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Descriptors and predictors of symptom experience, information needs and caregiver burden in Thai patients with advanced lung cancer and their family caregivers during palliative radiotherapy

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Abstract

Introduction: Patients with advanced lung cancer undergoing palliative radiotherapy often face significant both symptoms from lung cancer and side effects from radiotherapy, which affect their quality of life and require effective self-management strategies. Family caregivers play a crucial role in supporting patients throughout their cancer journey, necessitating a comprehensive assessment of their information needs and understanding of symptom management. Research on symptom experiences, information needs, and caregiver burden among patients receiving palliative radiotherapy is limited, particularly within the context of Thai populations. This thesis aimed to explore and quantify the extent of the symptoms experienced by Thai patients with advanced lung cancer, the information needs of these patients and their family caregivers during palliative radiotherapy, and the caregivers' burden, and also to identify predictors that influence symptom self-management, meeting information needs and affecting caregivers' burden.

Methods: The thesis employed an observational, correlational, repeated measures design, which used the Memorial Symptom Assessment Scale (MSAS); the information needs subscale from the Supportive Care Need Survey (SCNS) for patients and caregivers, and the Zarit burden interview to gather information about symptom prevalence, frequency, and severity and the distress caused by these symptoms, information needs, and the level of caregivers' burden. Participants included Thai patients diagnosed with advanced lung cancer and their family caregivers at four time points: before palliative radiotherapy (visit 1), weekly during palliative radiotherapy (visits 2 and 3), and a month post-palliative radiotherapy (visit 4). Quantitative data collection utilises standardised symptom assessment tools to quantify symptom burden, and demographic and clinical factors are examined as potential predictors.

Findings: Patients with advanced lung cancer (n=56) undergoing palliative radiotherapy and (n=56) of their caregivers were included. The most prevalent symptoms that patients reported were lack of energy, pain, cough, weight loss, and "I don't look like myself". Symptom prevalence peaked during the last week of treatment (Visit 3). The most frequent symptom across all four visits was fatigue. Symptom scores exhibited a consistent reduction from baseline at all visits. Most caregivers reported either no burden or little burden. The most frequent concern of caregivers was related to the apprehension about their relative's future. Burden scores indicated a trend of a decrease from baseline. Both patients and caregivers sought information primarily from healthcare providers, with discussions being the preferred information format. For both patients and caregivers, wanting information about managing fatigue was the most frequently identified information needed across all visits. Patients' information needs regarding self-help methods for recovery decreased from baseline across the visits. Caregivers' information needs concerning complementary and alternative therapies decreased from baseline in all categories. Symptom experience scores were associated with smoking history, gender, and radiotherapy type. Psychological symptom scores were higher in married patients with a smoking history. Symptom experience scores were associated with smoking history (p=0.027), gender (p=0.011), and radiotherapy type (p=0.037). Moreover, a smoking history was indicative of higher Global Distress Index scores. Gender and relationship status influenced increased caregivers' burden. Smoking history, age, treatment area, education level, and radiotherapy dose were predictors of heightened information needs. Gender and relationship status influenced caregivers' information needs. Male caregivers had a bigger reduction in information needs than females (p=0.041), and spouses/partners had a bigger information need than those with a different relationship to the patient (p=0.021). These findings provide valuable insights into the symptom experiences and information needs of patients during palliative radiotherapy for lung cancer and caregivers' burden and caregivers' information needs during taking care of these patients offering potential directions for tailored interventions and care strategies. Caregivers also experience their own challenges while supporting patients, highlighting the need for tailored information and support strategies for caregivers.

Conclusion: The results relate to Thailand but cannot be generalised to all patients and caregivers in Thailand due to the specific characteristics of the study sample and healthcare settings. This study highlights the importance of systematic symptom-monitoring to identify which symptoms may persist that may require more intense supportive care intervention. The caregivers report a low burden level, but fostering open communication channels between caregivers and healthcare providers can help address any concerns to ensure that they feel supported throughout the patient's treatment journey. The findings have implications for the development of patient-centred interventions that aim to enhance symptom self-management e.g. x and provide targeted information to both patients and their family caregivers. By addressing the identified predictors, healthcare professionals can better support the unique needs of patients and caregivers, ultimately improving the quality of care and patients' quality of life. Tailored interventions, if implemented, have the potential to address these complex needs and enhance the well-being of patients with advanced lung cancer who are receiving palliative radiotherapy.

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- McParland C, Johnston B, Alassoud B, Drummond M, Purpa C H I, Seckin M, Thanthong S (2023) Involving patients and the public in nursing PhD projects: practical guidance, potential benefits and points to consider. Nurse Researcher. https://doi.org/10.7748/nr.2023.e1891 open access
- Thanthong S, Kotronoulas G, and Johnston B (2024) Descriptors and factors affecting patients' symptom experiences for symptom self-management throughout palliative radiotherapy for advanced lung cancer: A systematic review is under review. Asia Pac J Oncol Nurs, 11(10). doi: 10.1016/j.apjon.2024.100577

List of Presentations

- European Oncology Nursing Society the PhD Research Workshop 2018 Oral Presentation: Predictors of the symptom experience and information needs in patients with lung cancer and family caregivers receiving radiotherapy in Thailand.
- European Association of Palliative Care Conference 2020 Poster Presentation: Symptom experiences in patients with advanced lung cancer undergoing palliative radiotherapy: a systematic review [A-1114-0022-00318].
- Presented my PhD thesis in the University of Glasgow 3MT competition 2018–2021: Descriptors and predictors of symptom burden and information needs on symptom self-management in Thai patients with advanced lung cancer and their family caregivers during palliative radiotherapy.

