiver as a coach', and 'Managing familiar and unfamiliar care needs'.

4.2.1 Our lives have changed

The first major theme, 'Our lives have changed', contributed to the overarching theme by highlighting how the magnitude of HNC diagnosis and its consequences made the participants adapt to a new reality characterised by uncertainty and disruption to their daily lives. The participants shared how difficult it was to adjust to the life changes caused by a patient's diagnosis. Their experiences included various changes, including their daily routines, relationships and future perspectives. These changes started at the patient's diagnosis and continued during the treatments, and extended beyond the treatment completion. It was prominent across the interviews that the participants experienced a shift in family dynamics as roles and responsibilities had changed, leading to a range of emotions. Jenny shared how her happy moment of pregnancy had turned upside down after her husband was diagnosed with HNC.

> “[When my husband was diagnosed], we just had a little boy, he just turned one. And I’m actually pregnant again with my number two…We went from expecting a baby, which was so exciting, to like this [HNC diagnosis and going through the surgery]. We were just like our world sort of turned upside down a bit.”

The caregivers of patients with HNC underwent significant changes in their lives as they took on different care responsibilities once the patient had started their treatment. Some participants described the experience of the transition to caregiving as “*it hits my life*”. Most of the participants juggled multiple roles, including caregiver, employee, parent, spouse or sibling. Care responsibilities and life changes varied depending on the patient’s cancer stage, treatment type, and the patient’s health outcome upon treatment completion. As caregivers tried to adapt to those challenges and life changes, they experienced a sense of uncertainty about the future. For example, Susan stated: “*I can’t think of the future which was very hard to look after my children at the same time. I just had to get through it.*” To some participants, caregiving changed their professional lives as the caregiving was no longer compatible with their full-time employment. This is illustrated by Josephine, a former physiotherapist, who explained: “*It is a huge change…compared to what I thought life would be like, compared to how I was working before. And you can’t work and do this [being a caregiver] at the same time.*”

Participants also experienced psychosocial distress, relationship changes and disruption in their daily normal routines due to the treatment side effects. These challenges included alteration in eating and meal patterns, changes in daily routine, adaptation to new roles, and changes in relationships with the individual with HNC. The participants adjusted to those changes throughout the course of the patient's illness. The experiences of these changes will be explored in three subthemes: 'Experiences of cancer diagnosis', 'Cancer never goes away', and 'Adjusting to the consequences of cancer diagnosis and treatment' (Table 4.1).

Experiences of cancer diagnosis

The first subtheme that emerged from the first major theme, "Our lives have changed", was 'Experiences of cancer diagnosis'. The initial diagnosis of HNC brought significant life changes and a range of emotions to the caregivers, such as fear, shock and feelings of uncertainty about the future. It was evident that some participants played an important role in HNC diagnosis as they encouraged the patients to seek medical attention immediately when they experienced early symptoms of HNC. As participants described during the interviews, paying attention to changes in patients' health conditions helped with early diagnosis. For example, Carolyn shared how her partner's HNC was detected.

> "He went to the dentist, and it was about six years ago now. And [what] the dentist found was sort of a bit of a lesion under his tongue. It looks like a white strip, sort of under the tongue. And they [dentist] said, [patient to] come back in four weeks or six weeks, and we'll [dentist will] check it out again. When he [her partner] came home to me, I said, you're not fighting [going] back [to the dentist] in six weeks. We gonna get it checked out now."

Josephine expressed her concern about her husband’s symptoms and encouraged him to seek a second opinion for the best care. She also described her emotional and practical struggles navigating the health system.

> “So my husband had been sick for about six months. And we’ve gone to various doctors and even emergency departments to try and get a definitive diagnosis. His local doctor kept on saying it was like pharyngitis. But it wasn’t until he got really, really sick. He lost eight kilos, couldn’t swallow. He was very, very sick. We knew something was drastically wrong. So, I was like, this has to be done. [We] went to the specialist at a hospital [for the second opinion] and at least they [doctors] have got a diagnosis.”

The majority of the participants described feeling shocked when they heard about their family member’s HNC diagnosis because they were not considered to be at high risk for HNC. Michael stated: “*The first one, when they found oral cancer, it was a major shock. She hasn’t had a puff of a cigarette and a whole lot. So, where’s this wrong?*”. Gemma also stated:

> “I think it’s been…it was such a surprise, because my husband wasn’t typical of people that get oral cancers. He wasn’t a drinker, and he wasn’t a smoker. So, to be diagnosed with an oral cancer, which is usually the domain of drinkers and smokers a lot of the time – It was actually quite a shock when he was first diagnosed.”

Since the diagnosis came so quickly and so abruptly, most of the participants felt devastated when they stepped into the world of not knowing what would happen next. One participant described their early experiences of diagnosis and the HNC treatment as “*We were devastated. Definitely! But, also just wasn’t sure of what that all meant, because it happened so quickly*” (Susan).

Therefore, the diagnosis of HNC in a family member had an emotional impact on the participants. The experience of the initial diagnosis was not only shocking but also caused fear of losing the family member. This was the case for Susan, whose father died of cancer, and she shared her experience as:

> “It was, like, devastating of the unknown. Because, you know, you hear the word cancer and you automatically think, you know, you’re going to die. Because, I mean, my dad, three years ago, just passed away with prostate cancer. So you know, yeah, so we know what cancer can do.”

Cancer never goes away

The second subtheme, ‘Cancer never goes away’*,* further explained how the participants’ lives have changed. The fear of cancer recurrence and the long-term care demands altered the participants’ lives. They experienced emotional challenges, ongoing caregiving responsibilities and uncertainty, even after the treatment completion or remission. Analysis of the interviews showed that participants lived in a state of vigilance and anxiety as the possibility of cancer recurrence remained an emotional threat, which prevented the caregivers from feeling that the cancer journey was over. Some patients’ health conditions improved after the treatment completion, but the participants stated that the threat of cancer recurrence and the possibility of death remained in the caregiver’s mind.

Most patients cared for by the participants attended regular follow-ups and PET scans to detect any cancer recurrence. Some participants reported that their anxiety heightened during these follow-up appointments. Accompanying patients for PET scans and follow-ups triggered feelings of uncertainty and fear about cancer recurrence.

> "It's still a little bit of a concern. He needs to get scanned every year for quite a while because they're not sure if it'll come back. It is a type of cancer, obviously. Most of the time, [cancer] does come back, you know. So, it's still sort of like – I don't know, still worrying that something's gonna pop up every time he gets a scan." (Jenny)

The family members of two participants had HNC relapse and required further treatments. These two participants stated that they were "*traumatised*" going through this journey again. Due to the unresolved nature of living with cancer, some participants took on the caregiving role for an extended period, which had a long-term psychological impact on the participants. For instance, Gemma has been caring for her husband for 12 years since her husband was first diagnosed. She explained how challenging this had been and how her caregiving experience intensified with each of her husband's relapses. Gemma said:

> "He had the surgery in 2009, and radiation in 2010, and chemo and it was quite successful. And then suddenly, in 2017, he got a second occurrence, which, that – that was the main blow. The first time, we just seem to get over it. And he could do most things quite normally. But after the surgery in 2017, certain things have gotten much harder…then, again in 2021. It was very traumatising because we…we started to think that this thing [HNC] was just going to keep coming back, which basically, it has been very hard."

Similar to Gemma, Daniel shared how he felt when he knew that his wife had developed another lump. "*You're feeling like you hope for the best. But you don't know. Deep down that you obviously think the worst has come back again. The cancer has returned.*" The waiting period for PET scan results caused a lot of stress for the participants as they were uncertain of the findings and worried about cancer recurrence. Susan said:

> "We are a little bit stressed of having a PET scan in December, because, you know, you think, okay, is this the journey, you know, you have those things at the back of your head, but then, but then you don't think about it all the time, you know, something is starting, it might come in your mind every now and again. You know, you just have to keep going. That's it!"

Even when the PET scan was negative, Victor, a father who cared for his daughter, described the uncertainty of his daughter's health condition and fear of cancer recurrence. He also believed that his daughter would continue to need his care, indicating his caregiving responsibilities would be ongoing due to his daughter's long-term side effects. He said:

> "So it's become easier now because she's all of the treatments finished. Her PET scan was clear. So, she's all clear. But, she's on tenterhooks for two years, she won't know for two years whether the cancer will come back or not come back. So she has to have regular scans for the next every three months. Yes – But she's not out of the woods yet, even though she's been pronounced clear. And all of that is still very difficult for her to eat. It's gonna take a long time to recover. She's constantly tired because of the chemo that she's had over the last five months. She's extremely tiny and she still needs continuing care. So, it's not over when you think it's over. It's not over. The care needs to continue long gone long past."

Adjusting to the consequences of diagnosis and treatment

The third subtheme that contributed to 'Our lives have changed' was 'Adjusting to the consequences of diagnosis and treatment'. Part of the life changes experienced by the participants was accepting the impact caused by HNC and adapting to these changes. In this study, many participants made adjustments to take on the caregiving role. For some individuals, daily priorities had to be adjusted to accommodate the care of family members. The participants consciously and thoughtfully made care plans and adjusted their other commitments to take on the caregiving role. These adjustments included changes to the caregiver's career, disruption to social and eating patterns, changes to communication, and taking multiple roles.

Patients' difficulties with swallowing and speaking limited the caregiver's opportunity to dine out and socialise as before the diagnosis, as Daniel stated:

> "So, a lot of things have changed. We don't go – we don't go to restaurants anymore. We'd be invited to other people's places for barbecues and for meals. And that doesn't happen as often now because people feel a bit awkward. They think, well, if they invite me and my wife for a meal, what fun is she going to do? She's going to sit there and watch this? So that's all changed."

While some participants had to resign from work, others who were interviewed took leave from work to take on caregiver responsibilities. The participants described that their life plans had been disrupted. For example, Josephine had imagined her retirement plan; however, that was totally changed due to the ongoing effects of HNC. She stated:

> "While I was working. I was always working. I'm retired now which is, I'm not too unhappy about [it] but I was earning income and had status and I, you know, could plan my life, I was planning retirement quite nicely. And my retirement now is totally, totally different to what it was, I planned it to be. And my aspirations of what we will do in the future is totally different. So, it is a huge change, compared to what, what I thought life would be like, compared to how I was working before."

For some participants, the diagnosis of HNC also changed the relationship between the participant and the patient. Most of the relationships between participants and the patients became closer as illustrated in the interviews.

> “You become less selfish, I suppose, and you became a team, become more of a team because you need to be together to battle everything…Well, you can’t get any closer…yeah, we become closer.” (Daniel)

However, this was different in one caregiver. Arthur, a husband of a wife with HNC, shared his experience as:

> “So as a husband, it [HNC diagnosis] did [changed their relationship] – because it changed our relationship a little bit – it did change. As I mentioned earlier, this operation was a huge blow to her. And her behaviour, after serious operation, she seemed to almost go back to her childhood in her behaviour, before I knew her. Let’s say, she almost became a bit like her mother…I saw aspects of her behaviours while she [wife] was sick, which is a bit like her mother. She [wife] had time, she [wife] was demanding. I could understand that because she’s sick. She’s really struggling and going through things. So, but it was interesting to observe that. So, it did change our relationship. And to be quite honest, I’m sorry to have to say this. But I think you'll understand it. We – we couldn’t have sex at all.”

One of the major changes that the participants experienced was a change in food preparation and cooking. As most of the people with HNC who were cared for by the participants in this study had difficulty swallowing, the participants changed their cooking style to suit the patients’ needs. For many participants, this required preparing food differently as patients could only tolerate a soft or pureed diet.

> “He came home with a nasal gastric tube and a pump, and he was on that for or a couple of, two or three weeks, and then was gradually able to start eating and drinking again. At that stage, he could only really eat things that were very…things like soups, curries, things that have a lot of sauce with them. Because from the radiation a few years before, he had lost all his saliva, because the saliva glands were all killed off in the radiation. So having no saliva makes it quite difficult to eat. So, everything he needed to eat would be things that had a lot of sauces or gravies, things like that…So a lot of effort went into my cooking food that he could eat, and that I can also eat so that I wasn’t cooking two separate meals. So yeah, it was just hard.” (Gemma)

Jenny also stated that:

> “he was still on puree at that stage. So, I was cooking a lot for him and trying to make it tasty enough that it wasn't just, you know, baby food. If we were having something, try and modify it a bit so that he could eat it.”

One of the participants, Sofia, even avoided eating in front of her husband who had HNC as she felt empathy for him.

All the participants in this study made themselves available whenever patients needed practical support, such as accompanying patients to appointments, supporting them emotionally when patients felt down and undertaking household tasks. Penny shared her experience of making some arrangements to accompany her daughter to her appointments.

> “I live in a regional area. My daughter lives in Sydney. And I was down there for Christmas…So, I went to all the appointments with that. We had to have seven weeks down in Sydney at the Cancer Centre while she had the operation. She

> had the operation and then we had to get back again to the chemo and radiotherapy. And that was seven weeks. I had two weeks after that off because I had to come back home [to her home at regional area]. I had appointments, and her husband went down for the first week and my other daughter went down to the second week while I was there [at her regional area]. And I stayed with her when they [patient's husband and patient's sister] went home and I didn't really come home [her home at regional area] till July."

4.2.2 Caregiver as a coach

The second major theme, 'Caregiver as a coach', contributed to the overarching theme of 'It is the hardest thing we have ever done' by explaining the multiple roles of the participants who acted as coaches by providing emotional, social and financial support; facilitating communication between patients and others; and monitoring patients' symptoms and overall well-being.

While participants were not always directly involved in the physical aspects of caregiving, they consistently positioned themselves as available and attentive supporters, ready to step in when needed. This role resembled that of a coach, offering guidance, encouragement and practical help while respecting the autonomy and preferences of the person receiving care. Michael's experience illustrates this dynamic well. He described his wife as highly independent, preferring to manage tasks on her own. Despite his willingness to assist, he acknowledged his limitations and adopted his supporting role. Michael said:

> "She is very independent. She likes to do her own things. I mean, I'll help her with as much as I can. But, I'm a bit clumsy. So, she finds that like…she feels better if she does things herself. So, I just prepared her medication and get her water, things like that you know."

Despite the independence of the patients, the participants remained essential in coordinating care and providing backup support. They facilitated communication between patients and other people, supporting patients emotionally, socially and financially, as well as assisting patients with daily activities and closely monitoring patient symptoms and overall well-being. The role of coaching also involved being available for the patients whenever required. Their presence was often described as a safety net – always available, always watching, always ready.

> “I know he is a very independent person but I’m like two steps behind him if he has forgotten something or if he needs scripts or you know, don’t forget this. Don’t forget that…so, basically, I care for him, I’m always his backstop.” (Josephine)

This theme entailed how participants transitioned into coaching roles through two subthemes: ‘Fostering resilience in patients’ and ‘Bridge to communication’ (Table 4.1).

Fostering resilience in patients

The first subtheme supporting the second major theme of ‘Caregiver as a coach’ was fostering resilience in patients. As coaches, the participants fostered resilience by providing emotional encouragement to the patients and offering practical strategies to cope with HNC. Analysis of the interviews indicated that the relationship between the participant and the patient significantly influenced the patient’s ability to endure HNC. During the interviews, the participants expressed their willingness to create an emotional connection by maintaining a positive relationship with patients, which, in turn, strengthened the patients’ resilience in facing the emotional toll of HNC.

Through the interview analysis, it was found that participants showed empathy when supporting patients by fostering a sense of hope and encouraging them to remain optimistic throughout the caregiving experiences. Some participants noticed that patients went through periods of depression and feelings of low mood. For example,

> "As far as concerned that – it was so dreadful after she'd had the chemotherapy because she was so so sick. And I just didn't know what to do…She [the patient] had some kind of nights and some nights, I'd be there [with the patient] and she was on my side. She'd get very depressed." (Penny)

So, the participants took different approaches to motivate the patients. Some participants kept the patients active and occupied with activities such as exercising, gardening and cleaning the house together. Daniel shared how he encouraged his wife to stay positive as:

> "We've been there for her, encouraging her to…We get up and three mornings a week, we go for a walk around with our running club. If I didn't ask her to do that, she wouldn't do it. So, I'm trying to encourage her to be a bit more active to get out and be active like she was before she had cancer. I have been trying to support her mentally and provide a little bit of encouragement and positivity to the whole situation. And also I got her to start taking some medicines…And that's got us going really well."

Josephine and Arthur provided emotional support by encouraging and reassuring the patient when the patient needed treatment. Although participants were not medical professionals, their supporting roles were significant during the patients' treatments. Their presence and practical assistance with various aspects of daily living, such as managing financial issues, household chores and transporting patients to medical appointments, helped patients to focus on their recovery, thereby boosting the patient's resilience.

> "He hates hospitals. So just basically just trying to tell him, it's not forever. We'll get out of here. You know, we're in this together and stuff like that. So, I really had to just really reassure him, that life would be better. And it took a long time for him to feel secure with that. But he just hated the whole process." (Josephine)

Arthur supported his wife during the operation and beyond the treatments.

> "I can understand that it was a major operation… they've all been affected…My wife has recovered, But she certainly struggled afterwards. And I just had to be there to sit with her and to be with her."

Emma stated that she closely monitored her husband's behaviours and emotional changes. She took the health surveillance role in supporting her husband:

> "He started to be quiet when he started thinking about the cancer. He's really worried about what to happen. So, I want to keep him busy…I was feeling a bit bad and I was thinking like…he didn't want to tell me everything. He went inside the car and I said that what was happening? You know, would you talk to the doctor or what?"

Some participants stated that supporting patients emotionally was challenging because the patient's emotional status changed during the illness, and the participants had to accommodate accordingly while trying to meet the patient's needs. Carolyn shared how she felt when her husband was not satisfied with her assisting in his tube feeding.