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Author’s declaration

I declare that except where explicit reference is made to the contribution of others, this PhD thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

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My timeline

Topic		Timeline	Duration
Conceptualisation and Proposal	Topic selection	05/01/2018-31/03/2018	3 months
	Proposal development	01/04/2018-30/05/2018	2 months
	University's ethics committee approvals	31/05/2018-14/01/2019	7 months
	PROSPERO approval for systematic review	01/10/2018-31/03/2019	6 months
	Three cancer centres in Thailand approval	01/03/2019-31/08/2019	6 months
Data Collection	Participant recruitment	02/08/2019	6 months
	Data collection	02/08/2019-28/01/2020	
Data Analysis	Quantitative techniques	01/02/2020-31/07/2020	6 months
	software used		
	Health check-up and diagnosed with CA Breast	01/08/2020-31/10/2020	3 months
Suspension due to health issue	First suspension for treatment	01/11/2021-30/04/2022	6 months
	Second suspension for treatment and recovery period	01/05/2022-31/03/2023	11 months
Writing and Revisions	Outline the time allocated for drafting different chapters	01/04/2023-30/09/2023	6 months
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Abbreviations

Abbreviation	Description
RT	Radiotherapy, or radiation therapy
Gy	Gray
PPI	Patient, Caregiver and Public Involvement
PTR	Palliative thoracic radiotherapy
LASA	The Linear Analogue Scale Assessment
LINAC	Linear accelerator
HADs	The Hospital Anxiety and Depression Scale
MDASI	The MD Anderson Symptom Inventory
ZBI	The Zarit Burden Interview
CSI	The Caregiver Strain Index
MCSI	The Modified Caregiver Strain Index
SACT	Systemic Anticancer Therapy
SCNs	Supportive care needs
SCNS	The Supportive Care Needs Survey - Patient version
SCNS-P&C	The Supportive Care Needs Survey - Partners and Caregivers version
MSAS	The Memorial Symptom Assessment Scale
PSYCH	Psychological
PHYS	Physiological
GDI	Global Distress Index
TNM	Tumour Lymph node Metastasis

Chapter 1 Background

1.1 Introduction

This thesis explores the symptom experiences, side effects, and predictors of symptoms in Thai patients with advanced lung cancer who are receiving palliative radiotherapy (RT), as well as the caregiver burden and the information needs of patients and caregivers in Bangkok, Thailand. The purpose of this chapter is to describe the background to lung cancer and its management, caregiving regarding patients with advanced lung cancer, and information needs of patients and caregivers. It identifies the research interest and identifies the research problem that motivated the study, the knowledge gap and the objectives and questions that this thesis raises to explain the motivation for the study. The research context that will guide the scope, length and limits of the thesis is presented. This chapter ends with an overview of how the chapters of this thesis are organised.

1.2 Background to advanced lung cancer, management, and symptom experiences

1.2.1 Advanced lung cancer

Lung cancer is the most common cause of cancer deaths worldwide, affecting both men and women. Smoking is the main cause, leading to about 85% of cases. Unfortunately, lung cancer is frequently found at advanced stages, limiting treatment possibilities. However, screening individuals at high risk holds promise for early detection, which significantly enhances survival rates (Beil et al., 2023). Implementing primary prevention strategies like tobacco control measures and minimising exposure to environmental risks can effectively lower lung cancer incidence and ultimately save lives (WHO, 2023).

Advanced lung cancer is common and deadly, representing an estimated 11.4% of total cancer cases for both sexes worldwide in 2020 (Baptiste et al., 2022). Fatalities from lung cancer in Thailand account for nearly 14.1% of all cancer deaths in the nation, and 70% of patients with non-small cell lung cancer (NSCLC) were diagnosed at this stage. Despite the decline in smoking that is shown in statistics in Thailand following the anti-tobacco campaign, the rate of lung cancer is still increasing. There are likely to be other risk factors, for example, asbestos and air pollution that need further study (Reungwetwattana et al., 2020). The prognosis of these patients is poor, at approximately 4 months at both the newly diagnosed stage IV NSCLC (Ko et al., 2017) and at the extensive stage in people with small cell lung cancer (Khakwani et al., 2014). Advanced lung cancer is a major problem in Thailand and in the rest of the world, and it is likely to keep increasing.

According to the tumour node metastases (TNM) international staging system, around 30% of patients diagnosed with NSCLC have what is called “locally advanced” disease, which is categorised as stage III. This is further divided into IIIA, IIIB, and IIIC according to the 8th TNM classification system (Detterbeck, 2018). Stage III NSCLC represents a diverse group of tumours characterised by locoregional spread, meaning the cancer has spread to nearby tissues and lymph nodes, but not metastasised to distant organs. While RT can be used as a standalone treatment with the goal of curing this type of lung cancer, long-term survival and tumour control rates are generally low. For example, the standard RT approach results in only an 8% five-year local tumour control rate (Alaswad, 2023).

This group experiences a wide range of clinical manifestations and typically has a substantial tumour burden (T3-4) and lymph node involvement (N2-3). The latest version of TNM (eighth edition) has introduced stage IIIC, which refers to a significant presence of cancer in the lung tissue along with involvement of lymph nodes on the opposite side of the body (T3-T4 and N3). Due to the extent of the disease, most stage III NSCLC patients are not considered suitable candidates for surgery. Even though they do not have distant metastases, their prognosis is generally poor, with variations among different sub-stages. The 5-year overall survival rate for these patients is approximately 20% after receiving concurrent or sequential chemoradiation therapy (Alaswad, 2023).

1.2.2 Management of advanced lung cancer

When treating patients with advanced lung cancer, many factors are considered, including the patient's overall health, the extent and location of metastases, histology, genetic profile, and individual preferences. The main goals are helping the patient live longer, easing symptoms, and improving their quality of life. Patients with advanced lung cancer often receive systemic anticancer therapy (SACT), which may include a combination of chemotherapy, targeted therapies, and immunotherapy. These complex treatment regimens frequently involve multiple medications, including supportive care drugs to manage side effects. This increases the risk of polypharmacy—the use of multiple medications simultaneously—and raises the potential for drug interactions, especially when patients are also taking medications for other health conditions (comorbidities) (Panchal, 2017). Combination RT and SACT are commonly used, and the choice of drugs depends on factors such as the histological type of the cancer and the patient's general health. Targeted therapy aims to block specific pathways that help cancer grow, especially in patients with certain genetic mutations or markers in their tumour. Immunotherapy is the immune checkpoint inhibitors, helps the immune system recognise and attack cancer cells, and it has led to significant advancements in treating advanced lung cancer (WHO, 2020).

Additionally, local treatments such as radiation therapy and surgery may be used to treat specific areas where the cancer has spread or to relieve symptoms caused by tumour growth (WHO, 2020). Several studies have shown that palliative care with anti-cancer treatment improved symptom management and quality of life and reduced psychological distress. International guidelines recommendations that support palliative care needs for patients with advanced cancer should be the standard of care. The most important part of integrated palliative care is the systematic assessment of patient report outcomes (PROMs) in terms of symptoms. PROMs are important to identify symptom experiences and should be considered when choosing and evaluating treatment outcomes (Kristensen et al., 2022).

Advanced lung cancer cannot be cured. Management is focused on symptom control whilst limiting treatment burden and toxicity. Palliative thoracic radiotherapy is effective for improving symptoms resulting from locally advanced lung cancer, such as haemoptysis, cough, chest pain, and dyspnoea, Response to symptoms 50–80% (Lefresne et al., 2017). A range of regimens is employed for palliative thoracic radiotherapy (RT) worldwide, varying from a single fraction in one day to over 30 fractions spread across at least 6 weeks. Extended regimens of 10 or more fractions, which deliver a higher biologically equivalent dose, are linked to a modest improvement in survival. In contrast, shorter courses of 1–5 fractions offer comparable symptom relief with greater convenience for patients and reduced toxicity (Fraser et al., 2019).

Palliative thoracic RT is a well-established treatment option for the management of symptoms of advanced lung cancer; it shrinks the tumour or reduces its impact on surrounding tissues (Araujo et al., 2020, Chiang and Herbst, 2021). RT breaks DNA, resulting in cell death. This has a more significant impact on cancer cells than on normal cells. Targeted symptoms often include cough, dyspnoea, haemoptysis, and pain (Nieder et al., 2017, Vinod and Hau, 2020). Palliative thoracic RT is tailored to the individual patient, and its effectiveness depends on dose, fractionation, duration, and targeted symptoms (Beck et al., 2017, Guhlich et al., 2022). The timeframe for experiencing symptom relief typically ranges from weeks to months after treatment completion (Jones and Baldwin, 2018). However, patients may still experience residual disease-related symptoms as well as radiotherapy-related side effects. RT-related side effects vary in terms of prevalence, frequency, severity, and burden. Acute side effects, such as fatigue and skin irritation, typically occur during or shortly after palliative thoracic RT and usually subside within a few weeks to 3 months (Khandelwal et al., 2024). In contrast, late side effects, such as scarring and lung fibrosis, may develop months after treatment, with a gradual onset and potential long-term persistence (Jones et al., 2014).

Because of the average survival time of about eight months, providing care to support patients with advanced lung cancer is key (Rueda et al., 2011) If disease-related symptoms and RT-related side effects are not adequately managed, they can lead to unplanned hospital visits, an increased burden, and reduced health-related quality of life. To enhance patient care and outcomes, it is essential to gain a comprehensive understanding of the frequency, severity, distress caused by and manifestation patterns of disease-related symptoms and RT-related side effects throughout palliative thoracic RT (Mercadante et al., 2017). This enhanced knowledge can enable multidisciplinary teams to work proactively towards tailored symptom control and can empower patients and families to self-manage at home (Carnio et al., 2016, Tocchi et al., 2015).

1.2.3 The patient's experience of advanced lung cancer/factors that moderate this experience

A patient's experience of lung cancer is often characterised by a variety of distressing symptoms, accompanied by physical and psychological burdens (Wong et al., 2017). These burdens can originate from the disease itself but also from its treatment, and cross the realms of physical, mental, social, and spiritual well-being and include different attributes of symptoms, for example severity, frequency, and the distress the symptoms cause (Basch et al., 2012). Advanced-stage cancer brings a wide range of symptoms, encompassing pain, nausea, vomiting, appetite loss, fatigue, and insomnia (Mohile et al., 2011, Piamjariyakul et al., 2010).

Psychological problems in patients with advanced cancer can include stress, anxiety, and uncertainty, fear of disease progression or death, loss and worries about loved ones, changes in social life, fear of recurrence, fear of disease distribution, hopelessness, depression, psychological problems, and depression (Kolsteren et al., 2022). The extent of symptoms curtails a patient's participation in social engagements. The inability to fulfil social and gender-based roles, coupled with isolation and financial difficulties, has a negative effect on the patient's role in the family, resulting in suffering (Samuelson et al., 2012, Sun et al., 2016). Many symptoms are intertwined with adverse outcomes in the context of advanced cancer, leading to functional impairment and a decline in functional capacity (Trajkovic-Vidakovic et al., 2012). To bridge the gaps in the existing literature, this study seeks to paint a comprehensive picture of the symptom experience within this specific context.

Early recognition and prompt management of acute side effects can prevent these side effects from persisting over time. This thesis examines the evaluation and treatment of radiation toxicity relating to lung cancer and emphasises the multidisciplinary team's role in assessing and treating patients with this condition (Majeed and Gupta, 2022). However, this role and the implications of it in Thailand, which is characterised as having a religious and family-oriented culture and is often affected by political turmoil, remains unclear. Diverse patient-related factors contribute to variations in symptom relief and the manifestation of side effects, underscoring the need for individualised care and monitoring for optimal outcomes (Stevens et al., 2015). Factors such as cancer stage and the patient's overall health can influence a patient’s specific symptom profile and their response to palliative thoracic RT (King et al., 2022). A lower functional status is a predictor of a higher level of symptom experience in patients receiving palliative RT for lung cancer, as it is linked to a higher physical burden and worse well-being (Wong et al., 2017, Zeng et al., 2012).

Many patients with cancer contend with draining symptoms linked to the disease or the toxicity of treatment. If these symptoms evade timely detection, they can become exacerbated, resulting in needless suffering, avoidable hospitalisation, and even fatalities. Past studies underscore that up to 50% of patients' symptoms escape notice by their care teams (Maguire et al., 2013, Hsieh et al., 2018). For advanced cancer patients undergoing RT, a multidisciplinary approach can enhance their quality of life (QOL). Notably, patients who completed their RT regimen reported a reduction in the usage of sleeping aids (Gentry et al., 2020).

The term "symptom experience" is used prominently in this thesis, necessitating a clear definition in the context of the subject matter. A symptom is characterised as a personal, subjective encounter reflecting alterations in an individual's biopsychosocial functioning, sensations, or cognitive processes (Dodd et al., 2001). The notion of symptom experience encapsulates a simultaneous perception, assessment, and response to deviations from one's usual state. These deviations may vary in terms of frequency or intensity. Furthermore, an intervention strategy may not necessarily alter the frequency or severity of a symptom; however, it can effectively mitigate the distress linked with it (Humphreys et al., 2013). Therefore, pinpointing symptoms could enhance our grasp of the symptom assessment and treatment in nursing practice and to suggest questions and hypotheses for nursing research.