> "There were things like that where I didn't really argue with him. I'd say what's the point? He [the patient] was feeling pretty awful. You know, we'd put the food down there, the [tube feeding] bottles, and I'd put six bottles on the table, and he would just have them, and then, he is someone who gets grumpy with me and tells me [the participant that the feed] didn't mix up very well. Yeah, I mean, it was 15 times that the testing [was] done. So, I just did. Look! [The participant was] having a terrible time. I wouldn't want to be putting up with him."

Providing emotional support became significantly more challenging when patients experienced communication difficulties as a result of HNC treatments. Participants described the emotional strain of trying to meet their patient's needs without clear verbal cues, often leading to frustration, miscommunication and emotional exhaustion. The inability to understand or respond effectively to the patient's needs not only hindered practical caregiving but also created emotional distance at times, despite the caregiver's best intentions. Mary shared how her mother's frustration, compounded by communication barriers, often left her feeling helpless and emotionally overwhelmed:

> "I think the biggest, hardest thing was the communication. I am the eldest, so she tends to take stuff out on me. So, when she gets frustrated, she's kind of, it's very obvious to me…When I don't do what she wants or as quick as she wants or…so that it's been a little bit hard…What you want it? Because I would do it, but I just don't know what you'd want, Mum. I'm really sorry. I know you're frustrated with me. I just don't understand what you're asking me to do. I'll do it. But I need to like, just give me one word. Like, because we find with Mum, we usually we just need one word. If we've got one word, we can figure it out."

Morgan also had similar experiences. She reported that

> "Because she got, her tongue was removed. So, she can't speak. Well, she does. But it's limited. And it's challenging to understand. Can be a bit frustrating for her. And frustrating for us, I guess at times, like I get frustrated because I feel upset that, for her. I feel upset that we're not getting it."

Bridge to communication

The second subtheme contributing to the major theme of 'Caregiver as a coach', was becoming a 'Bridge to communication'. Following surgery and/or additional treatments, some patients experienced pain and inflammation in the head and neck region, which made speaking more challenging. In response to this, the participants actively served as a bridge to overcome the patient's communication difficulties. Analysis of the interviews showed that the participants were a useful source of communication for the patients as they knew when and how to assist without losing the patient's autonomy. A few participants facilitated the patient's communication process both face to face and via telephone. In some cases, speaking on behalf of the patient had legal implications. Gemma shared her experience as:

> "Speech was very affected because he lost part of his tongue was removed. So, it meant that a lot of the things that happened by phone, he couldn't do anymore because people can't understand him on the phone. So, I would have to make a lot of phone calls on his behalf. And that had issues because I had to get registered as his, acting on his behalf. You know, the privacy thing made it difficult initially, that people wouldn't talk to me about various accounts and things he had, because I didn't have authority on those. So, we had to do a lot of paperwork to set things like that up."

> “I talk to this person [real estate agent]. Maybe this just needs to be worked on because, as I think of the chemo, he couldn’t talk. He couldn’t talk too much. He had so much blisters inside his mouth. It was so painful.” (Emma)

Josephine recalled how she had helped her husband communicate with the health professionals. She acted as an advocate for the patient when he required medical attention. When he was not able to speak properly, it was hard for the medical professional to understand. “*He couldn’t talk at this stage with this doctor about that, about the pain relief. So, the pain relief team was, we were in touch with her.*” While the participants acknowledged the patients’ limitations with speaking, they encouraged patients to communicate as far as possible by giving some advice, such as using FaceTime during the phone call or writing things down. For example,

> “Because she have a soft palate, her speaking is very nasally. And because she has a lot of phlegm in her mouth, most of the time. As the day wears on, it can be a little bit hard to understand her. And also, because she can only open her mouth about half an inch. It’s like talking with your mess and trying to talk with me in your mouth half an inch. You can do it. But it’s still a bit more difficult to understand that you might be, kind of like, a bit of mumbo jumbo, And yeah, when we talk to people on the phone, and that we make sure that we FaceTime that people can see what she’s saying. So they can sort of read her lips as well as she can get what she’s trying to say with her hands at the same time. And people find it quite easy to understand.” (Daniel)

4.2.3 Managing familiar and unfamiliar care needs

The third major theme, ‘Managing familiar and unfamiliar care needs’, revealed the scope of caregiving responsibilities and the skills required to fulfil them, from daily tasks to more specialised medical-related care. This theme also provided a deeper insight into participants' rewarding and challenging experiences in fulfilling various care needs, often requiring non-technical and technical skills. Therefore, these experiences supported the overarching theme 'It is the hardest thing we have ever done'.

Due to the complexity of HNC and its associated treatment side effects, participants were involved in a range of care. Some aspects of caring did not require specialised knowledge or technical skills, such as cooking and meal preparation. For example, Arthur said: "*Cooking is easy because you already know how to cook, and it's kind of like part of your life.*" In this situation, caregiving was described as fulfilling and rewarding to most of the participants. However, this sense of fulfilment was often accompanied by significant challenges, particularly in aspects of care that required technical knowledge or clinical skills. Tasks such as pain management, wound care and administering nutrition through feeding tubes were described as especially demanding, often pushing participants beyond the boundaries of their prior experience. Participants shared during the interviews how they gradually transitioned from a layperson to a semi-medical professional. Their positive and negative experiences in managing different care responsibilities will be explored in two subthemes: 'Nutrition as an opportunity to care' and 'Learning to manage new skills' (Table 4.1).

Nutrition as an opportunity to care

The first subtheme, 'Nutrition as an opportunity to care', contributed to the major theme of 'Managing familiar and unfamiliar care needs' as it explained how the participants felt useful and valued when they actively provided familiar care needs such as preparing food. Most of the participants took this opportunity to express their care and support to the patients. Monitoring the patient's nutritional status and ensuring nutritional requirements offered a tangible way for participants to demonstrate their care and commitment to the patient's health during the cancer journey. Many participants put a lot of effort into preparing a meal. Gemma said: "*a lot of effort goes into trying to find things for him to eat*". In describing their active role in nutritional support, Jenny mentioned:

> "I was cooking a lot for him and trying to make it tasty enough that it wasn't just, you know, baby food. If we were having something, try and modify it a bit so that he could eat it."

To some participants, meal preparation and nutritional care were more than a practical support. They found a meaningful way to express care and transform caregiving into a shared journey of mutual support. For example, Tom made an effort to search the internet for suitable food for his wife. Prior to her radiation therapy, she was able to feed herself slowly using a spoon. However, following the onset of treatment, she developed painful mouth ulcers that made eating extremely difficult. Tom's narrative highlighted how meal preparation became a powerful act of reciprocity and emotional connection. He also expressed his gratitude for being able to cook and prepare meals for her during that challenging time after the radiation. He said:

> "After the first week of radiation, she could not eat anything because she got ulcers in the mouth because of the radiation. She only had special milk, something like formula. I was cooking chicken porridge for her, really puree for her to try. She did try but she could not finish…I didn't know how to cook. Last time she cooked for me. And now, I feel great because

> it’s now my time to help. I feel blessed to be able to do my turn.”

Cooking and meal preparation were the caregiving tasks that most participants were familiar with and comfortable with, except for one participant. Arthur explained how he struggled with preparing food for his wife. Although he had previous experience with cooking, he found it challenging to adapt his cooking to meet his wife’s dietary needs. He said:

> “I had done cooking, but it was actually cooking this kind of cooking, you know. Because there are things which we normally would have…but my wife just can’t eat at that moment…When we came home, we [his wife] moved to eating by mouth, and that’s when I had to prepare the food. That point where I struggled the most.”

Participants experienced a range of emotional responses and challenges as they navigated the responsibility of meeting the nutritional needs of the patient. Emotions such as frustration, worry, stress and gratitude were commonly expressed among the participants. They voiced their concerns regarding the patient’s nutritional status. The participants were very vigilant about the patient’s body weight and intake, as they felt that it was one of their responsibilities to ensure the patient received adequate nutrition to promote recovery. Gemma shared her experience of emotional distress about her husband’s weight loss.

> “It was upsetting for me to see his weight going backwards, you know, he actually got down to about 63 kilos, which is very light for someone who’s six foot one.”

Most of the participants relied on nutritional supplements for the patients to prevent weight loss when they could not eat regular food due to HNC treatment consequences. For example,

> “She lost a lot of weight. And as she went from 65 kilos down to 48 kilos, well, that’s a lot. It is the biggest, a massive drop because the only intake of food for her is through her little bottles of Resources that she has every day.” (Daniel)

Penny described the practical challenges and resistance experienced in achieving the nutritional needs of her daughter as:

> “She was a bit…get so cranky with me because I had to try to get her to eat. I mean, I didn’t want her starving to death. I had to ensure that because they had their own protein supplement drinks. But, it is hard.”

Carolyn described her emotional and frustrating experience of trying to support her husband, who had lost both appetite and interest in food. She reflected on the emotional burden of caregiving: being physically present and emotionally committed, yet often unable to control or change the outcome.

> "He just had no appetite and no enthusiasm for food. And that was part of it. My jelly kept coming and we beat the jelly and then maybe a bit of apple puree, you know, baby apple puree. Really, it took a long time. And I think because of the discomfort, he hung on the feeding tube longer because it was his comfort zone to do so. You know, he was going through stomach and not through throat. Yeah. And, you know, given the sort of length of time to recovery and, you know, you're there with your, you know, the person that you love and want to come out of it…He was very, very stubborn about the water and that caused me a lot of stress. Because there was nothing I could do. I said, take spoonful and then he told me to say well, I had a half a glass today. Now I've had a half a glass of okay."

Similarly, Penny said: "*It's just very, very hard to watch someone not eating.*" Therefore, some participants allowed plenty of time for patients to swallow the food hoping that the patient could get enough nutrition:

> "It's taking me two hours to eat breakfast, is taking me two hours to try and eat lunch and another two hours to try and eat dinner. And of course, that meant we just couldn't do anything. By the time he had finished breakfast. It was nearly time for lunch. Yeah, he was spending six hours a day eating which, you know, was incredibly hard for him, but also very frustrating for me because I couldn't help him." (Gemma)

A few participants expressed gratitude that the patients had a PEG tube inserted as it helped to meet the patient's nutritional requirements. Susan stated:

> "Thanks God! He had the tube in his stomach because by week two, he couldn't eat anyway. So, you know, I remember the doctor saying it's up to you, but we highly recommend you put this in. So, I'm glad we did, even though we didn't want to,

> we just thought, you know, that’s just so invasive. But in the end, it’s honestly the thing that kept him going. I think, if he didn’t have, I don’t know what he would have done without the tube.”

Supporting patients with their nutritional needs required practical help from the participants in instances such as tube blockage, monitoring feeding schedules, and preparation of feeds and medications. Managing and assisting with tube feeding were opportunities to provide practical supports to the patient’s health. For example, Victor administered feeds via a PEG tube. He said: “*She had a tube in her stomach because she couldn’t eat through her mouth. I had to administer the feed for her.*” It was identified that most participants balanced between providing necessary support to participants and promoting patients’ independence and autonomy. That indicated their mutual respect and the dynamic of the relationship in caregiving. For example, Michael highlighted the importance of providing support in a manner that respected his wife’s autonomy.

> “She doesn’t want to ask for help. And she gets frustrated when I sort of hover around. She does like to control. But that’s it. Yeah. She needs the syringe, the thing that she uses to pull her in, she needs feeds shaken up. She needs hot water. She need medicine. Easily we couldn’t get dissolve Panadol. So, I was you know, I was the pill crusher. just silly little things, but just being there. I think was the important thing, but let’s just be there but don’t get in the way.”

Similar to Michael’s experience, Jenny also took a supportive role in tube feeding.

> "He was pretty good at doing it by himself. It was just because he was struggling to swallow. He was putting most of it through his PEG because he couldn't get it down. So sometimes I would just make like, I would get the dissolving Panadol and I've made it up for him. And I take it to him."

The participants adapted their supportive roles based on the specific needs and preferences of the person they cared for. For Sofia, she closely monitored her husband's feeding schedule. She said:

> "I was making charts of exactly when he had it, exactly when he had the Resource, etc. And then when he finished the treatment and came home from hospital, I would do the chart of exactly what he's done during the day. So, I knew what I was doing. And just so I could refer back each day, exactly what times he was having everything."

A few participants experienced a heightened stress level when the PEG tube was blocked, as they were concerned regarding the potential deprivation of nutrition for the patient if the tube remained obstructed. One of the participants shared:

> "We haven't had a problem where we haven't been able to unblock it. It's just a case of putting liquids through and really pumping it to try and clear it again. So, we use the big syringe that we use for the feed. We actually use the pump rather than just let it be gravity fed. We actually push it through with the big syringe and try and clear it and so far we've probably had all four or five occasions when that has happened since he had the tube putting in November, I think, maybe once a month, something like that happens, but we've always managed to clear it. But it is a little stressful thinking that he may not be able to get any nutrition if we can't clear it." (Gemma)

Gemma added how stressful it was to travel when the patient was being tube fed as she worried about tube blockage during the travel and the hassle of carrying heavy feeding cans along the way:

> “The liquid food is so bulky, that it’s, it’s hard to travel around with, with the food that he needs…and also quite difficult for me in terms of supporting him and, and the stress that you encounter. If you’re in a foreign place and you have a problem. It’s very, very stressful.”

Learning to manage new skills

Another subtheme comprising the major theme of ‘Managing familiar and unfamiliar care needs’ was ‘Learning to manage new skills’. Each stage of the HNC journey needed the participants to provide specific care to the patients. The participants were required to use various caregiving strategies, seeking support from health professionals and acquiring the knowledge and skills necessary to fulfil the caregiving role. The process of learning these skills involved different methods and resources. Some care needs, such as wound dressing, tracheotomy care, tube feeding and troubleshooting, and pain management, required technical skills and hands-on training. Many participants navigated those complex care needs through training from health professionals while patients were still in the hospital. Some participants reported that their learning experiences developed from trial and error, and from following written skill guidelines, verbal instructions and demonstrations by the health professionals. Michael and Sofia shared their tube feeding learning experience as:

> “When we were in hospital, when she was hospitalised, with the nursing staffs, [they] were very good at showing how to clean it [the feeding tube] out…how to sanitise or whatever you call it and how to hook it up and so on and so forth. Reasonably intelligent people could work ourselves anyway, we can’t do that situation. When we broke one of the…one of the…sort of plumbing pipe, those external things that we would connect to the syringe.” (Michael)

> “They [the nurses] showed me what to do with the PEG, how to rotate it, and how to flush it out with water. Yeah. And we were doing that when my husband came home from the operation.” (Sofia)

Although most participants received good support from health experts, some experienced challenges and unexpected issues that were not previously learned. For instance, although Sofia had learned how to care for PEG feeding, she experienced an unexpected situation when her husband was discharged to home.

> “At that stage [during the patient hospitalisation], we were flushing [the PEG tube], turning it every day, because they [the nurses] explained that it can close over. So, we were keeping it open and clean. And I was sort of cleaning under it, because it was weeping a bit as you know. After that, like, it’s sort of bit bloody and things like.”

For Victor, he developed new skills in medication based on the information sheet provided by the healthcare provider.

> "Well, when the hospital tells you roughly what she should take, and how often she should take it [medicine], and you develop those skills along the way, you know, you don't know exactly what to do. You look at a sheet and say, Okay, you take this particular medication for that condition. You take that medication for this…It is for every four hours, every three hours. The skill is developed as you learn, but you're not brought into the hospital and given a big long lecture on how to do it. They give you a sheet and say this is what, this is a medication. And this is how often you should give it. And that's all you send away with, you know. That was how I had been taught with skills."

Despite the commitment and efforts put in to learn these new skills, many participants felt ill-prepared, especially when their expectations contradicted the reality during the treatment and post treatment. The unexpected side effects of treatments and witnessing the patient suffering from symptoms without being able to improve or control the situation caused emotional distress to the participants.

> "I was really shocked by how severely she was affected by the operation. Now I understand that because it was a major operation. And, you know, there are many muscles and nerves in the face, and they've all been affected. About a week after the surgery, that's when things began to go downhill because she wasn't able to take things by mouth. And that was quite a shock. When I realised that, this was weird, you know, things were much tougher than I thought." (Arthur)

Most participants stated that they received information about the treatments and potential side effects from the health professionals. However, for Michael, his wife underwent surgery twice due to recurrence, in addition to chemotherapy and radiation. His wife later developed a mouth ulcer post treatment. Michael underestimated the severity and duration of treatment side effects, leading to emotional distress. He said:

> "It's become a bit of a surprise. [The doctors said] You'll have cancer treatment side effects, and so forth. But they didn't emphasise. I sort of understand why I don't think you need to know anything to worry about it. But it was a lot more than I thought it was. It was quite distressing. I was quite surprised at how ugly it was. The ulcers in the mouth are just horrible, horrible. And I thought that it would clear up after five or six weeks. We've just been close to the tipping point for so long waiting for that improvement. And it took a lot longer than I thought. Very very slow. I would have liked to know how it would be. So, I could prepare for that and myself a little bit. They [doctors] said, well…can be five or six weeks. But it actually took nine or 10 weeks."

Some participants described that they would have benefited from more information during the initial diagnosis, as they had limited knowledge about HNC. Gemma shared how communication gaps could happen between health professionals and participants.

> "Sometimes the doctors, although they've been pretty good, they are so used to dealing with it that they don't realise that you're missing a piece of the puzzle. That you didn't realise that this particular thing was going to happen along the way…perhaps they [doctors] just assume you know…There have been gaps in communication."

Unlike Gemma, some participants reported that they could not absorb all the information at once because they felt overwhelmed by the sudden diagnosis and the need to accommodate the patient's multiple appointments during the initial treatment.

> "Actually, I think because it happened so quickly. Like we went from getting results, going to a neck surgeon, then getting a diagnosis, thinking like this all happened within five days. And yeah, so, it's just really, you know? I feel like sometimes you don't consume. Because I do not consume all the information at the beginning, because I was so overwhelmed. The diagnosis and so, you know." (Susan).

The participants described during the interviews the need for ongoing support. Some participants suggested that having a regular check-in from a health professional throughout the cancer trajectory would have been beneficial. Some of the participants in this study were in lockdown due to the COVID-19 pandemic. Thus, they had limited opportunities to meet with other people or to seek medical advice. Therefore, some participants thought that even a quick phone call by a health professional would have been very helpful. Susan said:

> "Look! We were in lockdown, so it would have been a little bit difficult, but I actually think a quick 15-minute phone call, you know, you don't have to get on Zoom. But just a phone call to say, you know, Hey, how are you? How's going? Just touch in base. That's just a normal conversation. And, and I think that is probably what's missing. I couldn't go into the hospital [due to visitor restrictions]. But the more I think about it, just having a connection, have a phone call once a week from the same person during the six weeks, or maybe seven weeks [after discharge] just for question, and peace of mind. Really."

Half of the participants stated their desire to connect with other participants in similar situations, suggesting that this kind of network would be beneficial to fulfil the caregiver role. The participants appreciated the support and dedication from the health professionals, but they still wanted to hear other caregivers' stories and share their experiences with each other.

> “Probably just somebody that I could go and sit and talk to and say, well…this is what’s happening. You know, what do I do? What can I do? I’ll keep saying it. The nurse was fabulous. But she had a job to do. She couldn’t sit and talk with me all day. I can’t hold anyone down there. Even the nurses in the radiation, they were really good. So, having someone to talk to who was going through a similar situation would have been helpful.” (Penny)

Arthur explained how emotional isolation could be experienced as a caregiver in clinical environments, where the focus is primarily on the patient. Arthur suggested that peer support could have offered not only practical advice but also emotional solidarity.

> “I mean, she [patient] was only in radiotherapy for 5–10 minutes, sometimes with a dietitian, which she’d be longer, say 20–25 minutes. And that will give me an opportunity to speak to somebody. But everyone’s so busy. I can understand why they can’t do that. They’re rushing off their feet here, there, everywhere. Looking after everyone…I can understand why that wasn’t the case…I think that getting you together with other carers, and even being taken aside by one of the medical staff. It never happened…It would be interesting to talk with other carers because I’m sure that others have also had these problems encountered.”

Jenny commented on the need for connection with someone who truly understands and has personally navigated the complexities of caregiving, while she described the emotional support offered by her friends and family.

> “I think being able to talk to somebody who has been through similar or, you know, have a bit of guide, would have been helpful. Because my friends and family’s one thing, they’re going through it with you, but your friends don’t really

> understand. As well, as much as they're there to support you and listen, and, you know, if you wanted to cry, they would cry with you. Like, that's fine, but they don't really understand how scary or how hard it is. So, I think somebody that has been through, it would have been helpful."

Sofia expressed that hearing from others who have gone through similar caregiving experiences would be beneficial, not necessarily for advice, but to gain emotional clarity and reassurance.

> "I think that probably would help. Mainly to hear what they [the other caregivers] went through. And sort of thing. Oh, you know what this is, this is quite normal, what we're feeling or what my husband feeling is quite normal? and that type of thing? I think that would be very good."

4.3 CONCLUSION

In this chapter, the experiences of caregivers of individuals with HNC were explored. Three key findings were identified. Firstly, participants face many life changes, including alterations in their daily routines, relationships and future perspectives, and they adjust to these changes to fulfil the caregiving role. Secondly, participants take on a coaching role by providing psychological support, facilitating communication and offering practical assistance, while encouraging patient independence and resilience through their caregiving experiences. Lastly, the findings also provided deeper insights into participants' rewarding and challenging experiences in addressing various care needs, suggesting potential support needs to improve caregiving experiences. These findings will be discussed further in the following chapter.

Chapter 5: Discussion and Conclusion

5.1 INTRODUCTION

This doctoral study aimed to understand the experiences of those caring for someone with HNC in Australia to identify their support needs. Using an interpretive inquiry approach, the experiences of caregivers for individuals with HNC were explored through in-depth interviews with 15 participants. The findings from this study revealed the experiences of HNC caregivers, which are influenced by the Australian healthcare system. Exploring caregivers' experiences identified opportunities to better support caregivers in preparing for the complexities of care needs. While individual caregiving experiences may vary or change throughout the cancer trajectory, reflecting on caregivers' experiences from the time of diagnosis through to post treatment provided valuable insights into the evolving and dynamic nature of caregiving over time.

5.2 SUMMARY OF FINDINGS

For participants, caregiving was both a shared experience and a life-changing responsibility. This transition was emotionally and psychosocially challenging, making caregiving one of the most difficult roles participants had ever assumed. The participants reported stress, shock, frustration and fear of cancer recurrence as constant vigilance was needed to manage medication, physical care, appointments and nutrition. Knowing that the patient's cancer could relapse at any time created a sense of living with uncertainty and fear in the caregivers.

The participants experienced significant changes in their lives as they managed various challenges associated with complex HNC treatments and their side effects. They had to adjust to new roles and responsibilities, which included psychosocial impacts, relationship changes and disruptions to their daily routines. Major adjustments reported by participants in this study centred around meal and social life adjustments. The participants made these adjustments in their daily lives to prioritise care for the individual with HNC.

Although the patients in this study were relatively independent in managing their own care, the caregiver participants played a crucial role as coaches in providing care for the patients. The role of caregiving involved providing emotional, social and financial support; facilitating communication between patients and others; and monitoring patients’ symptoms and overall well-being. The patients supported by the participants in this study required minimal physical care but substantial emotional support. The participants continuously supported the patients by maintaining a sense of hope and encouraging them to remain optimistic throughout the cancer trajectory. Additionally, some participants facilitated the patient’s communication as the treatment side effects affected their ability to talk. Despite the challenges faced, especially after hospital discharge, the participants remained positive and committed to their coaching roles.

Many participants in this study gained a sense of purpose in managing both familiar and unfamiliar care needs. They reported developing a stronger bond with the person with HNC during difficult times. The participants took an active role in preparing food and monitoring the nutritional status of the patient. They found these roles an opportunity to show care and felt useful and valued. Some participants experienced challenges in managing care needs that they had not previously learned. In summary, the complexity of caregiving made it feel like the hardest job they had ever done, but through collaborative effort and mutual support, participants navigated these challenges. These experiences will now be discussed further.

5.3 CAREGIVING IS A SHARED AND LIFE-CHANGING EXPERIENCE

One of the most striking aspects of caregiving in this study is that participants described their experiences as both shared and life changing. Throughout the interviews, the participants frequently used the words "*we*", "*us*", "*together*", "*we can't*" and "*our*" to reflect the nature of caregiving experiences, whether they were the parent, the partner or the child of the patient with HNC. These descriptions indicate that HNC diagnosis and its associated treatments affected both patients and their family members. The shared experience began at the point of initial diagnosis. The emotional reactions commonly experienced by caregivers during the initial diagnosis, such as shock, frustration and denial, are typical for anyone unexpectedly facing a cancer diagnosis (Balfe, Keohane, O'Brien, et al., 2017; LeSeure & Chongkham-Ang, 2015; Sato et al., 2021; Shaw et al., 2013). In the current study, the participants could not understand why patients were diagnosed with HNC as the patients were not drinkers or smokers. Traditionally, heavy smoking and alcohol consumption were well-known risk factors for HNC. However, the trend has been changing lately, and younger individuals who have never smoked or been heavy drinkers have been diagnosed with HNC, particularly oropharyngeal cancer (Ward & van As-Brooks, 2024). The participants also demonstrated a shared experience of vigilance and health monitoring during the initial diagnosis process, as they actively supported the patients in seeking medical attention immediately upon noticing symptoms of HNC. Similar shared experiences have been reported in patients with breast cancer and prostate cancer whose family members shared decision-making during the diagnosis and treatment, indicating that patients and caregivers usually navigate the difficulties of a cancer diagnosis together by maintaining collaboration and a sense of unity (Cincidda et al., 2023). The emotional response and the relationship between caregiver and patient can vary when faced with diagnosis and managing the consequences of illness in their everyday lives (Burris et al., 2019). Researchers have used the term ‘dyads’ in describing the cancer experience and its dynamic and relational interactive nature, where individuals influence and support each other (Li & Loke, 2014; Nardella et al., 2025; Sterba et al., 2017; Sterba et al., 2016).

The lives of study participants were disrupted as a consequence of HNC and its treatments. Unlike other types of cancer, HNC treatments often require invasive and complex surgeries, leaving the patients with visual disfigurement and changes to body functions. In turn, this affects the patient’s psychosocial status (Geiss et al., 2024; Lin et al., 2024). Completion of the treatments may not be the end of the HNC trajectory as recovery and rehabilitation can take months or sometimes years (Ward & van As-Brooks, 2024). Most of the participants interviewed viewed becoming a caregiver as a life-changing responsibility, describing it as a life experience where “*it will never be the same anymore*” and feeling “*never out of the woods*”. What was once considered to be their normal lives changed as they took on extra roles associated with their caregiving responsibilities.

The participants in this study also experienced notable changes in the relationships they had with the person they were caring for, and this was characterised by a deepened sense of mutual support and collaboration as they navigated the illness together. Regardless of whether the caregiver was the spouse, child or parent of the patient, they developed a partnership-like dynamic, working together to manage the challenges of HNC. This shared experience strengthened their bond, fostering a commitment to caregiving, and reinforcing their emotional and practical support for one another. The participants progressed through the HNC trajectory together with the patient, and they demonstrated unwavering dedication to care responsibilities, regardless of the challenges they encountered. This finding is different from a previous study conducted by Weaver et al. (2022). In that study, the relationship the caregivers had with patients became more maternalistic after they became a carer (Weaver et al., 2022). Some caregivers in the study by Weaver et al. also expressed not liking their role, due to the demands on their time and not being able to live their lives in the way they wanted (Weaver et al., 2022). The study found that it was more difficult for caregivers to fulfil their role as a carer when their relationship with the patient deteriorated. It also suggested that the caregiver’s relationship with the patient became strained as the patient’s behaviour changed and when the caregivers’ social life was restricted (Weaver et al., 2022).

In this study, most participants felt ill-prepared for the transition to the role of caregiver. This was due to the nature of HNC and the ongoing adverse effects of HNC treatments. With HNC, caregiving can be more challenging than with some other types of cancer due to the complexity of HNC treatments, duration of treatments, and the requirement for caregivers to take a more active role in care provision. This transition to the caregiver role became more difficult when the patient was discharged from the hospital, and care continued at home. The transition has been shown to be a complex interaction between individuals and their surroundings, leading to feelings of disconnection, loss of familiar routines, unmet needs, and outdated expectations that no longer align with new circumstances (Schumacher & Meleis, 1994). In this study, the transition to a caregiving role involved new roles and activities that the caregivers had never done before. Previous research suggests that caregivers usually feel inadequate and lack confidence to take on the caregiving role without adequate preparation, and have doubts and uncertainties (Hashemi-Ghasemabadi et al., 2016; Yakar et al., 2019). A study by Dri et al. (2020), exploring the experiences of caregivers for patients who had had a laryngectomy, found that most of the caregivers felt overwhelmed by the responsibilities and the physical care required by the patient (Dri et al., 2020). Feeling inadequate often becomes evident when the caregivers are required to provide physical and emotional care to the patient at home (Ang et al., 2016; Ugur et al., 2014; Xu et al., 2024). The transition to caregiving and its challenges have been widely studied in palliative care (Aoun et al., 2017; Hudson et al., 2019; Xu et al., 2024). The present study confirmed the existing understanding of caregivers’ challenges and indicated the need for caregivers to be adequately prepared to manage their responsibilities.

Another shared experience in this study was that the participants had little capacity to make future plans due to the uncertainty associated with patient recovery and cancer recurrence. The participants’ descriptions, such as “*we* *used to exercise together*" and "*we were meant to travel together*", showed how HNC had changed their daily activities and their future plans. Many participants described the loss of shared activities. Their lives and plans had been put on hold and became focused on the patient's recovery and well-being due to the uncertainty of HNC. These findings are consistent with previous studies that suggest that living with uncertainty is due to the unpredictability of their disease and its related changes (Blindheim et al., 2013; Dri et al., 2019; Kitrungrote et al., 2008). Similar to the current findings, life disruption and meal patterns changes were commonly reported in other studies (Patterson et al., 2013; Penner et al., 2012; Röing et al., 2008). Caregiving for HNC patients was a "*never-ending journey*" as described by some participants, as side effects associated with HNC treatments can be both short and long term, requiring continued support and care from the caregivers. Patients and caregivers often face the ongoing effects of cancer treatments even after completion of the treatments, and they continue to experience physical and psychosocial issues following treatment (Kantor & Suzan, 2015; Numico et al., 2015).

5.4 MAKING ADJUSTMENTS TO ACCOMMODATE CHANGES

The participants in this study made adjustments to accommodate the changes that were needed to enable them to support the patient with HNC. These included role adjustment, learning new skills and lifestyle adjustments, as well as communication and relationship adjustments. Many participants experienced role shifting from being a spouse, partner or parent to becoming a semi-professional caregiver who was responsible for managing the side effects of HNC treatments at home. The process of acquiring these skills varied; while some received formal instruction from healthcare providers, others relied on trial and error, written guidelines or observational learning. Among the variety of caregiving tasks, meal preparation emerged as a central aspect of caregiving in this study, indicating the nutritional challenges faced by caregivers of patients with HNC. This finding aligns with a qualitative study by Dornan et al. (2022a), that found that following treatment, patients often experience social eating as a conscious and emotionally charged process, shaped by anxiety, embarrassment and altered self-image. Caregivers, therefore, play a critical role not only in preparing meals but also in facilitating social participation and emotional comfort during eating. Dornan et al. (2022b) further highlighted how caregivers adjust routines and expectations to support the patient's evolving needs. In current study, caregivers described this task as both supporting the patient's recovery from their treatments and as an expression of care. It also highlights the caregivers' concern about the patient's health status, their constant adaptation to the patient's nutritional needs and the emotional weight of those adaptations. These results are consistent with those of previous studies, indicating that caregivers tried their best to provide adequate nutrition by adjusting their cooking style and assisting with the patient's feeding tube (Fronczek, 2015; Nund et al., 2014; Patterson et al., 2013).

These changes in mealtime and eating habits affected other social activities, such as eating out in restaurants and attending social events. Many caregivers avoided attending social events and also avoided eating in front of the patient. It was found that the caregivers had no hesitation in making adjustments to their daily life, and prioritised the patient's needs over their own. Caregivers also experienced challenges in negotiating patients' emotional changes during and after treatment. However, they remained committed to caring for the patients and fostered their resilience. A previous study showed that the caregivers hid their emotions and held the burden silently to minimise the distress for other family members and the patient (Halkett et al., 2020). As the patient's ability to perform his or her daily routine became limited, extra roles were expected from caregivers and they often undertook multiple roles simultaneously. For example, these included things such as taking care of the children, handling daily household chores and maintaining employment commitments while they were taking on the caregiver role (Fronczek, 2015; Penner et al., 2012). For many caregivers, their priorities change to make sure they are available to assist and support the needs of HNC patients (Halkett et al., 2020). Caregivers make patients their first priority without thinking about themselves (Dri et al., 2020).

Some participants experienced difficulties communicating with the patients. The participants in this study reported the emotional impact of losing verbal connection when they could not fully understand and meet the patient's needs. As the HNC treatments affected the patient's ability to talk, the participants also took an active role when the patient was required to communicate with someone, such as health professionals. Studies have shown that communication challenges affect the relationship between caregivers and patients (Dri et al., 2020; Nund et al., 2015; Nund et al., 2014; Penner et al., 2012). One study reported that caregivers had negative experiences regarding intimacy and sexuality when their partners required a long-term gastrostomy (Mayre-Chilton et al., 2011). This is different from another study of the experiences of caregivers for HNC patients who had had a laryngectomy (Dri et al., 2020). In this study, the caregivers demonstrated understanding of the patient's loss of their voice, which gradually led to a better relationship between the caregiver and the patient (Dri et al., 2020). In contrast to Dri et al. (2020), another study (Weaver et al., 2022) indicated that HNC treatments affected patients' physical and mental status, which in turn had negative effects on the caregivers' ability to keep good relationships with the patients and do their jobs as caregivers. That study also reported that the caregivers felt overwhelmed to handle all the changes, and some of them did not like being caregivers (Weaver et al., 2022).

Adjusting to becoming a caregiver also involved learning new skills. Although the transition from the hospital to home care left caregivers feeling unconfident, most of them sought support from health professionals and from their external social network. Some caregivers received formal instruction from healthcare professionals on how to care for a PEG tube, mucositis and wound dressing, while others relied on trial and error or observation. The current study showed that most caregivers had a positive experience with health professionals, and having external support, such as friends and families, helped them adjust to becoming caregivers. During the interviews, most of the participants expressed appreciation towards nurses, dietitians, speech therapists and the oncology team. This could be because the study participants were recruited from one of the best hospitals that provide cancer care to patients.

Studies have also suggested that the socioeconomic status of caregivers and the availability of support from health professionals can influence caregivers' ability to cope with the caregiving burden (Adejoh et al., 2021; Ochoa et al., 2020). However, a few caregivers in this study described the need for more information about HNC, treatments and associated side effects to prepare them better as caregivers. Some of the caregivers still struggled with the post-treatment side effects. For example, a few participants felt inadequate in managing the patient’s pain, while a few of them did not fully understand the extent and the nature of surgical interventions and their consequences. The participants experienced dissonance between expectations and reality of treatment consequences. These findings on managing unpredictable care are in line with a previous study describing the tasks and difficulties of caregivers of someone with oral cancer (Liang et al., 2019). The caregivers in the current study also highlighted that it was difficult to remember all the information given during the initial medical consultations as the caregivers often felt overwhelmed by the cancer diagnosis. These findings are in line with previous studies that reported that caregivers needed more time to absorb and understand a large amount of information provided at the time of patient diagnosis (Chen, 2014; Fronczek, 2015; Wang et al., 2021) Caregivers’ information needs vary along the cancer journey, and they use different sources of information to meet their knowledge needs (Chen, 2014).