1.2.4 Patients’ experiences during palliative radiotherapy

Navigating patient-caregiver experiences during palliative radiotherapy can present intricate challenges encompassing the management of physical symptoms, emotional turmoil, and communication hurdles. One of the most formidable hurdles faced by patients and caregivers in the realm of palliative RT is effectively managing symptoms, particularly pain. Research has revealed that patients undergoing palliative RT often grapple with pain, which can prove arduous to control and can substantially affect their quality of life. Caregivers, too, may encounter difficulties in addressing their loved one's pain, potentially leading to emotional distress (Cheng and Chen, 2023, Chi et al., 2016).

Various variables influence the experiences of both patients and caregivers. For patients, these are factors such as gender, primary cancer type, and prior surgeries, and for caregivers, aspects like gender, co-residence, previous caregiving experience, and transportation mode are associated with higher caregiving-related anxiety and depression (Sung et al., 2021). Notably, caregiver and patient variables significantly predict caregivers’ anxiety and depression. Common characteristics among caregivers experiencing heightened anxiety and depression include being female, caring for male lung cancer patients, caring for non-surgical patients, cohabiting, being younger, driving the patient to appointments, having prior caregiving experience, and perceiving a greater overall burden. A deeper exploration of influencing factors is warranted to better discern predictors of caregivers' psychological well-being (Govina et al., 2019).

Beyond physical symptoms, the scope of patient-caregiver experiences during palliative RT encompasses emotional and psychosocial dimensions. Patients may grapple with anxiety, depression, and other emotional symptoms linked to their condition and treatment, while caregivers may contend with heightened stress, anxiety, and depression (Chayadi et al., 2022). Communication obstacles may arise, particularly concerning end-of-life discussions and decisions (Cheng and Chen, 2023). Furthermore, significant associations between caregiver burden and patient-related variables such as self-efficacy, sleep disturbances, and social support have been documented. Elevated patients-related symptoms such as depression, fatigue are linked to increased caregiver burden (Johansen et al., 2018).

In the context of these challenges, some studies underscore the pivotal role of supportive relationships and effective communication between patients and caregivers during palliative RT. Patients who feel supported by their caregivers and healthcare providers report better QOL and reduced emotional distress. Caregivers who perceive that there is effective communication with healthcare providers demonstrate enhanced coping mechanisms and have lower emotional distress levels (Chen et al., 2022).

In summary, the literature surrounding patient-caregiver experiences during palliative RT underscores the critical importance of holistic support for patients and their caregivers. This support entails adept symptom management, emotional assistance, and communication training for both parties. By addressing these multifaceted needs, healthcare providers can contribute significantly to enhancing the quality of life of patients and caregivers during the intricate journey of palliative RT.

1.2.5 Factors influencing the experience of symptoms

There are many factors that increase the symptoms of patients with advanced lung cancer undergoing RT. The predictors (age, gender, cancer type, performance status) are likely to influence the severity, type, and duration of symptoms experienced by patients undergoing RT. For example, older patients might experience more fatigue, while those with poorer performance status might have more intense pain or shortness of breath (Fraser et al., 2019, Koch et al., 2020, Llamas-Ramos et al., 2022, Pandya et al., 2019, Wong et al., 2017). Repeated investigation of the experience of symptoms of patients with lung cancer is crucial, as symptoms fluctuate during the course of radiation therapy sessions. Repeated and consistent assessment of specific symptoms can empower patients to recognise, interpret, and address symptoms early on.

However, even routine inquiries by healthcare providers may not yield results until patients grasp the significance of specific symptoms and comprehend how to monitor by themselves. Recognising symptoms allows for early intervention. This could involve medication, lifestyle adjustments, or other therapies to manage the symptoms effectively (Kotronoulas et al., 2017). Psychosocial care addresses the emotional and mental well-being of the patient, which is crucial for coping with the disease and treatment. By combining these approaches, patients are better equipped to manage their symptoms, improve their quality of life, and potentially even improve treatment adherence (Singer et al., 2017). Recognising physical symptoms and providing supportive and psychosocial care should be developed to reach a better outcome for patients with advanced lung cancer during treatment and after treatment.

By emphasising symptom management and information need, there is a substantial opportunity to enhance symptom identification and early interventions, thereby averting complications and improving outcomes. Early identification of symptoms in patients with advanced lung cancer is critical for prompt management and improved outcomes. Addressing symptoms like pain, fatigue, and nausea proactively can prevent escalation, complications, and improve treatment tolerance, potentially enhancing survival. Early intervention also leads to a better quality of life throughout the treatment journey. Empowering patients through education and communication enables them to self-monitor and report symptoms, facilitating timely interventions and better symptom control. Furthermore, integrating technology like patient-reported outcome measures (PROMs) can enhance symptom monitoring and facilitate early intervention, ultimately contributing to better patient well-being and treatment outcomes (Payne et al., 2023).

1.3 Background to caregivers’ burden

1.3.1 Caregivers

The impact of cancer extends beyond patients, affecting their immediate social circles. Limited research has addressed the mental health and needs of patients’ caregivers. Lung cancer patients and their families face various disease- and treatment-related symptoms, financial challenges, and changes in overall health status. Family members often take on increased responsibilities when caring for patients during advanced stages of cancer. Studies by Islam et al. (2016) and Adelman et al. (2014). underscore the importance of addressing gaps in patient engagement and caregiver burden. Enhancing patient-provider communication, improving patient navigation, and implementing new patient orientation programmes are recommended to enhance healthcare outcomes. Factors contributing to caregiver burden include having a female gender, a low education level, co-residence with the care recipient, extended caregiving hours, depression, social isolation, financial distress, and lack of choice regarding assuming the caregiver role. Multicomponent interventions have been identified as being the most effective, with the components 'needs assessment' and 'psychoeducation' showing particular effectiveness (Becquéa et al., 2019).