5.5 AREAS FOR IMPROVEMENT IN HEAD AND NECK CANCER CARE

This study identified areas for improvement in HNC care. Overall, the participants had a positive experience with the health services offered by the patient’s HNC team. The participants described the health professionals involved in the care as “*amazing*”, “*very helpful*” and “*wonderful*”. During the interviews, the participants were asked: What would have helped you in caring for someone with HNC? Their responses revealed three primary areas in which future practices could be enhanced to better support caregivers.

5.5.1 Providing information on managing treatment side effects

The participants described how it would have been helpful for them to have more information about managing treatment side effects, as some of them felt unprepared to manage them at home. Informal caregivers often encounter challenges in managing the side effects of HNC treatments (Langegård et al., 2023). Studies have shown that acute toxicities of HNC treatments, such as dermatitis, mucositis, xerostomia, weight loss and dysphagia, may continue for months or a few years after completion of therapy (Vashistha et al., 2024). Some side effects may last longer than caregivers expected or can become permanent after treatment completion. For example, patients can experience a permanent loss of saliva, osteoradionecrosis, necrosis of the oral cavity, and other complications such as dental caries and chronic sinusitis, especially in patients treated for nasopharyngeal cancer (Brook, 2020). A study has shown that caregivers need more support, particularly during treatment phases when side effects are most pronounced (Wang et al., 2021). Caregivers often demonstrate a high level of informational need regarding their caregiving role and managing patient symptoms (Longacre et al., 2015). Therefore, caregivers should be not only informed of the potential side effects but also educated with the necessary skills for when symptoms arise.

5.5.2 The importance of peer support among caregivers

Some participants in the current study expressed a desire to meet with other HNC caregivers if given the opportunity to share their experiences with one another. Peer support was seen as a vital resource for sharing experiences, coping strategies and emotional encouragement. Additionally, some participants reflected on the emotional isolation they felt, even when surrounded by supportive friends and family. These findings are in line with previous studies, which frequently reported caregivers' feelings of isolation and the need for understanding from others who have faced similar situations (van Hof et al., 2022; Zeng et al., 2023). It is suggested that sharing experiences among caregivers can foster a sense of community and provide practical strategies for coping with the demands of caregiving (van Hof et al., 2022). Caregivers often encounter barriers such as a lack of informational resources and a support network (Wang et al., 2021). Engaging with others who share similar experiences can help overcome these challenges by providing emotional and practical support (Abolfazl Akbari et al., 2020).

5.5.3 Regular check-ins with the healthcare team

Some participants from the current study also suggested that they would like to check in with health professionals regularly after the patient's treatment is completed. They suggested that regular check-ins could offer opportunities to ask questions, receive updates and address emerging concerns throughout the cancer trajectory. Evidence has shown that caregivers often feel neglected by healthcare providers and may struggle with caregiving responsibilities without professional guidance, particularly during the transition from hospital to home (Chase et al., 2021; Longacre et al., 2015). The caregivers of HNC patients often continue to experience supportive care needs even two years after treatment completion (van Hof et al., 2023). Regular caregiver check-ins can enhance communication between healthcare teams and caregivers, facilitating the early identification of caregiver distress and unmet needs

(Petricone-Westwood et al., 2021). By echoing the concerns raised in previous research, this study adds to the growing body of evidence that incorporating caregiver check-ins as part of standard oncology care may enhance both caregiver and patient outcomes.

5.6 CLINICAL IMPLICATIONS

The role of nurses, doctors and allied health professionals in supporting patients with HNC and their informal caregivers is critical, as evidenced by the participants' positive experiences in this study. In Australia, the optimal care pathway for people with HNC provides the standard of care that should be available to all patients with HNC. It also offers guidance and support to health professionals and service providers for optimal care at each stage of the patient's disease (Cancer Council Victoria, & Department of Health Victoria, 2021). Given that HNC is a shared life-changing experience for both patients and their caregivers, integrating caregivers into the care pathway may provide more comprehensive and holistic support for them. Generally, patients have access to a large amount of resources. However, Rogers and colleagues argued that these resources are not readily available to caregivers (Rogers et al., 2024) According to their study, caregivers can find it challenging to articulate their feelings during medical consultations; they are not the ones directly facing HNC and often prefer to remain in the background (Rogers et al., 2024).

The present study has shown that HNC is a shared experience, and it changes many aspects of the lives of both patients and caregivers. The impact of treatments can last for years and, sometimes, the consequences of HNC can be permanent. Therefore, it is important to provide ongoing support for both patients and their caregivers. Despite the growing interest in caring for cancer survivors, a review of survivorship programs found that caregivers are usually not included in these programs, and little is known about the outcomes of such programs (Elizondo Rodriguez et al., 2022). The Australian Cancer Survivorship Centre, in collaboration with the Peter MacCallum Cancer Centre, has initiated a program to provide personalised survivorship care plans tailored to the specific cancer treatment history of each cancer survivor. The care plan includes details about possible short- and long-term effects of treatments, psychosocial effects and well-being recommendations (Australian Cancer Survivorship Centre, 2025). However, this type of care plan is not available for the HNC population. Long-term survivorship support should include caregivers because the ripple effect of HNC extends beyond the person who is diagnosed. It also affects the caregiver’s well-being, and the caregiver’s needs can change over time (Kim et al., 2020). It would be beneficial for caregivers of individuals with HNC to have access to a tailored long-term care plan, which can promote their well-being.

Cancer has become understood as a shared experience, and this understanding is supported by a growing body of research around cancer support and some theoretical frameworks that focus on the interdependent nature of cancer experiences (Ludwig & Banner, 2022; Milbury et al., 2019; Sterba et al., 2016; Titelman, 1998). The Family Systems Theory by Bowen offers a useful perspective on how cancer can impact the entire family (Titelman, 1998). This theory explains that family members are emotionally related. A significant event, such as a cancer diagnosis, can disrupt the family dynamic, resulting in shared emotional and physical experiences (Titelman, 1998). Therefore, health professionals can view caregivers as co-partners in HNC management and offer them adequate support and education programs relevant to their needs.

Providing caregiver education and support is crucial for nurses to empower caregivers, improve patient outcomes and alleviate caregiver strain. Nurses can enhance caregiving skills by applying evidence-based interventions (Loerzel et al., 2014; Wang et al., 2023). It was evident in the current study that nurses play a vital role in delivering and reinforcing skills to enhance caregivers' ability to manage complex cancer caregiving tasks. Education enables caregivers to manage daily caregiving tasks more effectively, from wound care to feeding support, while preparing them for potential changes in the patient's condition (Sak-Dankosky et al., 2022). With better preparation, caregivers can adapt their role more confidently, alleviating the anxiety and stress that often accompany such responsibilities (Lai et al., 2019).

Supportive interventions, such as structured training, counselling or peer support programs, can equip caregivers with coping strategies and resources to manage the emotional demands of caregiving in the field of cancer care (Jabaley et al., 2020; Lewis et al., 2022). These interventions can be more effective when conceptualised through the lens of Social Support Theory (Cohen & Wills, 1985). According to this theory, social support can minimise the negative effects of stress and enhance psychological well-being of individuals. The theory identifies different types of support, such as emotional, informational, and instrumental (Cohen & Wills, 1985). Each support plays a critical role in helping caregivers navigate complex and emotionally taxing situations. For example, emotional support can foster the caregivers a sense of belonging and validation, informational support can provide guidance and knowledge about HNC, and instrumental support can offer them practical help, including guiding them how to prepare meal, showing them how to do a wound dressing and tube feeding for someone with HNC. By facilitating access to these forms of support, nurses can cultivate a holistic and nurturing environment that not only meets the clinical needs of patients but also addresses the psychosocial and emotional needs of caregivers, ultimately improving outcomes for both. This approach can improve caregivers' well-being and strengthen their ability to provide consistent, high-quality care, ultimately benefiting patient outcomes. By routinely assessing caregivers' needs and implementing supportive interventions, nurses can bridge the gap between informal and formal care, ensuring that caregivers receive the guidance necessary to fulfil their roles effectively (Sak-Dankosky et al., 2022; Wang et al., 2021).

Recently, the Australian Cancer Nursing and Navigation Program (ACNNP) was initiated by Cancer Council Australia to provide support for cancer patients, their families and caregivers through a digital platform (Department of Health, 2025) . The ACNNP offers guidance on accessing services, understanding treatment options, and managing the emotional and practical aspects of cancer care. Patients and their families can contact the hotline or participate in a live chat when support is needed (Department of Health, 2025). It is important to raise awareness among nurses about programs like the ACNNP to ensure they can effectively refer patients and integrate these resources into care planning.

Offering the interventions in multiple delivery formats may enhance accessibility for caregivers (Griffin et al., 2014). For example, a pilot study on a Qigong mind body program for cancer caregivers demonstrated the feasibility and acceptability of delivering the intervention through both community-based and internet-based formats. This approach allowed caregivers to choose the modality that best suited their individual needs and circumstances, highlighting the value of adaptable delivery methods in enhancing caregiver engagement and participation (Shani et al., 2021). Additionally, an intervention for carers of patients with advanced lung cancer, named CareSTEPS (Self-Care, Stress management, Symptom management, Effective communication, Problem-solving and Social support), was designed to enhance psychological functioning and alleviate carer burden. The carers received a manual containing information on self-care, stress management, symptom management, communication and problem-solving skills. They also received psychoeducation and skill training via telephone for six weeks. The study demonstrated a notable enhancement in carers' psychological functioning and decreased burden (Rangel et al., 2024). It is important to note that providing supportive interventions for caregivers has transitioned from in-person to telehealth, e-health or mobile health formats due to advancements in information technology. Previous literature reviews have demonstrated that adopting technology-mediated interventions to facilitate convenient access to supportive resources is feasible and acceptable (Molassiotis & Wang, 2022). These interventions can enhance the interaction between caregivers and the healthcare team, reduce decision-making, improve personal well-being, and foster a more intimate relationship and communication with cancer patients

(Cox et al., 2017; Luo et al., 2020; Nguyen, Mason, et al., 2023). A study indicated that a nurse-led phone follow-up for advanced cancer patients in early palliative care could enhance their treatment experience (Valenti et al., 2023). This approach could help patients and families improve their quality of life and symptom control, while securing prompt care without travel or cost. It could also enhance continuity, oncological therapy adherence and acute care visits (Valenti et al., 2023). The integration of technology into carer support offers numerous advantages. Nevertheless, disparities in technological access, such as advanced age and low socioeconomic level, must be acknowledged as they can be barriers to implementing these supportive interventions successfully (Lin et al., 2025; Reddick et al., 2024).

Awareness of caregivers' experiences and their support needs should be raised among healthcare professionals. As nurses are a valuable resource for patients with cancer and their families, it is important for nurses to stay updated with available resources and support programs that enable them to provide holistic care to patients' informal caregivers. This can be achieved by a range of strategies. In Canada, nurses were offered continuing education to enable them to keep pace with the complexity of cancer care. The ongoing training for oncology nurses involved online learning, which provided up-to-date information about cancer care and resources. The training also involved a professional support and mentorship program to support the nurses' professional development (Esplen et al., 2018). Regular networking with other nurses and knowledge-sharing can be useful to improve overall cancer care (Kuck & Rosselli, 2022).

An ongoing assessment of caregivers' needs may contribute to enhancing the care and management of patients with HNC, and it is essential to identify the concerns of caregivers promptly. Telephone follow-up by nurses in cancer care has emerged as an important strategy for improving patient and family support. Studies have shown that nurse-led telephone interventions can effectively meet the requirements of cancer patients and their caregivers, particularly in terms of psychological support and information (Bouleftour et al., 2021; Valenti et al., 2023).

While professional healthcare support is essential in the management of HNC, sustainable community-based and peer-support initiatives should also be considered, given that many caregivers continue their roles well beyond the completion of formal treatment. Evidence highlights the importance of non-clinical support that complements medical care by addressing the emotional, social, and practical needs of survivors, caregivers, and their families. Interventions such as support groups, counselling, educational programs, creative activities, and wellness initiatives help ensure that individuals affected by cancer do not face their journey alone (Kolambel, 2025). Patient Advocacy Groups (PAGs) are also an important source of support for patients with cancer and their caregivers (Dave et al., 2024). PAGs often provide educational resources, helping patients and caregivers better understand diagnoses, treatment options, and side effects, which empowers them to make informed decisions. They also offer emotional and peer support, connecting individuals with others who share similar experiences, thereby reducing feelings of isolation and anxiety (Yan et al., 2020). By filling critical gaps in care and fostering a sense of community, these services can enhance quality of life, promote resilience, and offer a model for integrating holistic, person-centered support into the cancer care continuum (Dockham et al., 2016).

5.7 STRENGTHS AND LIMITATIONS OF STUDY

The use of interpretive inquiry provided a means to gain a deeper insight into the experiences of caregivers of individuals with HNC in Australia, to identify their needs. One-on-one interviews with participants allowed them to express their thoughts in their own words, leading to a rich understanding of their caregiving journey. By including caregivers of individuals diagnosed with various types of HNC, encompassing both male and female caregivers from metropolitan and regional areas, this study captured a diverse range of caregiving experiences. This broader representation contributes to a more comprehensive understanding of the challenges and needs faced by caregivers across different contexts.

This study has a few limitations. One methodological limitation identified in this study was the use of telephone interviews for data collection. The absence of visual cues may have limited the researcher’s ability to observe participants’ non-verbal communication, such as facial expressions and body language, which can provide important contextual and emotional information. In addition, all the patients with HNC in this study had identified caregivers. The caregivers in this study predominantly belonged to a middle socioeconomic background. The patients received care from one of the best cancer institutes in a metropolitan area of NSW, Australia. This lack of socioeconomic diversity in the current findings may not be transferable to populations with different cultural or socioeconomic backgrounds or different healthcare systems. Additionally, the study was unable to recruit caregivers who did not speak English, limiting the cultural and linguistic diversity of the sample. Most participants also demonstrated relatively good levels of health literacy, which may have influenced their caregiving experiences and access to support. Consequently, the perspectives captured in this study may differ from those of caregivers with lower health literacy or from more diverse backgrounds.

5.8 RECOMMENDATIONS FOR FUTURE RESEARCH

Based on the research findings, future research should consider the following recommendations:

- Future research should include participants with non-English speaking backgrounds, and participants from different cultural, socioeconomic and healthcare contexts.
- Researchers should explore possible caregiver-specific interventions to build capacity in the multiple roles that caregivers must perform in assisting patients with HNC.
- Future studies can also examine the experiences of HNC patients who do not have an identified caregiver; understanding how these individuals navigate the healthcare system and manage the demands of treatment alone could inform the development of targeted support strategies for this often-overlooked group.
- For improving future practice, how cancer nurse specialists collaborate with other healthcare professionals and how this teamwork enhances the patient and caregiver experience can be further explored.

5.9 CONCLUSION

This doctoral study provides insight into how caregivers of individuals with HNC experience caregiving. Interpreting caregivers’ accounts of their experiences reveals how they share these experiences with patients and how their lives have changed as a result. The findings contribute to a growing body of literature on person-centred care, and suggest that caregivers should also be included in this care model, as cancer is a shared experience. Additionally, this study makes several notable contributions to nursing practice and educational development. The findings lay a foundation for developing supportive interventions that address the needs of caregivers of individuals with HNC. Finally, the combined findings from this and previous studies offer direction for healthcare practices and the implementation of ongoing social and professional support programs for caregivers, enabling them to better manage their caregiving roles without neglecting their own psychosocial needs.