Guiding someone through a cancer diagnosis, treatment, and recovery requires understanding, encouragement, patience, and substantial energy. Caregivers take on diverse roles, serving as advocates, nurses, organisers, and financial analysts (Morgan et al., 2022). The emotional and physical toll of caring for someone with a life-threatening illness can be draining, often causing caregivers to overlook their own needs. Despite the dedication to a loved one's care, caregiver burnout is a legitimate concern. It is crucial to maintain control over one's life, avoiding complete immersion in the loved one's illness. (Søvold et al., 2021). Encouraging assistance from others, educating oneself about the patient's condition, and promoting the loved one's self-sufficiency are key strategies, along with acknowledging periods of sadness and connecting with fellow caregivers for shared experiences and support (Kilic & Oz) (Kotronoulas et al., 2017). Caregiving often results in chronic stress, impacting caregivers' physical and psychological health. Depression is a common negative effect of caregiving. However, caregiving can also be beneficial, allowing caregivers to feel good about themselves, learn new skills, and strengthen family relationships (Schulz and Sherwood, 2008).

1.3.2 Caregiver burden

Caregivers provide complex care to patients with advanced lung cancer without proper preparation (Tan et al., 2018). Dealing with advanced lung cancer presents a multifaceted challenge that imposes both physical and emotional burdens on patients and their caregivers. Caregivers play a pivotal role in attending to the patient's physical well-being, managing symptoms, ensuring medication adherence, and facilitating communication with healthcare professionals. In addition to these practical responsibilities, caregivers provide indispensable emotional support, aiding patients in maintaining social connections. As the ageing population increases, the significance of caregivers grows, but it is anticipated that the available pool of caregivers will decrease. The conceptual understanding of caregiver burden guides the design of specific interventions to identify and prepare the caregiver for their critical role (Morgan et al., 2022). Additionally, since caregiver burden is closely linked to the patient's disease progression, the needs of informal caregivers often fluctuate over time. As the patient's symptom burden increases, caregivers’ distress and anxiety also rise (Badr et al., 2015).

Zarit, Todd, and Zarit (1986) proposed a comprehensive definition of caregiver burden: the degree to which caregivers perceive that caregiving has adversely affected their emotional, social, financial, physical, and spiritual well-being. The prevalence of caregiver burden has risen due to an ageing population, a higher number of individuals living with chronic illnesses, and a lack of formal support for caregivers (Adelman et al., 2014). Three core aspects characterise caregiver burden: the caregiver's self-perception, the multifaceted strain experienced, and the time invested. Contributing factors include insufficient financial resources, conflicts arising from numerous responsibilities, and a lack of opportunities for social engagement. The repercussions of this strain encompass a decline in the quality of care provided, a reduction in the caregiver's quality of life, and deterioration in their physical and mental health.

Caregiver burden is a dynamic, multifaceted strain experienced by caregivers of advanced-stage cancer patients, closely intertwined with the evolving needs of the patient throughout the course of the disease (Morgan et al., 2022). The defining attributes of caregiver burden of the advanced-stage cancer patient were identified as decreased self-efficacy, a decreased quality of life, increased anxiety, increased depression, and time sensitivity. Antecedents were identified as predictors of negative outcomes without intervention. The consequences for those who are not supported were highlighted. Previous studies indicate a significant association between caregiver burden and being female, having limited educational attainment, cohabitating with the patient, providing long-term care, experiencing underlying depression, facing social isolation, and encountering financial constraints (Adelman et al., 2014, Morgan et al., 2022). Furthermore, caregiver burden exhibits positive correlations with symptoms of depression and anxiety (Yuen and Wilson, 2021).

The concept of caregiver burden has pivotal significance in this study, necessitating a clear definition for contextual clarity. Generally, caregiver burden refers to the perceived emotional, social, physical, financial, and/or spiritual strain experienced as a result of providing care (Zarit et al., 1980). It's crucial to acknowledge that the impact of cancer and its associated treatments extends beyond patients to encompass family caregivers. Leonidou and Giannousib (2018) expound upon the variability in caregivers' experiences, which are contingent upon factors such as the illness stage, the nature of their relationship with the patient, and the type and frequency of care rendered. In their analysis, they discern four overarching themes characterising caregiver experiences: challenges arising in their caregiving role, the reverberations of a cancer diagnosis on interpersonal connections, available support networks and inner strength resources, and unaddressed needs.

El-Jawahri et al. (2017) demonstrated a clear link between elevated levels of caregiver burden and more adverse psychological outcomes. Consequently, recognising the intricate interdependence between the health outcomes of caregivers and patients underscores the imperative of viewing these two entities as an inseparable unit (Tan et al., 2018). However, it remains pertinent to acknowledge that patients and caregivers alike need to navigate symptom management at home, engage in self-management strategies, and access comprehensive information regarding lung cancer and its potential side effects.

1.3.3 Caregiver burden in the context of palliative thoracic radiotherapy

When it comes to patients with advanced lung cancer undergoing RT, the treatment journey can be incredibly demanding for both the patient and their caregiver. RT, while essential for treatment, can induce a range of side effects that may impede the patient's ability to carry out daily activities, necessitating increased support from their caregiver. Notably, caregiver burden in the realm of cancer care has shown a positive association with symptoms of depression and anxiety (Yuen and Wilson, 2021). Additionally, the impact of RT on a patient's quality of life can lead to feelings of depression, anxiety, and social isolation (Lindell and Danoff, 2021). Consequently, caregivers often face substantial challenges, including heightened responsibilities for daily care, financial stress, and emotional turmoil. The demands of caregiving can also result in social isolation, fostering sentiments of loneliness and depression (Northouse et al., 2013).

Research on interventions has yielded notable insights. In one study, the group that had early palliative interventions experienced significantly greater improvement in depression scores from baseline than those whose interventions were delayed (Dionne-Odom et al., 2015). In a study involving the Vivekananda Yoga Program for patients with advanced lung cancer and their caregivers, significant improvements were observed in patients' mental health and caregivers' sleep problems. Moreover, mild improvements in caregivers' physical functioning were also recorded (Milbury et al., 2015). Psychosocial interventions have also shown promise, with interventions targeting caregivers' self-care and interpersonal connections as well as patients' symptom management effectively reducing depression among caregivers. Meanwhile, a systematic review showed music therapy to cancer caregivers emerged as a valuable approach for alleviating caregivers' anxiety and depression (Fu et al., 2017).

In conclusion, the weight borne by caregivers of patients with advanced lung cancer undergoing RT is a significant concern demanding dedicated attention and support. Caregivers need resources to navigate both the physical and the emotional demands of caregiving, alongside financial and social support. Acknowledging the burden caregivers face enables healthcare professionals to better cater to the holistic well-being of both patients and their dedicated caregivers.