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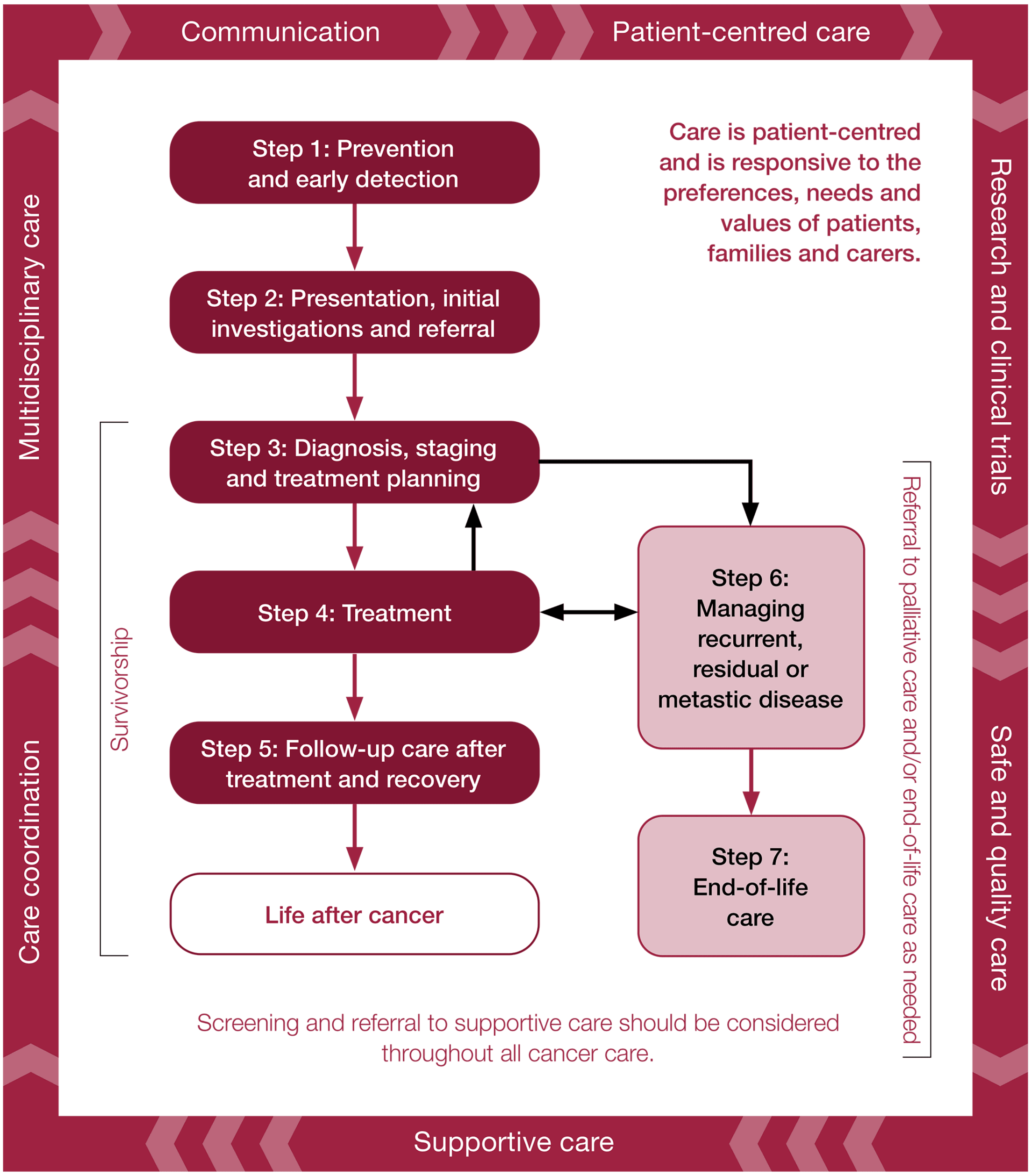
Appendices

Appendix A. Optimal care pathway



Source: Cancer Council Victoria & Department of Health Victoria. (2021). *Optimal care pathway for people with head and neck cancer* (2nd ed.). Cancer Council Victoria. https://www.cancer.org.au/assets/pdf/head-and-neck-cancer-2nd-edition

Appendix B. Publication

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The Experiences and the Needs of Caregivers of Patients With Head and Neck Cancer

An Integrative Review

KEYWORDS
Caregivers
Carers
Experiences
Families
Head and neck cancer
Literature review
Support needs

Background: Head and neck cancer (HNC) is a devastating disease, and its corresponding treatments can result in substantial functional challenges for patients. These patients require a considerable amount of care, and the tasks of caregiving can be challenging for the caregivers. To date, there is no published literature review on the experiences and the needs of caregivers of patients with HNC. **Objective:** To synthesize the literature on the experiences and needs of caregivers of patients with HNC in order to inform the development of an educational intervention for the caregivers. **Methods:** An integrative literature review was conducted to examine the current knowledge about the experiences and needs of caregivers of patients with HNC. A systematic literature search strategy was conducted in CINAHL, MEDLINE, PsycINFO, and Scopus. The dominant or recurrent themes were identified using thematic synthesis. **Results:** Twenty studies met the inclusion criteria. Three central themes were identified. These were the following: disruption to daily life, the impact of caregiving, and the availability of information and support. **Conclusions:** Head and neck cancer affects the caregivers' lives physically, psychosocially, and financially. Caregivers identified the need for informational, financial, and educational support on an ongoing basis in assisting their loved ones with HNC. **Implications for Practice:** Ongoing assessment of caregivers' support needs may contribute to enhancing the care and management of patients with HNC and is

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essential to promptly identify the concerns of caregivers. Clinicians should view the caregivers as copartners in HNC management and offer adequate support and education programs relevant to their needs.

Head and neck cancer (HNC) is a group of malignant conditions that occur in/on the lips, mouth, pharynx (which includes the nasopharynx, oropharynx, and hypopharynx), larynx, salivary glands, paranasal sinuses and skin, soft tissues, and bones of the head and neck.[1] Each year, approximately 52 140 new cases of cancer of the oral cavity, pharynx, and larynx, which comprise most head and neck squamous cell carcinomas, are diagnosed in the United States.[2] In Australia, HNC was the seventh most commonly diagnosed cancer in 2017.[3]

Several risk factors have been associated with the development of HNC. Heavy alcohol intake and smoking are well-known risk factors and are more common in populations with lower health literacy and socioeconomic resources.[4] Other risk factors identified worldwide include chewing betel leaves that contain additives such as slake lime in Southeast Asia, drinking mate in South America,[5] eating large amounts of preserved or salted food in childhood, poor oral hygiene, occupational exposure to substances such as asbestos, and synthetic turare caused by alcohol and tobacco use.[1] More recently, there has been an increase in the number of women and younger adults who are nonsmokers being diagnosed with HNC; this increase is attributed to the human papillomavirus.[1]

Treatments offered to patients with HNC can include a combination of chemotherapy, radiation, and surgery. The treatment choices are dependent on the stage and location of the cancer. Generally, surgery is considered the first-line salvage treatment for recurrences that are resectable with the exception of conditions associated with potentially high complication rates such as fibrosis and scarring from previous treatment.[6]

Head and neck cancer and its corresponding treatments can result in substantial functional challenges for patients. Deficits in speech and swallowing are both highly prevalent and considerably limiting for this population.[7] If surgery is the treatment of choice, patients may lose parts of their face and experience postoperative neck-shoulder dysfunction or trismus, visible scarring, and changes in ability to make a facial expression.[8] The recovery time for surgery is dependent on individual circumstance, but can take weeks to months to recover function. Radiation can also cause disfigurement and changes in skin color, skin tissue, and its elasticity.[1] Patients often need to have teeth extracted prior to having radiation,[9] again leading to aesthetic and functional alterations.

The persistence of symptoms and treatment adverse effects will vary depending on each person's situation, complications, and healing process. Some patients who are treated with chemotherapy or radiation therapy may experience short-term adverse effects such as the inability to eat solid foods due to mucositis. Skin rash and burning, osteoradionecrosis, and problems with mucous secretions may also occur. Furthermore, some patients may encounter long-term residual adverse effects such as permanent xerostomia and accompanying complications such as dental caries.[8]

Beyond these visible changes, HNC and the adverse effects of the treatments can disrupt the core functions of a patient's daily life, such as ability to eat, speak, and interact with others; breathing; and the ability to move the neck, shoulder/s, or arm/s. As such, the patient with HNC bears a significant physical and psychological burden.[9] The physical and functional changes related to HNC can represent a significant loss for patients, with many describing a sense of losing who they are as a person.[10]

Caregivers are essential members of the HNC survivor's support team, providing essential practical care and psychological support throughout the illness trajectory. This caregiver may be a spouse, a partner, a child, another relative, or in some cases a friend. The caregiver often plays an important role in the care of the patient with HNC; the value of caregiving should not be underestimated. Because of the complexity of cancer treatment and the increased demand for care provision in the outpatient and home setting, the role of caregivers has gained prominence.[11] The physical care that caregivers of patients with HNC may be required to perform includes tracheostomy care, pain management, wound dressings, management of drainage systems, enteral feeding, and dysphagia management.[12] Appropriate training and education by health professionals are necessary to enable caregivers to perform these tasks competently. It is also essential to ensure that the caregivers are involved in care planning so that they are prepared for the role, which may represent significant contribution in patients' care.[13]

The role of the caregivers, readiness to be a caregiver, and their concerns are poorly documented and underappreciated by healthcare providers. A comprehensive understanding of caregivers' experiences and support needs is required. However, to date, this has not been fully explored among HNC caregivers. Thus, a literature review was undertaken to synthesize the findings from the research studies published in peer-reviewed journals to identify the experiences and the support needs of caregivers of patients with HNC. We also aimed to reveal knowledge gaps about this topic and in doing so identify further areas for research. The question that informed this literature review was: What are the experiences and the support needs of caregivers of patients with HNC?

■ Methods

An integrative review of published studies concerning caregivers' experiences and support needs was undertaken as it allows for various primary research methods to be summarized to provide a more comprehensive understanding of a particular problem.[14] An integrative review adopts a 5-stage approach to the review process, namely, (1) identification of the research problem, (2) searching the literature, (3) evaluation of the data, (4) analysis of the data, and (5) presentation of the results.[14]

A systematic literature search guided by the PRISMA framework[15] was undertaken in April 2018 for this review. With the assistance of a librarian at the University of Sydney, the following databases were searched: CINAHL, MEDLINE, PsycINFO, and Scopus. Search terms such as “head and neck cancer,” “head and neck neoplasms,” caregiver/s, carer/s, family, family member/s, experience/s, need/s and support/s were used. Other related terms such as facial cancer, oral cancer, laryngeal cancer, thyroid cancer, and tracheal cancer were also used when searching the PsycINFO database to maximize the identification of relevant articles. Medical Subject Headings and free search terms were combined to enhance the search. The search was limited to research studies published in peer-reviewed journals from 2008 to 2018 due to recent advances in treatments with a reduction in surgery volume, changes to the delivery of radiotherapy, and interventions to improve voice and swallowing functions.[16] The experiences and the support needs of the caregivers of patients with HNC prior to this time may have been different. The search was also limited to studies published in the English language. Reference lists from the studies that were identified via electronic search were also searched to maximize search results. This search strategy is detailed in Table 1.

The original database search located 45 studies in CINAHL, 54 studies in MEDLINE, 26 studies in PsycINFO, and 39 studies in Scopus. Six studies were identified by hand searching, resulting in a total of 194 studies. First, duplicates were removed and titles, and abstracts were then reviewed based on the inclusion and exclusion criteria (Table 2). Studies were then retrieved on the basis of topic relevance and depth of information related to the research question. Original studies were included regardless of the theoretical approach, the process of data collection, or method of analysis. Few studies focused on the caregivers exclusively. Some of the studies focused on both caregivers and patients. As long as caregivers’ views were included, the studies were eligible. Three researchers independently reviewed the studies identified. Any discrepancies between the researchers were resolved through discussion until consensus was reached. After the application of inclusion and exclusion criteria, a total of 20 studies were included in the literature review. A depiction of the search strategy using the PRISMA flow diagram is presented in the Figure.

For this review, studies were divided into quantitative studies, qualitative studies, and mixed-methods study design. The Critical Appraisal Skills Programme evaluation checklist for cohort studies was applied to assess the quantitative studies[17] (Table 3), while a critical appraisal of qualitative studies was performed using 10 questions from the Critical Appraisal Skills Programme qualitative checklist[26] (Table 4). A Mixed-Method Appraisal Tool was used for the mixed-methods study[38] (Table 5). These appraisal checklists and tools are made up of a series of questions that enabled the researcher to acquire a deeper understanding and appreciation of the rigor or trustworthiness of the published studies necessary for making a judgment about their quality for inclusion in the review. The limitation identified in some of the quantitative studies reviewed was inadequate sample size. For example, there were only 59 caregivers in the study of Longacre et al[19] and 40 caregivers in the study of Hiremath et al,[22] which may limit the generalizability of the findings. Notably, in the majority of the qualitative studies, there was a lack of discussion regarding the relationship between researchers and participants. Subsequently, the influence of potential bias cannot be determined. Despite these limitations, the overall study strengths outweighed their weaknesses, and the decision was made not to exclude any from the review. This resulted in 20 studies being included in the review.

The literature review aimed to extract and synthesize study findings related to the review question regarding the experiences of caregivers of patients with HNC. The review question served as a framework for thematic analysis in accordance with the method of thematic analysis described by Thomas and Harden.[39] First,

Table 1 • Database Search Strategy

Name of the Database	Platform	Total No. of Search Results From the Database	Search Strategy
CINAHL	EBSCOhost	45	“Head and Neck Neoplasms+” OR “head and neck cancer” AND Caregivers OR caregiver* OR carer* OR Family+ OR “family member*” AND Life Experiences+ OR experience* AND Health Services Needs and Demand+ OR Information Needs OR need* OR Support, Psychosocial+ OR Nutritional Support+ OR support* Limit: 2008 to current, English
MEDLINE	OvidSP	54	exp “Head and Neck Neoplasms” OR “head and neck cancer” AND exp Caregivers OR caregiver* OR carer* OR exp Family OR “family member*” AND experience* AND exp “Health Services Needs and Demand” OR exp Psychosocial Support Systems OR exp Social Support OR exp Nutritional Support OR exp Financial Support OR support* OR need* Limit: 2008 to current, English
PsycINFO	OvidSP	26	“head and neck cancer” OR “facial cancer” OR “oral cancer” OR “laryngeal cancer” OR “thyroid cancer” OR “tracheal cancer” AND exp Caregivers OR caregiver* OR carer* OR exp Family OR “family member*” AND experience* AND exp Health Service Needs OR exp Psychological Needs OR exp Needs OR exp Support Groups OR exp social Support OR need* OR support* Limit: 2008 to current, English
Scopus		39	ABS (“head and neck cancer” OR “facial cancer” OR “oral cancer” OR “laryngeal cancer” OR “thyroid cancer” OR “tracheal cancer”) AND ABS (caregiver* OR “family member*” OR carer*) AND ABS (experience*) AND ABS (need* OR support*) Limit: 2008 to current, English

Table 2 • Study Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Published in English language	Published in language other than English
Relevant primary research study	Articles other than relevant primary research articles (eg, review papers, editorials, dissertations, conference abstracts, commentaries, discussion papers, irrelevant topics and interventional studies)
Related to caregivers of patient with head and neck cancer only	Related to caregivers of patient with other types of cancer or related to only patient with head and neck cancer
No restrictions of research method	Interventional study

studies were categorized according to whether they employed a quantitative, qualitative, or mixed-methods study. The findings relevant to the review questions in each article were then extracted. The authors then read and reread the extracted data to become familiar with it. Each line of the text was coded according to its meaning and content. The codes were compared for differences and similarities and then grouped into categories. The patterns and relationship between the categories were then analyzed and collated into themes. Each of the codes and categories was discussed among the authors to determine the consistency of interpretation. Finally, findings were summarized under thematic headings that were agreed on by the 3 researchers.

■ Results

Overview

The studies originated from the United States (n = 2), the UK (n = 8), Australia (n = 2), the Netherlands (n = 1), Taiwan (n = 2), and Sweden (n = 2). One study each was also conducted in

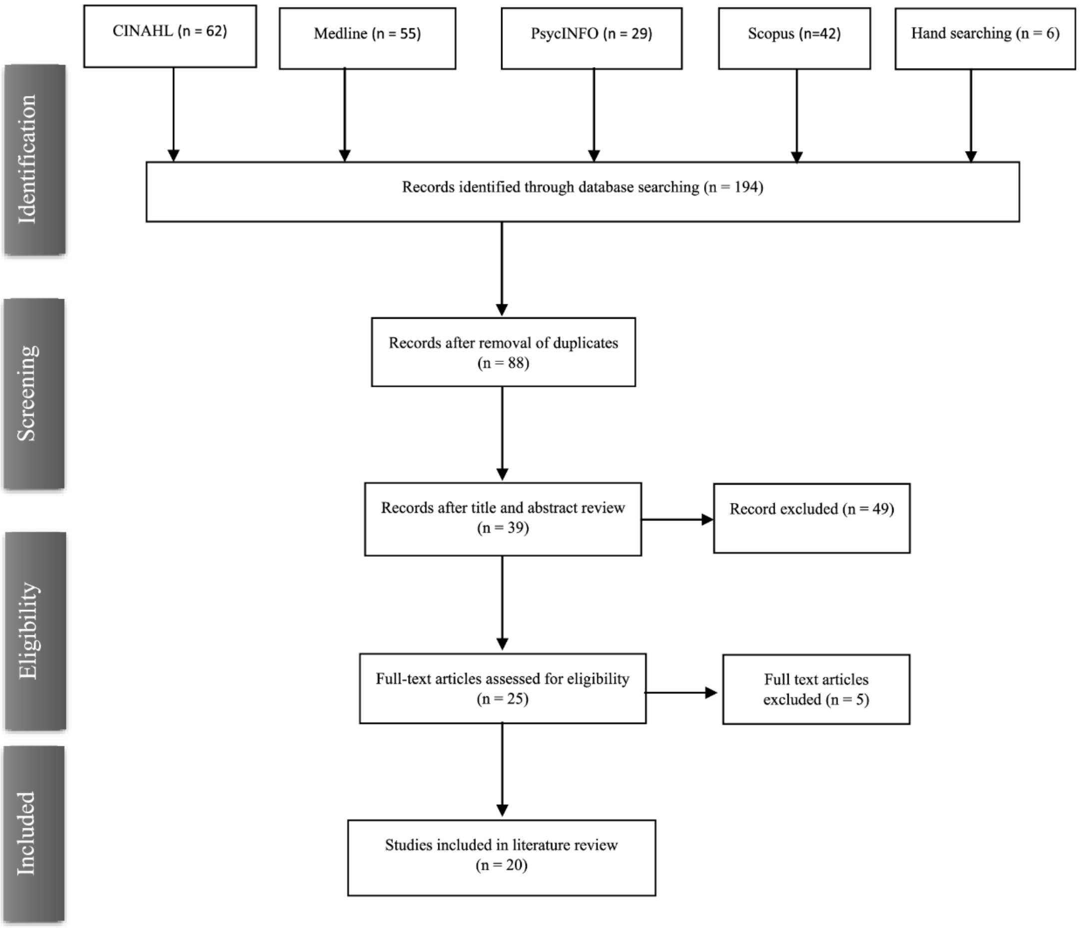

Figure ■ PRISMA flow diagram.

Table 3 • Critical Appraisal Skill Program Cohort Study Checklist

Screening Question	Checklist	Chen et al,[18] 2009	Longacre et al,[19] 2015	Offerman et al,[20] 2015	Balfe et al,[21] 2016	Hiremath et al,[22] 2017	Patterson et al,[23] 2013	Hanly et al,[24] 2016	Hung et al,[25] 2013
A. Are the results of the study valid?	1. Did the study address a clearly focused issue?	Y	Y	Y	Y	Y	Y	Y	Y
	2. Did the authors use an appropriate method to answer their question?	Y	Y	Y	Y	Y	Y	Y	Y
Detailed questions	3. Was the cohort recruited in an acceptable way?	Y	Y	Y	Y	Y	Y	Y	Y
	4. Was the exposure accurately measured to minimize bias?	Y	Y	Y	Y	Y	Y	Y	Y
	5. Was the outcome accurately measured to minimize bias?	Y	Y	Y	Y	Y	Y	Y	Y
	6a. Have the authors identified all important confounding factors?	X	X	X	Y	X	X	X	X
	6b. Have they taken account of the confounding factors in the design and/or analysis?	X	X	X	X	X	X	X	X
	7a. Was the follow-up of subjects complete enough?	X	X	X	X	X	X	X	X
	7b. Was the follow-up of subjects long enough?	X	X	X	X	X	X	X	X
B. What are the results?	8. What are the results of this study?	Y	Y	Y	Y	Y	Y	Y	Y
	9. How precise are the results?	Y	Y	Y	Y	Y	Y	Y	Y
	10. Do you believe the results?	Y	Y	Y	Y	Y	Y	Y	Y
C. Will the results help me locally?	11. Can the results be applied to the local population?	Y	Y	Y	Y	Y	Y	Y	Y
	12. Do the results of this study fit with other available evidence?	Y	Y	Y	Y	Y	Y	Y	Y

Abbreviations: X, not reported; Y, reported.

Thailand, India, and Canada. The studies addressed the experiences and the support needs of caregivers of HNC patients with a variety of research aims and methods. Whereas 7 studies used a quantitative approach, 12 studies used a qualitative study design, and 1 study used mixed methods. Caregivers in the studies were spouses, partners, relatives, family members, children, or friends of the patients.

The focus of 16 of the studies reviewed was solely caregivers of patients with HNC, whereas four studies included views from both caregivers and patients. The majority of the participants in 19 studies were females with the exception of 1 study that included more males than female participants (15 females, 127 males).[25] A summary of the key characteristics of the included studies is presented in Table 6. Three central themes that emerged from this literature review were identified concerning the experiences and the support needs of caregivers of patients with HNC. These were disruption to daily life, the impact of caregiving, and the availability of information and support.

Disruption to Daily Life

The caregivers experienced disruption to their daily lives as the diagnosis and treatment of HNC created changes in daily routines, as well as a shift in roles and responsibilities between the patient and the caregiver. Kitrungrote and colleagues[27] used a phenomenology approach to study the experiences of caregivers of a spouse with HNC undergoing radiation therapy in Thailand. By interviewing 15 spouses, it was found that the caregivers experienced challenges with new daily adjustments as a result of caregiving.[27] These included difficulties with new living arrangements and restrictions on their social life. Similar to Kitrungrote and colleagues,[27] Röing et al[28] interviewed 7 spousal caregivers to explore how treatment for oral cancer affected their lives. Experiences reported by the caregivers included disruptions to their meal patterns as they had to make changes in their cooking styles and meal routine to accommodate the needs of the patient. While Kitrungrote et al[27] and Röing et al[28] took a qualitative approach, Patterson and colleagues[23] used a mixed-methods study design to explore the quality of life of caregivers of a patient with dysphagia. Their findings also revealed that the caregivers experienced disruptions to their normal mealtime because they modified their diets in response to the swallowing difficulties experienced by those for whom they were caring.[23] Disruption in relation to the lifestyle and meal patterns were commonly reported in the studies reviewed.[23,28,36] For example, caregivers reported disruptions to activities previously undertaken such as eating in restaurants, attending social functions, traveling together, and going out in public with relatives or friends.[36]

Disruption to the daily life of the caregivers also involved changes in their roles and duties. As the patient's ability to perform his/her daily routine became limited, extra roles were expected from

Table 4 • Critical Appraisal Skills Program Qualitative Research Checklist

Screening Question	Kitrungrote et al,[27] 2008	Röing et al,[28] 2008	Mayre-Chilton et al,[29] 2011	Nund et al,[30] 2014	Schaller et al,[31] 2014	Fronczek,[32] 2015	Nund et al,[33] 2015	Taylor et al,[34] 2016	Balfe et al,[35] 2017	Penner et al,[36] 2012	Balfe et al,[21] 2016	Balfe et al,[37] 2017
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5. Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Has the relationship between researcher and participants been adequately considered?	X	X	X	X	X	X	X	X	X	X	X	X
7. Have ethical issues been taken into consideration?	Y	Y	Y	X	Y	Y	Y	Y	Y	Y	Y	Y
8. Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9. Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10. How valuable is the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Abbreviations: X, answer not available; Y, reported.

caregivers, and they often undertook multiple roles simultaneously. Examples included taking care of the children, handling daily house chores, and maintaining employment commitments while taking on the caregiver role.[32,36] With such a disruption in daily life, the caregivers experienced uncertainty with their future lives due to difficulties adjusting to those disruptions.[27]

The Impact of Caregiving

The act of caregiving can impact caregivers in multiple domains of their lives: psychological, physical, social and financial. These impacts are interrelated to each other and have the potential to distress the caregivers as much as cancer itself. Several studies reported that caregivers experienced a range of distressing psychological effects such as anger, stress, fear, worry, and guilt.[22,30,32,36] Balfe et al[21] interviewed 31 long-term caregivers (>1 year postdiagnosis) to explore the triggers of their emotional distress. Findings indicated that the fear of illness, lifestyle restrictions, competing demands, facial disfigurement of the patient, financial problems, comorbid health problems, and witnessing the patient's suffering were the key triggers of emotional distress among long-term caregivers.[21] As reported by Nund and colleagues,[33] the caregivers also experienced stress and feelings of helplessness related to meal preparation as they were inadequately prepared to manage a patient with dysphagia. The caregivers also often felt unprepared and anxious about assisting the patient with a feeding tube.[36]

Another qualitative study involving 6 caregivers from Canada reported that emotional distress could result in physical exhaustion.[36] The effort required by caregivers to take care of their loved ones often led to their own health becoming neglected.[27] This finding had also been described by Röing and colleagues,[28] who found that the caregivers put their health on hold when dealing with their partner's sickness and treatments, which became their priority.

Studies also reported that difficulties in communication with the patient and changes that occurred during the mealtime impacted the social relationship between the caregivers and their patients.[30,33,36] Offerman and colleagues[20] conducted a cross-sectional study to explore the long-term impact of a total laryngectomy on the relationship between the patients who had the laryngectomy and the partners. Findings suggested that there was a significant impact on social life and sexual relationships between the patient and the partner. Another study was conducted by Mayre-Chilton and colleagues[29] in which 3 caregivers and 6 patients with HNC were interviewed with the aim of understanding the experiences of gastrostomy tube feeding. Their study found that the caregivers had negative feelings and perceptions toward intimacy and sexuality when the patients required long-term gastrostomy.

Financial hardship was another implication for caregivers that was reported in several studies. Financial burden was related to the medical bills, treatment-related expenses,[18,22,29] and treatment-related commuting.[35] Because of the financial difficulties, in some cases, the caregivers and the patient had to wait for the funding to be approved before commencing the treatment.[29] Financial pressures also caused additional worries and anxiety and

Table 5 • Mixed-Method Appraisal Tool

Types of Mixed-Methods Study Components	Methodological Quality Criteria	23
Screening question (for all types)	Are there clear qualitative and quantitative research questions, or a clear mixed-methods question?	Y
	Do the collected data allow address the research question?	Y
Qualitative	1. Are the source of qualitative data relevant to address the research question?	Y
	2. Is the process for analyzing qualitative data relevant to address the research question?	Y
	3. Is appropriate consideration given to how findings relate to the context?	Y
	4. Is appropriate consideration given to how findings relate to researchers' influence?	Y
Quantitative descriptive	1. Is the sampling strategy relevant to address the quantitative research question?	Y
	2. Is the sample representative of the population understudy?	Y
	3. Are measurements appropriate?	Y
	4. Is there an acceptable response rate (60% or above)?	Y
Mixed methods	1. Is the mixed-methods research design relevant to address the qualitative and quantitative aspects of the mixed-methods question?	Y
	2. Is the integration of qualitative and quantitative data relevant to address the research question?	Y
	3. Is appropriate consideration given to the limitations associated with this integration?	Y

Abbreviations: X, answer not available; Y, reported.

prevented the caregivers' ability from doing the best they could for the patient.[35]

Availability of Information and Support

Lack of information about how to care for someone with HNC was reported in several studies. The caregivers described little knowledge about pain and pain management or the indications for and management of feeding tubes.[29,31,36] This lack of information was also identified by Balfe and colleagues,[40] who conducted a cross-sectional study in Ireland involving 197 HNC caregivers. Findings from this study revealed that the need for information about the benefits and adverse effects of treatments was not met.[40]

Studies also reported how the caregivers preferred to receive the information.[19,30,32,34] A phenomenological study of 9 family caregivers was undertaken to develop an understanding of their caregiving experiences.[32] Findings showed that caregivers needed more time to absorb and understand a large amount of information provided at the time of patient diagnosis.[32] The information needs of carers were also a focus of Longacre and colleagues[19] in a survey of 59 caregivers; 76.6% of the caregivers preferred to receive the information from the health professionals, and only 23.4% of the caregivers would go to an informal resource such as the internet or a friend.[19] Unlike Longacre and colleagues' study, Taylor and colleagues[34] used a longitudinal qualitative approach to understand the different types of information needed by patients and caregivers from the diagnosis to the follow-up phase. There was a need for honest and open discussions with the health professionals about the treatment plans and outcomes as the caregivers in their study experienced changes from what had been initially discussed about the patient's treatment outcome.[34] It was also important that information provided was practical, personalized, and delivered in lay terms rather than in medical terms.[30]

The caregivers obtained support from the healthcare networks; however, the caregivers felt that this was only short-term support.[37] Interviews with caregivers of patients who developed speech and hearing difficulties as a result of chemotherapy for HNC found that caregivers did not receive sufficient support to deal with difficulties in communication they now experienced.[33]

The caregivers experienced caregiving burden when the available health services did not meet their needs.[24] Several of the studies included in the review highlighted the importance of holistic care and ongoing support for caregivers. There was also a lack of integrated care as the relatives described a meeting with several specialized health professionals, which often resulted in an inconsistent view of the patient's situation.[31] Some caregivers expressed inadequate contact with and a lack of information from the nurse and the consultant on how to manage posttreatment complications.[32,34] Although the above studies indicated the negative experiences with a various form of supports, caregivers from a study in Taiwan were satisfied with social support provided during the first 3 months after the patient's discharge. In that study, Hung and colleagues[25] studied caregivers' satisfaction with the available social support at 4 times points: before discharge, 1 week, 1 month, and 3 months after discharge and also noted that the caregivers had unmet needs of social support, especially wife caregivers and those caregivers who spent a longer time caring for the patient during the first 3 months postdischarge.

■ Discussion

Despite the diversity in characteristics of study participants' cultural background, the country, age, and gender, this review has identified the experiences and the support needs of caregivers of a patient with HNC. The key issues identified within this review provide health professionals, service providers, policy makers, and educators with broad insights into common elements of caregivers' experiences of a patient with HNC from which potential options for improving their health and well-being can be considered. Like other types of cancer, a diagnosis of HNC disrupts the life of a caregiver as new role and duties arise, and normal living patterns are no longer congruent with changing situations. Such a transition required the caregivers to

Table 6 • Summary of the Key Characteristics of the Included Studies

No.	Author/Year Country	Study Aim/s	Methodology/Design No. of Participants, Gender, Age Group	Key Findings
1	Kitrungrote et al,[27] 2008, Thailand	To describe the experiences of caregivers of spouses with HNC undergoing RT	Hermeneutic phenomenology 15 spousal caregivers Gender: 12 females, 3 males Age: 38–67 y	Caregivers wanted to care and comfort for the spouses. Caregivers suffered from uncertainty of their future lives, the caregiving strain (physical, social, emotional, and financial), and the difficulties with the new living arrangements. Caregivers readjusted themselves by rearranging their life and holding onto hope for a cure and hope for a longer life for their ill spouses. Caregivers felt positive about successful caregiving.
2	Röing et al,[28] 2008, Sweden	To describe oral cancer and its treatment as experienced by the patients' spouses.	Phenomenology 7 spousal caregivers Gender: 3 women, 4 men Age: 35–78 y	The spouse made changes in role as he adopted a caring and supportive role. Thoughts about caregiver's own body and health put on hold as their partner's well-being became first priority. Caregiver adapted their lifestyle and eating habits to meet the needs of their partners.
3	Mayre-Chilton et al,[29] 2011, UK	To understand the views and experiences of gastrostomy tube feeding at home for both HNC patients and their caregivers.	A qualitative study 3 caregivers Gender: 2 female, 1 male Age: 40–70 y (Involved both patient and caregivers)	The lack of knowledge and understanding had an evident negative impact on caregivers. They experienced difficulty in intimacy. They expressed the importance of nutritional support by having a gastrotomy tube and became dependent on the tube. They experienced financial and psychological difficulties that had a negative impact on caregiving.
4	Nund et al,[30] 2014, Australia	To report on the experiences of carers of people with dysphagia (nongastrostomy dependent) following nonsurgical treatment for HNC and to identify the support needs of this group.	Phenomenology 12 carers Gender: 10 females, 2 males Age: 1 > 65 y, 11 < 65 y.	Dysphagia disrupts caregiver's daily life, especially in mealtime. Carers feel anger, stress, helpless, guilty over the changes to meal preparation. Carers adapt to patient illness and negotiate a new normal. Carers believed that information provided needed to be practical, personalized.
5	Schaller et al,[31] 2014, Sweden	To describe how the relatives experienced the patient's situation, especially with respect to pain, and how the relatives themselves experienced the situation.	A qualitative study 21 relatives Gender: 18 females, 3 males Age: 20–89 y	The relatives described little knowledge of pain and its management. The relatives described the need for support from the healthcare professionals.
6	Fronczek,[32] 2015, USA	To describe and understand the lived experience of family caregivers of patients with HNCs.	Phenomenology using van Manen's human science approach 9 family members Gender: 8 females, 1 male Age: 43–76 y	Carer needs time to absorb and understand large information (during diagnosis). Some caregivers felt unsure about whom (which healthcare professional) to contact to get the answer relating to the patient care. The caregivers experienced lifestyle changes related to adjusting to treatment plans and assuming responsibilities. The caregivers experienced sympathy, guilt and fear of recurrence.

(continues)

Table 6 • Summary of the Key Characteristics of the Included Studies, Continued

No.	Author/Year Country	Study Aim/s	Methodology/Design No. of Participants, Gender, Age Group	Key Findings
7	Nund et al,[33] 2015, Australia	To explore the lived experience of communication changes following chemoradiotherapy treatment for HNC from the perspective of survivors and carers.	A qualitative study 9 caregivers Gender: 8 females, 1 male Age: 45–60 y (Involved both patient and caregivers)	Carers faced challenges regarding support for communication. Changes in communication impacted on their family and social lives.
8	Taylor et al,[34] 2016, UK	To explore the different types of information used by laryngeal cancer patients and their carers from diagnosis into the follow-up phase.	A longitudinal qualitative study 17 carers Gender: 14 females, 3 males Age: not specified (Involved both patient and caregivers)	The information received at diagnosis appeared to contribute to an "illusion of certainty" that life would return to normal at the end of treatment. However, as patients progressed into follow-up, many were propelled into a "reality of uncertainty" due to the "disconnect" between the expectations both patient and carer developed from information received over the cancer trajectory.
9	Balfe et al,[37] 2017, Ireland	To investigate the difficulties that caregivers of adult patients experience accessing or receiving social support from their networks; strategies that caregivers use to overcome and address those difficulties; and caregivers' experiences of receiving social support from official health networks.	A qualitative study 31 caregivers Gender: 24 females, 7 males Age: 60.1 y (mean)	The caregivers reported difficulties obtaining social support from their networks. The caregivers experienced the support from official healthcare networks, but this appeared to be short-term in nature.
10	Penner et al,[36] 2012, Canada	To explicate the lived experience of caring for a dysphagic relative with advanced HNC receiving tube feeding.	A descriptive phenomenology 6 family caregivers Gender: 4 females, 2 males Age: 47–74 y	The caregivers experienced changes in their roles and lives. Caregivers feel anxious about undertaking the responsibility of providing feeding via a tube. Family caregivers also find themselves challenged in managing symptoms such as pain and leakage. The caregivers experience emotional turmoil and physical exhaustion. The caregivers reported that their social lives had diminished.
11	Balfe et al,[21] 2016, Ireland	To identify and describe the triggers of emotional distress among long-term caregivers of people with HNC.	A qualitative study 31 caregivers Gender: 24 females, 7 males Age: 60.1 y (mean)	Understandings and fears of illness, lifestyle restrictions and competing demands, facial disfigurement, financial problems, comorbid health problems and witnessing suffering were the key triggers of emotional distress among long-term caregivers.
12	Balfe et al,[35] 2017, Ireland	To explore the effect that treatment-related commuting has on carers of patients with HNC.	A qualitative study 31 carers Gender: 24 females, 7 males Age: 60.1 y (mean)	Treatment-related commuting had an impact on carers economically and psychologically.