1.3.4 Factors influencing caregiver burden

The impact on spouses and partners is especially pronounced, as marriages and long-term relationships are particularly susceptible to the challenges posed by cancer. The aftermath of a cancer diagnosis can trigger emotions ranging from despair and worry to anger and even hopelessness (Lütscher et al., 2022). The impact of cancer varies among couples, with some experiencing strengthened bonds through shared adversity while others grapple with new or exacerbated difficulties. Partners might assume the role of a disease "expert", coordinating treatment schedules or liaising with medical staff, to regain a semblance of control. This strategy, if comfortable for both parties, can help patients to cope. However, maintaining adaptability and attending to each other's needs remains crucial (Cheng and Chen, 2023).

Various patient-related characteristics play a role in shaping caregiver burden. Elements such as self-efficacy, sleep disturbances, and social support have demonstrated significant connections to caregiver burden. Notably, higher levels of depression, fatigue, and symptoms in patients were notably linked to an elevated caregiver burden (Hannon et al., 2015). The gender factor also influences the equation, with both female patients and female family caregivers showing an increased likelihood of experiencing fatigue and sleep disturbances.

Female caregivers, partners, and those cohabiting with the patient with a low educational level were found to be more susceptible to heightened anxiety and depression symptoms, severe impacts of caregiving on their lives, compromised health, and diminished quality of life. Multivariate analysis underscored that psychological distress was the lone predictor of global health and quality of life (Iconomou et al., 2001, Johansen et al., 2018).

Patients and their families present a spectrum of needs encompassing physical, psychological, social, and spiritual dimensions, in addition to informational needs. Patients chiefly seek symptom management, a dignified appearance, compassionate care, the presence of family members, respect, and a comfortable environment. Families yearn for pertinent information, knowledge, and facilities that will enhance their caregiving capabilities. They depend heavily on healthcare professionals to assist them with patient care (Cheng and Chen, 2023). In one study, the correlation between caregiver burden and depressive and anxious symptoms was positively influenced by perceived social connectedness. Interestingly, increased social connectedness led to a diminished association between caregiver burden and depression, even after controlling for significant demographic and caregiver-related factors (Yuen and Wilson, 2021). At a 4-month follow-up, all caregiving experiences exhibited correlations with dimensions of spiritual well-being. Spiritual well-being encompasses various dimensions, including a sense of meaning and purpose in life, feeling connected to something greater than oneself, having faith in something beyond the physical world, maintaining hope for the future, and experiencing inner peace and harmony. These dimensions contribute to a holistic sense of well-being that extends beyond physical and mental health (Baykal, 2023). However, a multivariate analysis highlighted that caregivers' perceptions of family support stood as the sole caregiving experience associated with spiritual well-being at this juncture. Specifically, a lack of familial support was linked to having lower levels of meaning and peace (Adams et al., 2014). In summary, family support matters for our well-being, and understanding its impact can guide interventions and support systems.

A range of factors such as gender, lower educational attainment, co-residency with the care recipient, a high number of caregiving hours, depression, social isolation, financial strain, and lack of choice in taking up a caregiving role contribute to an increased caregiver burden. Various practical methodologies are available for evaluating caregiver burden that encompass caregivers and care recipients and the overall care requirements. Meta-analyses underscore the mild to moderate efficacy of several psychosocial and pharmacological interventions in alleviating caregiver burden and its accompanying indicators of distress (Secinti et al., 2023). These interventions often yield improvements in symptoms linked to caregiver burden (Adelman et al., 2014).

In summary, the caregiver burden is influenced by several factors and especially affects spouses and partners in marriages and long-term relationships. Key factors affecting caregiver burden include patient-related characteristics such as self-efficacy, sleep disturbances, and social support. Higher levels of patient depression, fatigue, and symptoms correlate with increased caregiver burden, particularly for female caregivers and those with lower qualifications or those who co-reside with the patient. Patients and families need support in various areas, and families rely on healthcare professionals for assistance. Social connectedness can reduce the impact of caregiver burden on depressive symptoms. Family support is crucial for caregivers' spiritual well-being, with a lack of support linked to a lower level of a sense of purpose and well-being. Contributing factors to caregiver burden include gender, a lower education level, co-residency, high caregiving hours, depression, social isolation, financial strain, and a lack of choice regarding taking on a caregiving role. Psychosocial and pharmacological interventions can moderately alleviate caregiver burden, and the distress associated with it.

1.4 Background to information needs

Many national health service programmes are patient-centred, so they are designed to empower patients to actively participate in decision-making regarding their treatment and care. Ethically and legally, healthcare providers have a duty to obtain valid consent for all investigations and treatments. For patients to provide valid consent, they must receive sufficient and clear information to inform their decisions. While providing crucial information at the consent stage is essential, healthcare providers should also address information needs at other stages of the patient's care pathway. Receiving a cancer diagnosis is a highly distressing time for patients and their families and thrusts them into an unfamiliar situation where effective patient-centred information is vital for their well-being and treatment success Durnin et al. (2021). While the physiological needs of RT patients may be well supported through information leaflets, the personal information needs of these patients and the information needs of caregivers appear to be less effectively managed.

Information needs assessment is one of the cornerstones of cancer care, and the pivotal concept of information needs takes centre stage in this research. Information needs pertain to the essential knowledge needed to relieve confusion, anxiety, and fear; to facilitate informed decision-making for individuals or families; and to aid in the acquisition of coping skills (Fitch, 2008). While some individuals, with the help of appropriate information and a supportive rapport with their cancer care team, are able to harness their own coping resources when navigating their cancer experiences, others need supplementary support (Fitch and Steele, 2010). Information is significant for several reasons: it underpins the design of personalised patient care, it guides decisions regarding resource allocation; and it highlights potential avenues for enhancing the quality-of-care delivery (Fitch and Steele, 2010).

Information concerning symptom self-management is of paramount importance for patients, empowering them to proactively manage certain symptoms before they intensify. However, for outpatients, the emphasis is on information concerning managing symptoms and complications at home, including strategies for symptom control. Connected to this is the necessity of addressing the unmet needs of this patient population regarding supportive care (Kotronoulas et al., 2017). Improving the quality of care provided to patients with advanced lung cancer requires gaining a clear understanding of their needs, taking steps to increase clinicians’ awareness of such needs, and identifying innovative ways to offer a comprehensive care intervention. Hence, delving into patient and caregiver information needs becomes paramount.