(continues)

Table 6 • Summary of the Key Characteristics of the Included Studies, Continued

No.	Author/Year Country	Study Aim/s	Methodology/Design No. of Participants, Gender, Age Group	Key Findings
13	Chen et al,[18] 2009, Taiwan	To examine caregivers' perceived levels of caregiving burden and to examine the predictive factors for caregivers' caregiving burden with newly diagnosed oral cancer patients during the postoperative period.	A cross-sectional correlational design 122 caregivers Gender: 113 females, 9 males Age: 7 are more than 65 y, 75 are 40–64 y, 40 are less than 40 y	The caregivers perceived a moderate caregiving burden and experienced higher levels of financial problems.
14	Longacre et al,[19] 2015, USA	To explore HNC caregivers' informational needs related to interacting in the medical setting as a caregiver, and whether greater needs were associated with concerns about managing patient pain or distress and to explore how caregivers prefer to receive information relevant to providing care, and if informational needs were associated with such preferences.	A cross-sectional study 59 family caregivers Gender: 48 females, 11 males Age: 54.6 y (mean)	The caregivers reported that they would first seek caregiving information from a formal healthcare professional (doctor, nurse, or social worker) (76.6%, n = 47), whereas 23.4% reported that they would first go to an informal resource (eg, Internet, family or friend, nonprofit). A high percentage of caregivers reported needing information on how to reduce a patient's pain or distress at diagnosis (66.1%), treatment start (74.6%), and at treatment end (44.1%).
15	Offerman et al,[20] 2015, the Netherlands	To explore the long-term impact of a total laryngectomy (TL) on the partner and on the relationship between laryngectomies and their partners.	A cross-sectional study 144 partners Gender: 121 females, 23 males Age: 66 y (mean) (Involved both patient and caregivers)	Female partners of laryngectomies experienced more depression than male partners and more fear for new treatments than male partners. The partners of laryngectomies experience a psychosocial impact of the consequences of TL especially on their social life (35%) and on their sexual relationship (31%).
16	Balfe et al,[40] 2016, Ireland	To examine the unmet supportive care needs of long-term HNC caregivers, and the factors associated with those needs.	A cross-sectional study 197 HNC caregivers Gender: 150 females, 47 males Age: 57 y (mean)	Managing fears about cancer recurring was the most commonly reported individual need. Loneliness and financial stress were consistently and significantly associated with high levels of unmet need. The overall unmet need scores declined with increasing time since diagnosis. Caregivers identified 'accessing information about the benefits and adverse effects of treatments' as one of their top ten moderate/severe needs.
17	Hiremath et al,[22] 2017, India	To assess the burden among caregivers of patients with oral cancer using burden inventory.	A quantitative study 40 caregivers Gender: 26 females, 14 males Age: 21–50 y	Many caregivers experience significant burden, particularly with respect to their physical and psychological well-being, economic circumstances, and social and personal relationships.
18	Patterson et al,[23] 2013, UK	To explore the quality of life of informal carers of HNC patients pre-treatment and post-treatment and its relationship to patient-reported dysphagia.	Mixed method 96 caregivers (89 females, 7 males) responded the questionnaire 8 caregivers participated in the interview (7 females, 1 male) Age: 45–76 y	Some caregivers experience difficulties with food preparation and had concerns about nutritional content, texture and food preferences of the patient. The caregivers experienced lifestyle changes in the context of eating.

(continues)

Table 6 • Summary of the Key Characteristics of the Included Studies, Continued

No.	Author/Year Country	Study Aim/s	Methodology/Design No. of Participants, Gender, Age Group	Key Findings
19	Hanly et al[24] 2016, Ireland	To investigate the relationship between unmet supportive care needs and carer burden and happiness, in HNC.	A quantitative study 197 caregivers Gender: 136 females, 43 males Age: 23–85 y	Unmet healthcare service needs were significantly associated with carer burden.
20	Hung et al,[25] 2013, Taiwan	To examine changes in social support and predictors in caregivers of oral cavity cancer patients over the 3 mo after patients' first discharge.	Prospective longitudinal study 142 caregivers Gender: 15 females, 127 males Age: 31–84 y	Caregivers had mild-to-moderate levels of needs and were satisfied with available social support during the first 3 mo after discharge. The peak for both overall and individual needs of social support was before discharge. Caregivers with longer caregiving time were associated with dissatisfaction during the first 3 mo after discharge.

make daily adjustment to fulfill the role as a caregiver. Life disturbances and transition experiences are common among caregivers of patients with any type of cancer; however, nurses can guide and assist them in adjusting this transition and to enhance their caregiving experience.[41]

This review showed that the caregivers experienced the physical, psychosocial, and financial impact of caregiving. Findings related to physical and psychosocial challenges faced by caregivers are echoed in a review of the caregivers' role and needs in cancer care,[13] which confirms the validity and relevance of the findings from this review. Psychological distress of caregivers with any cancer patients has been reported in the literature.[42,43] However, in this review, the psychological distress of caregivers with HNC patients was mainly related to meal preparation, pain management, feeding, and meeting the nutritional needs of the patients. Challenges encountered with meal preparation and social impact related to eating and drinking are similar to findings from another study in which caregivers of patients with cancer experienced distress especially during mealtime and food preparation.[44] Thus, the psychosocial and nutritional aspects of care must also be addressed to optimize care for a family with an HNC patient.

This review suggests that there is a need for an educational program to prepare caregivers for the complexity of the role required of them. The need for knowledge and skills seemed to be important in the caregivers. It was evident from the literature that the caregivers struggle with dysphagia, tube feeding, and meal preparation.[33,36] Despite the need for these skills, many family caregivers who provide care for loved ones are dependent on home care technologies such as tube feeding, but received no formal training.[45] Because of the nature of the disease, the patients with cancer need to continue their treatments in outpatient centers, and often home care is required.[46] As such, the caregiver training is essential as they often have to depend on home care technologies such as enteral nutrition.[47]

A previous review of caregivers of patients with other types of cancer identified the needs as assistance with personal adjustment to illness, psychosocial support, transportation, finances, home care, and medical information.[13] Although Glajchen[13] identified the importance of providing information for the caregivers, it was unclear in his review what types of cancer or treatment these caregivers were handling. In this review, we identified an information need on pain management, nutrition, and posttreatment complication for the caregivers with HNC who had received various HNC treatments.

The need for ongoing support is in agreement with Osse and colleagues,[48] who argue that many caregivers of cancer patients require professional support and coordination of health services in managing the patient's symptoms. The use of multimedia has been found useful in patient and caregiver education for cancer pain management.[49] Support from the health professional should be made available to the caregivers in managing the symptoms, reducing their anxiety and promoting their well-being. Collaboration from the healthcare professional is vital to the support of caregivers and patient. For example, the involvement of a dietitian can be beneficial in the development of education for caregivers in meeting the nutritional needs of their patients.[50] Availability of social support and fulfilling the needs can shape the caregiver's experience.

To develop a tailored education program and to ensure that caregivers are adequately supported, the needs of a patient with HNC have to be identified. The caregivers are equally important as the patient in understanding their needs and receiving psychosocial support during and after the treatment.[12] The needs of those caring for a patient with HNC will vary in accordance with the time since diagnosis,[18] and this must be taken into consideration. Duration of caregiving and the extent of the caregiving tasks should also be taken into consideration as these may influence the individual experience of caregiving and thus should be addressed in the development of support program for the caregivers.

■ Relevance to Clinical Practice

The psychosocial and nutritional aspects of care must also be addressed to optimize care for a family with an HNC patient. Counseling and effective coping strategies need to be taught to manage the symptoms and to deal with the care demands.

Clinicians should view the caregivers as copartners in HNC management and should offer adequate support and education programs relevant to their needs.[30]

Nurses and clinicians should develop an awareness of the caregivers' experiences of caregiving and their needs in both the short and long term. Information about the various supports available should be readily accessible to caregivers and patients to ease the transition from inpatient to outpatient or home-based care.[24]

An ongoing assessment of caregivers' needs may contribute to enhancing the care and management of patients with HNC; it is essential to promptly identify the concerns of caregivers. The implementation of ongoing financial, social, and professional support programs is strongly recommended for HNC patients and their family members to enable them to make sense of their illness experiences without neglecting the psychosocial dimension of caregivers.

■ Strength and Limitation of the Review

Describing the explicit purpose of review, including methods and steps in synthesis, allows it to be replicated and enhances its creditability. Nevertheless, this review did not include studies published in the gray literature or in languages other than English, which may underestimate the total inclusiveness of literature. Although the included studies were relevant regarding reporting the experiences and the support needs of caregivers of patients with HNC, considerable variations in age, duration of diagnosis, socioeconomic background, and differences in cultural and contextual determinants could compromise the generalizability and transferability of current findings to a specific group of caregivers of someone with HNC.

■ Conclusion

Caregivers experience life disruption and have considerable support needs, especially in the educational and informational domains. However, there are still unanswered questions about how the caregiver can best be helped to take this role on. Future research should explore possible carer-specific interventions to build capacity in the multiple roles they must perform in assisting their loved ones with HNC. It is also important to consider the future development of a specific HNC caregiver competency assessment tool to enable the comprehensive identification of the needs and provision of appropriate support to address these.

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Appendix C. Participant information sheet/consent form

Participant Information Sheet/Consent Form

Non-Interventional Study

Chris O'Brien Lifehouse

Title	**The experiences and the needs of caregivers of patients with head and neck cancer**
Short Title	**Caregivers of patients with head and neck cancer**
Protocol Number	**X18-0517 & HREC/18/RPAH/737**
Coordinating Principal Investigator/ Principal Investigator	**Jacqueline Bloomfield/ Sarah Davies**
Associate Investigator(s)	**Kate White/Su Htet Htet Aung**
Location	**Chris O'Brien Lifehouse**

Part 1 What does my participation involve?

1 Introduction

You are invited to participate in this research project: "The experiences of caregivers of patients with head and neck cancer." This is being conducted as there is a lack of current research providing an in-depth understanding of the caregiving experiences and the needs of caregivers from their own perspectives. The research project aims to explore the experiences of caregivers to identify their education and information needs in the long-term care of individuals who have been treated for head and neck cancer.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what is involved. 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 doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part. 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

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

2 What is the purpose of this research?

Head and neck cancer affects not only the patients but also their immediate family members. Head and neck cancer patients require a considerable amount of care and support, and the tasks of caregiving can be challenging. There is a need for carer-specific interventions to build capacity in the multiple roles they must perform in assisting someone with head and neck cancer.

This study aims to explore the experiences of caregivers to identify caregivers' education and information needs in the long-term care of individuals who have been treated for head and neck cancer.

We hope the study findings will help healthcare professionals, service providers, policymakers, and educators better understand caregivers' experiences and their needs. It is anticipated that this will inform the development of an education and support program designed for caregivers of people with head and neck cancer. The results of this research will be used by Mrs Su Htet Htet Aung to obtain a Doctor of Philosophy degree.

3 What does participation in this research involve?

If you agree to participate in this study, you will be invited to take part in interviews or a focus group discussion. You can elect to participate in an individual interview with yourself and the researcher/s or in a small focus group (5-6 family carers). The individual interviews will be conducted via telephone at a time that is convenient with you. If you decide to participate the one-on-one interviews (a maximum of two), the first interview will take approximately 60 to 90 minutes. If a second interview is needed to explore further or clarify anything that you said in the first interview, it is anticipated that this will take approximately 30 minutes. If you elect to participate in the focus group discussion, you will be provided with a choice of dates. The interview will take approximately 60 to 90 minutes. The focus group interview will be held in a room at Chris O'Brien Lifehouse in Camperdown. During the individual interviews or the focus group, we will invite you to share personal experiences about caregiving, as well as the support you received or were offered. We will also ask you what could have helped you in your role as a caregiver. With your permission, the focus group discussions and individual interviews will be audio-recorded and additional notes may be taken. These recordings will later be transcribed by the researcher.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoid the researchers or participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid.

4 What do I have to do?

If you are a caregiver of a patient with head and neck cancer, and the person you are caring for is currently receiving treatment or has received treatment within the past 12 months, you are invited to participate in this study. Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with the researcher now or in the future. You may stop the individual interview or leave the focus group discussion at any time if you do not wish to continue, and the audio recording will be erased, and the information provided will not be included in the study.

5 Other relevant information about the research project

The study is being conducted by Su Htet Htet Aung, a Registered Nurse who is undertaking a PhD (Nursing) at the University of Sydney, under the supervision of Associate Professor Jacqueline Bloomfield and Professor Kate White in the Faculty of Medicine and Health. This study also involves a Nurse Practitioner from Lifehouse, Sarah Davies (Head and Neck Cancer Nurse Practitioner).

6 Do I have to take part in this research project?

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 at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign, and you will be given a copy to keep. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the treatment of the person you are caring for, your relationship with those treating you or your relationship with Chris O’Brien Lifehouse.

7 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research. However, possible benefits may include increased nursing and medical knowledge about the needs of carers of people with head and neck cancer and improvement in future support for them.

8 What are the possible risks and disadvantages of taking part?

The interview may cause psychological distress to you when you recall your experiences from the past related to you or your family member. If you become upset or distressed as a result of your participation in the research, the study researcher will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research project team. This counselling will be provided free of charge.

9 What if I withdraw from this research project?

You can withdraw from the individual interview or focus group interview at any time. But, once the interview or focus group discussion have been completed and analysed, your responses cannot be withdrawn. This is because they are anonymous and therefore, we will not be able to tell which responses are yours.

10 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include, for example, in the event of a pandemic such as COVID-19.

11 What happens when the research project ends?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by contacting the Principal Investigator, A/Professor Jacqueline Bloomfield. This feedback will be made available to the participants via a lay summary. You will receive this feedback after the study is finished.

Part 2 How is the research project being conducted?

12 What will happen to information about me?

In the interview and focus group transcripts and field notes, a person’s name will be replaced with a pseudonym. Other information such as address, date of birth, occupation, institutions, etc. (if the participant describes) will be replaced with a meaningful descriptive term to maximise the protection of participants’ identities. The original version of documents and identifiers will be separately stored from the edited version. Interviews will be transcribed by Su Htet Htet Aung, and analysis will be conducted by all researchers involved in the study.

Pseudonyms will be used in all transcripts and the dissemination of results. No information about a participant or an organisation mentioned in the interview will be used in any way that is identifiable. Only fully non-identifiable data will be presented when disseminating results.

As specified in the University of Sydney Research Data Management Policy, all data, such as electronic files, audio recordings and transcripts of interviews, will be stored on the secure research data shared drive accessible by a password-protected computer on the University of Sydney’s server. Data in hard copy and consent forms will be stored in a locked cabinet in the Cancer Nursing Research Unit (CNRU) located at Level 6 Chris O’Brien Lifehouse. All these physical data and materials will be digitised as soon as collected, and the hard copies will be destroyed.

Access to data will be restricted to the approved members of the research team only. Data will be stored for a minimum of 5 years as specified by the Australian Code for the Responsible Conduct of Research and the University of Sydney Research Data Management Policy. The materials for this study will ultimately be disposed of via deletion of any electronic documents or data related to the study. The University of Sydney IT department will be consulted to ensure eh deletion is complete and files are not retrievable for any source.

By signing the consent form, you consent to the relevant research staff collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission.

In accordance with relevant Australian and/or NSW privacy and other relevant laws, you have the right to request access to the information collected and stored by the research team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the research team member named at the end of this document if you would like to access your information.

13 Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

14 Who is organising and funding the research?

This research project is being conducted by Ms Su Htet Htet Aung to obtain a Doctor of Philosophy degree. This research received no sponsorship.