1.4.1 The concept of information needs

The concept of information needs pertains to the essential information individuals require to grasp their diagnosis, explore available treatment choices, understand a prognosis, and effectively manage symptoms and treatment side effects. Within the context of patients with advanced lung cancer undergoing palliative RT, information needs take on a comprehensive and multifaceted nature. These needs encompass not only medical insights but also practical guidance, emotional support, and psychological assistance.

Studies underscore the fact that lung cancer patients and their family caregivers often shoulder substantial burdens and grapple with substantial information needs during symptom self-management. A considerable proportion of caregivers (71.4%) face intense emotional burdens while caring for their afflicted relatives during cancer treatment, leading to unmet needs for emotional and psychosocial support (Borges et al., 2017). The bulk of these unmet needs pertain to information about treatment and information about how patients can be involved in treatment decisions (Lütscher et al., 2022). Both patients and caregivers seek information actively and display substantial information needs (Durnin et al., 2021).

Recent research aimed at comprehending the symptom experience of individuals with lung cancer highlighted fatigue and discomfort as the most frequently cited symptoms. However, the study also underlined that these patients concurrently grappled with multiple symptoms (Kiteley and Fitch, 2006) . Another investigation by Chen et al. (2016) delved into the unmet supportive care needs of caregivers who had a family member with post-operative oral cancer. The study, involving 102 participants, identified caregivers' foremost needs in terms of information and healthcare system support. It also pinpointed factors associated with caregivers' unmet needs. The study found that the severity of patients' symptoms and lack of familial support were tied to caregivers having unmet supportive care needs.

1.4.2 Information needs of patients with advanced lung cancer

The diagnosis and treatment of cancer have profound effects encompassing social, emotional, psychological, spiritual, and practical dimensions for those grappling with the illness. As the disease progresses and symptoms intensify, patients encounter numerous challenges as they try to navigate their circumstances. A significant number of patients experience unmet needs regarding personal care, information dissemination, communication, occupational functionality, and emotional connection, and these are linked to reduced functioning (Fitch and Steele, 2010). Supportive care needs (SCNs) entail the need to manage patients' symptoms and side effects, to promote adaptation and coping mechanisms, to enhance comprehension and informed decision-making, and to mitigate functional deficits. Identifying and addressing these needs can mitigate patient distress, enhance their quality of life, alleviate dissatisfaction with treatment, and, consequently, curb escalating healthcare utilisation and costs (Maguire et al., 2013).

The concept of information needs among cancer patients undergoing RT encompasses the type and quantity of information needs that must be met for informed decision-making, comprehension of the treatment journey, and effective management of treatment side effects. Ensuring the provision of sufficient information is crucial for fostering patient contentment, adherence to treatment, and overall well-being. Although healthcare providers (HCPs) are a primary source of information for patients and caregivers, factors such as time constraints, varying communication styles, and individualised needs can sometimes hinder comprehensive information transfer. Consequently, patients and caregivers often seek information from reliable online resources, support groups, and libraries. To optimise information exchange, patients and caregivers should prepare questions in advance, be proactive in seeking clarification, utilise teach-back methods, and explore reliable sources. HCPs can enhance communication by using clear language, providing tailored information, encouraging dialogue, offering written resources, and utilising technology for information sharing. Patients' greatest need for information often pertains to symptom management, with fatigue, shortness of breath, and cough being prominently mentioned (Giuliani et al., 2016). Patients recognise the value of information-seeking as an effective strategy for optimising their physical and mental health and managing symptoms and disease outcomes (Dongen et al., 2020). This drive for information persists throughout the various stages of cancer management, including diagnosis, treatment, follow-up, and survivorship.

Supportive care constitutes a pivotal aspect of managing lung cancer and caters to the distinctive needs of both patients and caregivers. It encompasses a wide array of services and interventions aimed at enhancing the quality of life of individuals with cancer. It aims to deal with the management of physical symptoms like pain, fatigue, and breathlessness, while also addressing psychosocial needs such as anxiety, depression, and social isolation. Given the prevalence of physical and psychological symptoms linked to the disease and its treatment, individuals with lung cancer require substantial supportive care (Giuliani et al., 2016). However, there might be instances where healthcare routines fall short in addressing patient needs. Supportive care might not always cover all needs. Due to an often-dire prognosis, many individuals with lung cancer experience a rapid and aggressive disease trajectory. The severity of symptoms tends to escalate, challenging daily activities. Historical records have documented symptoms like breathlessness, coughing, anorexia, and weight loss (Sarna et al., 2004).

Studies reveal that patients with advanced lung cancer undergoing palliative RT exhibit a strong appetite for information. Research by Durnin et al. (2021) highlighted patients' considerable demand for knowledge about their illness and its management, encompassing treatment choices and the prognosis. Although findings concerning the influence of age, diagnosis, family history, and education status on patients' information-seeking behaviours and preferences are inconclusive, it's apparent that informational needs are diverse and context-dependent. In the study conducted by Palmer et al. (2020) in cancer survivors, an average of four health information needs were identified. The most prevalent domains were side effects and symptoms, health promotion, and tests and treatment. Participants who were younger, had an ethnic minority background, lower levels of education, or experienced financial stress exhibited a higher number of information needs.

Information-seeking patterns evolve over time for lung cancer patients, yet the enduring need for information regarding cancer recurrence and metastasis underscores the importance of effective communication between healthcare providers and patients. This communication should also address patient concerns about nutrition, social welfare resources, and holistic recovery information. Understanding patient-specific needs while considering factors such as age, gender, disease stage, education, employment, and familial responsibilities is essential for tailoring communication and educational programmes (Hsieh et al., 2018).

Age, gender, disease stage, education, employment status, and the presence of children were found to be significantly associated with information needs across multiple subscales over time; therefore, clinical healthcare providers should consider these factors and prepare structured and culturally appropriate content when communicating medical information to lung cancer patients. In addition, Hsieh et al. (2018) found that patients with lung cancer were most concerned about the disease itself and gaining access to recovery-related information. In addition, there was a high demand for information regarding diet and social welfare resources. However, information needs in each domain have decreased significantly over time.