15 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the Sydney Local Health District (SLHD). Approval to conduct the study at Chris O'Brien Lifehouse has also been obtained.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

16 Further information and who to contact

The person you may need to contact will depend on the nature of your query.
If you want any further information concerning this project you can contact the researcher on 0444579479 or any of the following people:

Clinical contact person

Name	*Sarah Davies*
Position	*Head and Neck Nurse Practitioner*
Telephone	*(02) 85140027*
Email	*Sarah.davies@lh.org*

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	*Anna Swansn*
Position	*Research Governance Manager*
Telephone	*(02) 85140410*
Email	*researchgovernance@lh.org.au*

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	*Sydney Local Health District*
HREC Executive Officer	*Patricia Plenge*
Telephone	*029516766*
Email	*RPAEthics@health.nsw.gov.au*

Local HREC Office contact (Single Site -Research Governance Officer)

Name	*Maree Larkin*
Position	*Research Governance Officer*
Email	*Maree.larkin@health.nsw.gov.au*

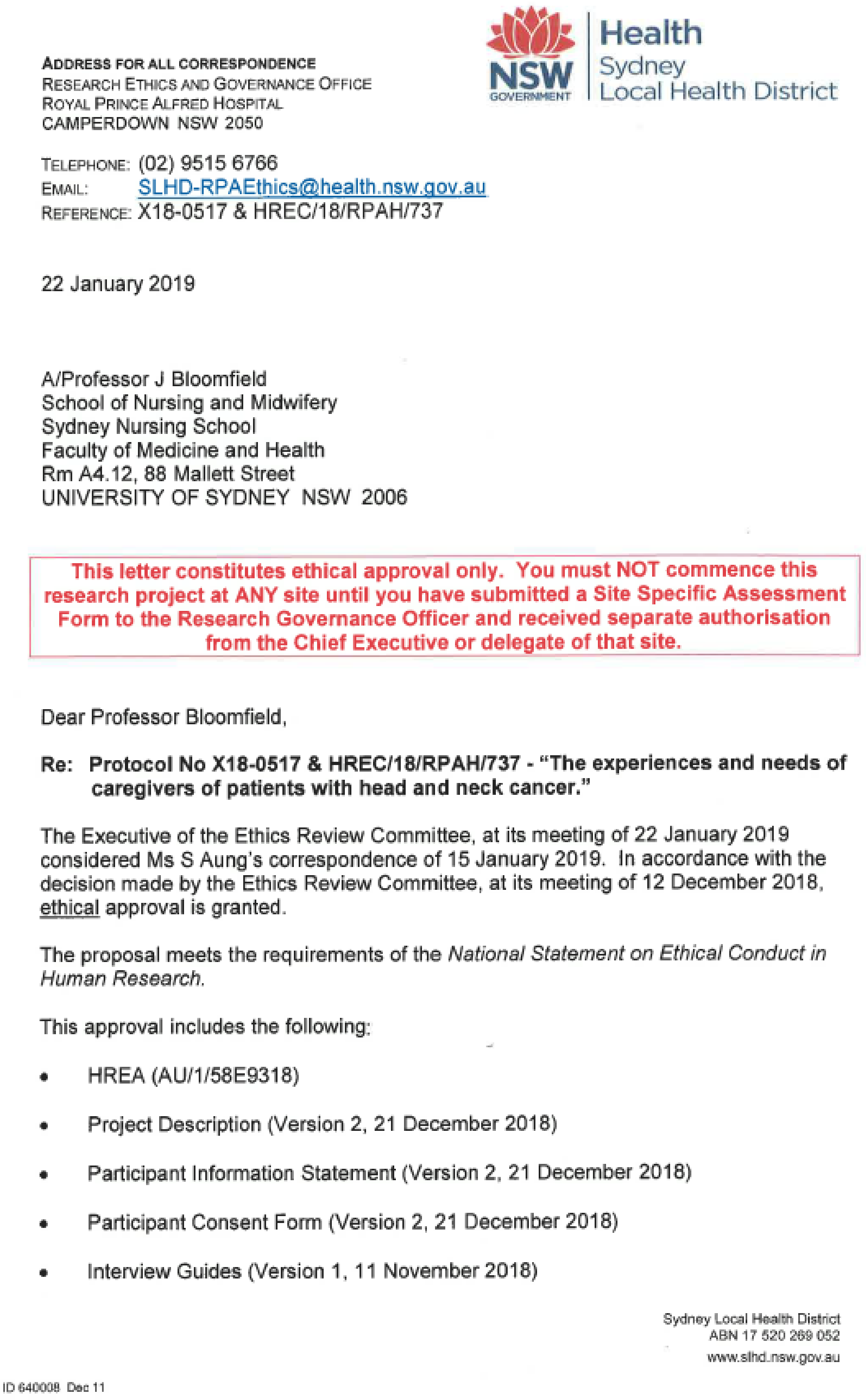
Appendix D. Interview guide

The following questions may not be conducted in the strict order.

Questions

1) Tell me about your journey since you had been informed that your loved one was diagnosed with head and neck cancer.
2) How does it affect to you and your life?
3) What are the key challenges/needs you have experienced when you look after your loved one?
4) Tell me about your experiences with health care providers throughout the journey (Prompts; helpful, not helpful, constraints, examples?).
5) What support did you find helpful and not helpful at that time, and why?
6) What could have helped you to perform better as a caregiver?
7) What message/suggestion would you like to give to health care professionals, in the interest of developing carer-specific intervention in the future?
8) Is there anything else you would like to talk about?

Appendix E. Ethics approval



NSW GOVERNMENT
Health
Sydney
Local Health District

ADDRESS FOR ALL CORRESPONDENCE
RESEARCH ETHICS AND GOVERNANCE OFFICE
ROYAL PRINCE ALFRED HOSPITAL
CAMPERDOWN NSW 2050

TELEPHONE: (02) 9515 6766
EMAIL: SLHD-RPAEthics@health.nsw.gov.au
REFERENCE: X18-0517 & HREC/18/RPAH/737

22 January 2019

A/Professor J Bloomfield
School of Nursing and Midwifery
Sydney Nursing School
Faculty of Medicine and Health
Rm A4.12, 88 Mallett Street
UNIVERSITY OF SYDNEY NSW 2006

This letter constitutes ethical approval only. You must NOT commence this research project at ANY site until you have submitted a Site Specific Assessment Form to the Research Governance Officer and received separate authorisation from the Chief Executive or delegate of that site.

Dear Professor Bloomfield,

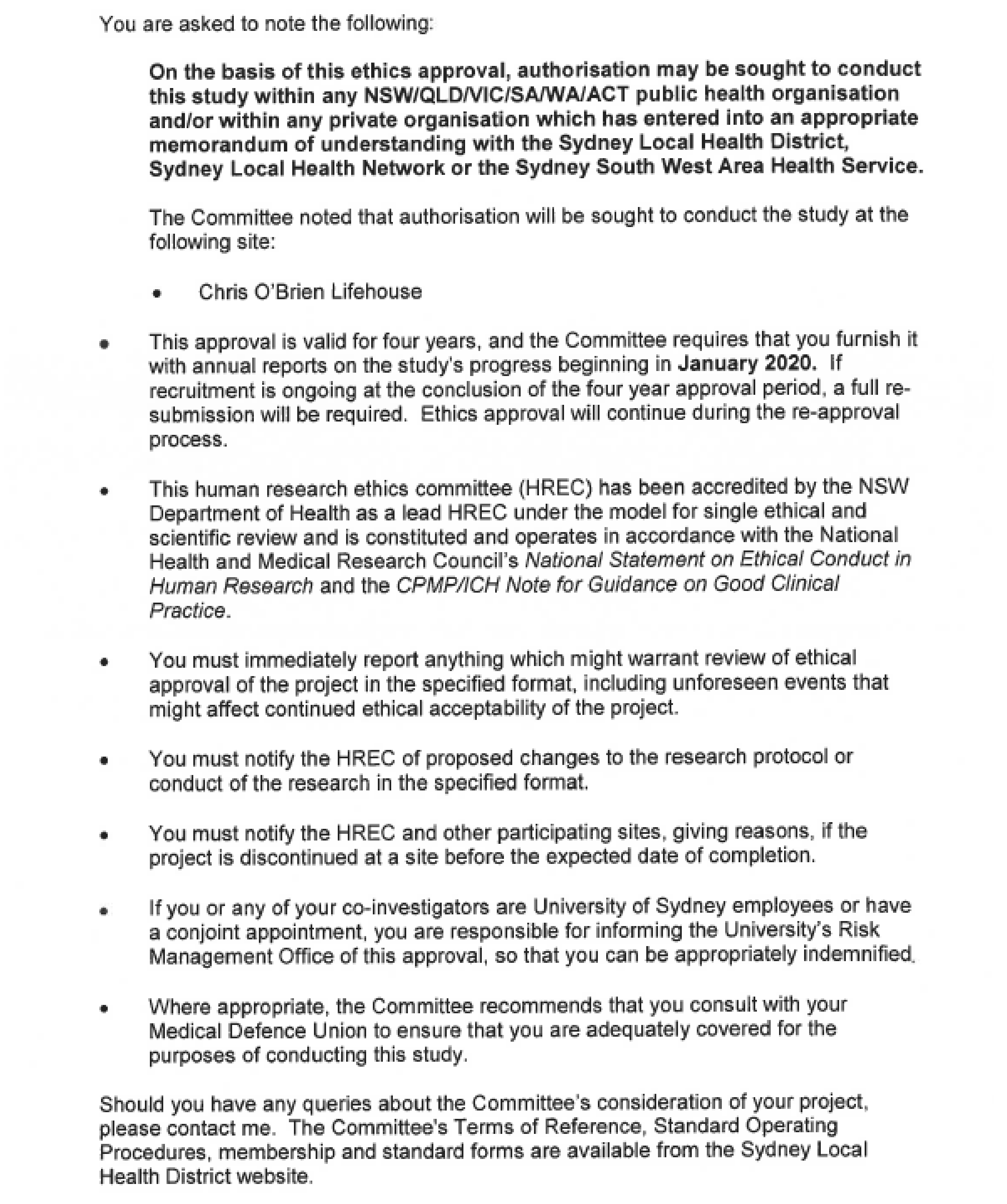
Re: Protocol No X18-0517 & HREC/18/RPAH/737 - "The experiences and needs of caregivers of patients with head and neck cancer."

The Executive of the Ethics Review Committee, at its meeting of 22 January 2019 considered Ms S Aung's correspondence of 15 January 2019. In accordance with the decision made by the Ethics Review Committee, at its meeting of 12 December 2018, ethical approval is granted.

The proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research.*

This approval includes the following:

- HREA (AU/1/58E9318)
- Project Description (Version 2, 21 December 2018)
- Participant Information Statement (Version 2, 21 December 2018)
- Participant Consent Form (Version 2, 21 December 2018)
- Interview Guides (Version 1, 11 November 2018)



You are asked to note the following:

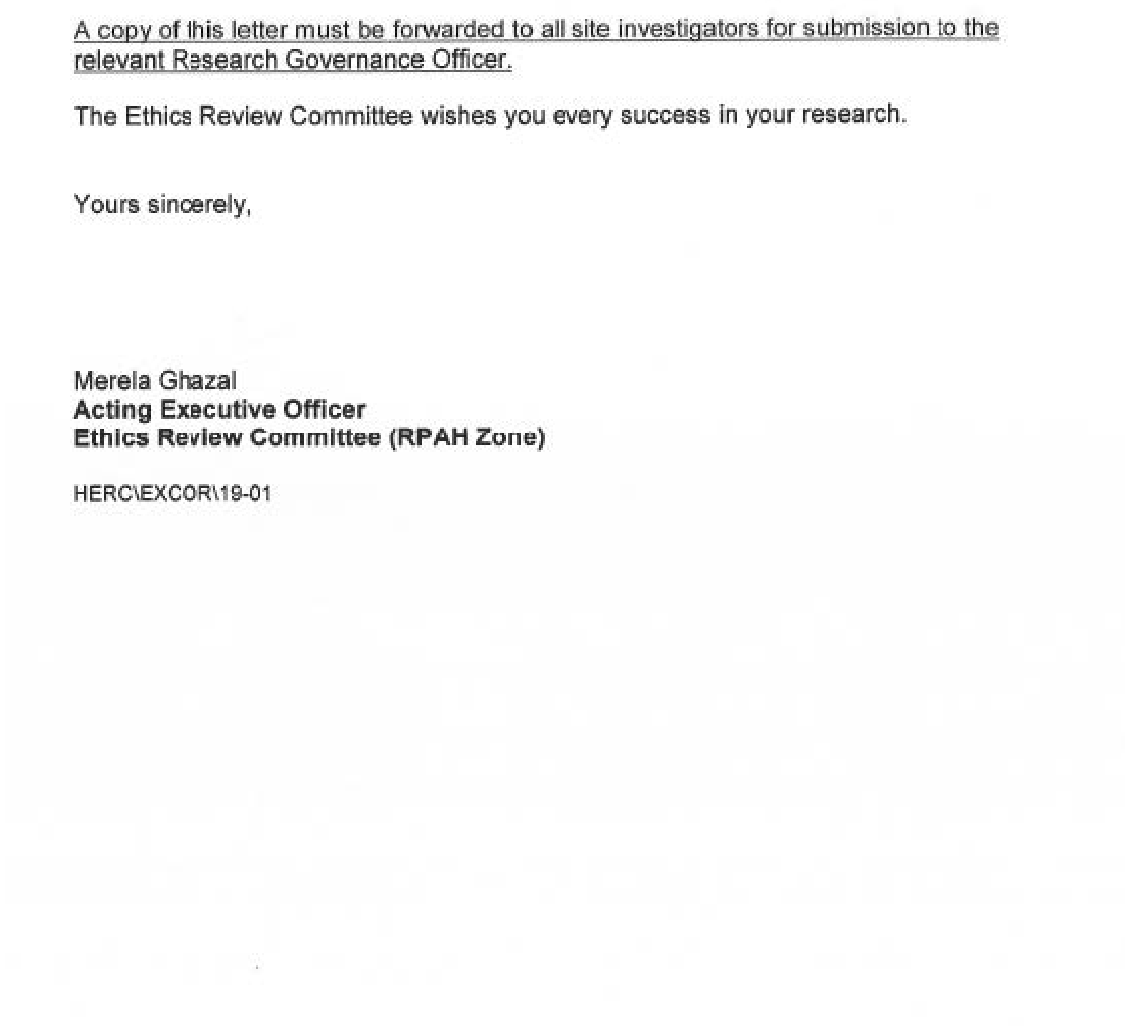
On the basis of this ethics approval, authorisation may be sought to conduct this study within any NSW/QLD/VIC/SA/WA/ACT public health organisation and/or within any private organisation which has entered into an appropriate memorandum of understanding with the Sydney Local Health District, Sydney Local Health Network or the Sydney South West Area Health Service.

The Committee noted that authorisation will be sought to conduct the study at the following site:

- Chris O'Brien Lifehouse

- This approval is valid for four years, and the Committee requires that you furnish it with annual reports on the study's progress beginning in **January 2020.** If recruitment is ongoing at the conclusion of the four year approval period, a full re-submission will be required. Ethics approval will continue during the re-approval process.
- This human research ethics committee (HREC) has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review and is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.
- You must immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
- You must notify the HREC of proposed changes to the research protocol or conduct of the research in the specified format.
- You must notify the HREC and other participating sites, giving reasons, if the project is discontinued at a site before the expected date of completion.
- If you or any of your co-investigators are University of Sydney employees or have a conjoint appointment, you are responsible for informing the University's Risk Management Office of this approval, so that you can be appropriately indemnified.
- Where appropriate, the Committee recommends that you consult with your Medical Defence Union to ensure that you are adequately covered for the purposes of conducting this study.

Should you have any queries about the Committee's consideration of your project, please contact me. The Committee's Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Sydney Local Health District website.



A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

The Ethics Review Committee wishes you every success in your research.

Yours sincerely,

Merela Ghazal
Acting Executive Officer
Ethics Review Committee (RPAH Zone)

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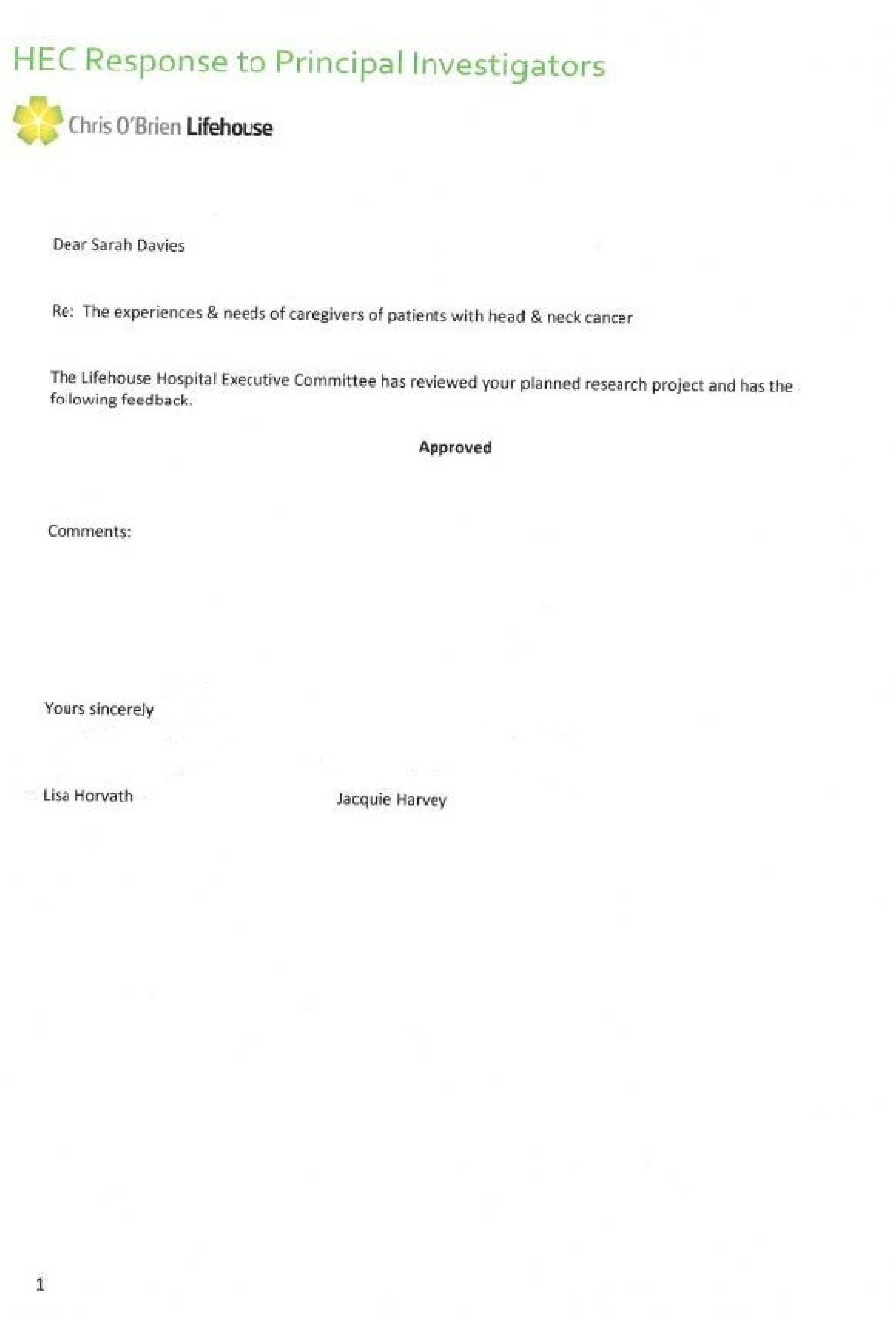
Caregiving does not happenAppendix F. Site-specific approval



HEC Response to Principal Investigators

Chris O'Brien Lifehouse

Dear Sarah Davies

Re: The experiences & needs of caregivers of patients with head & neck cancer

The Lifehouse Hospital Executive Committee has reviewed your planned research project and has the following feedback.

Approved

Comments:

Yours sincerely

Lisa Horvath Jacquie Harvey