Halkett et al. (2010) identified patients with breast cancers' specific information needs during RT, highlighting that these needs were most pronounced during their initial appointment with their radiation oncologist and at the planning appointment. The study also indicates that patients continue to express information needs throughout treatment, even if they've received information previously.

In conclusion, cancer patients undergoing RT exhibit distinct information needs encompassing treatment-related aspects, side effects, prognosis, and expected outcomes. Providing personalised, comprehensive information tailored to individual preferences can improve patient satisfaction, enhance their overall treatment journey, and enable effective collaboration between healthcare providers and patients.

1.4.3 Caregivers’ information needs regarding lung cancer

Family caregivers are individuals who provide unpaid care for a loved one who is dealing with illness or disability. This caregiving role can bring about emotional and physical challenges, often leading caregivers to seek information to better comprehend their loved one's health condition, offer improved care, and manage their own well-being. This collection of information that caregivers seek is termed their "information needs". Throughout the progression of the illness, caregivers encounter changing roles and must adapt accordingly (Flemming et al., 2019).

A study of caregivers for individuals with advanced lung cancer found that their most significant unmet needs included access to information about the disease and available resources, better communication and coordination with healthcare providers, and assistance with daily living tasks such as transportation and household chores. It was observed that caregiver-reported patient anxiety and sleep problems predicted the overall supportive care needs of caregivers. There was a positive correlation between patient anxiety and caregivers’ needs concerning healthcare professionals/services, interpersonal communication, and psychological/emotional support. Caregivers' fatigue was linked to their informational and healthcare professional/service needs. Moreover, caregivers' sleep disturbances were associated with their overall caregiving needs, their needs relating to everyday tasks, and psychological/emotional support (Chen et al., 2016).

A caregiver is an individual who helps a person who is unable to care for themselves with healthcare tasks or helps someone who requires assistance to manage their illness or cancer treatment (Chen et al., 2016, Morgan et al., 2022). Caregivers are pivotal resources for patients; however, their emotional strain and individual needs often remain inadequately addressed (Lütscher et al., 2022). Providing useful information to caregivers equips them to respond effectively to patients’ symptoms, conceivably alleviating the caregiving burden. The information needs of patients and families are intricately tied to their unique circumstances, with priorities often undergoing shifts during the course of cancer treatment (Durnin et al., 2021). The top unmet supportive care need found in one study among all caregivers was concern about cancer recurrence (44.5%) (Pongthavornkamol et al., 2019).

Numerous studies have delved into the information needs of family caregivers, revealing that they frequently require information on various topics, including:

- The disease or condition: Caregivers want to know the specifics of the disease or condition affecting their loved one, encompassing its origins, symptoms, advancement, and potential treatments. This knowledge helps caregivers to comprehend what lies ahead and how to provide suitable care (Cheng and Chen, 2023).
- Medication management: Caregivers seek guidance on effectively managing their loved one's medications, encompassing dosages, potential side effects, and interactions with other drugs (Zhu et al., 2021).
- Self-care: Caregivers also seek information about maintaining their own well-being, including stress management, maintaining their health, and locating resources that support their individual needs, thus enabling them to be more effective caregivers (Cheng and Chen, 2023, Zhu et al., 2021).
- Community resources: Information about community resources such as support groups, respite care, and financial aid is also relevant to caregivers (Zhu et al., 2021).
- Communication with healthcare professionals: Effective communication with healthcare providers is crucial for caregivers. This involves knowing how to ask pertinent questions, grasping medical terminology, and advocating for their loved one's needs (Zhu et al., 2021).
- Legal and financial matters: Caregivers might require knowledge of legal and financial aspects associated with caregiving, including power of attorney, guardianship, and insurance (Bonacchi et al., 2019).

For family caregivers, the impetus to seek information stems from a desire to alleviate stress, support their loved one's decisions, and play a role in the decision-making process. Healthcare providers grapple with the challenge of fulfilling family caregivers' information needs, especially when they aren't always present during consultations. Constraints on consultation time and appointments further complicate this dynamic, with healthcare providers often focusing primarily on the patient's needs (Durnin et al., 2021). Home circumstances also impact information needs, with patients without a caregiver expressing a greater demand for information. However, including family caregivers in information-sharing sessions can streamline the process and reduce the time required.

The perception of caregivers regarding symptom experiences and information needs similarly imposes a weight on caregivers throughout a patient's treatment trajectory. Insights from the relevant academic literature will guide healthcare providers when they are devising individualised care strategies and constructing an informational framework for patients and their caregivers for self-managing symptoms at home. Hence, the primary aim of this study is to scrutinise the trajectory of symptom burden in patients, the parallel burden of caregiving, and the requisites of both patients and caregivers concerning information regarding patient-driven self-management of symptoms at home, specifically during palliative RT for lung cancer. The iterative assessment of this dual burden and the information needs linked to self-managing symptoms at home can empower healthcare professionals to forge bespoke services and care plans for patients and their caregiving family members. Additionally, the study will delve into psychosocial and clinical predictors underpinning the emergence of symptom burden among patients and the burden of care among caregivers, as well as the need of both groups for information. The predictive insights that emerge are poised to enable healthcare professionals to pinpoint patients and caregivers who are susceptible to distress during the course of palliative radiation therapy for lung cancer.

During the early stage of palliative therapy, it is standard practice to address caregivers' specific support needs (Lütscher et al., 2022). As stated by Sanson-Fisher et al. (2000), a need for supportive care signifies a requirement for assistance or support resources to be provided where assistance is sought. In the context of this study, the researchers defined the need for supportive care among family caregivers of patients with advanced lung cancers as their desire to receive support and responses. This encompasses their need for comprehensive care for the patient's cancer-related challenges, for the emotional and psychological aspects, support in relation to the impact on patient care routines, and a consideration of spiritual concerns.

The study of emotional burden and needs of caregivers of patients with brain metastases stated that most caregivers said that they had unmet needs regarding emotional and psychological support, primarily linked to information needs and participation in patient treatment decisions throughout the cancer journey (Lütscher et al., 2022). Additional unmet needs included addressing patients' personal concerns and apprehensions related to daily care tasks and effective communication. Inadequate information provision might lead to trial-and-error caregiving, and the caregivers longed for accurate information and training in home care practices. They sought assistance concerning managing daily patient routines and desired updates on disease progression (Chen et al., 2016).

Certain caregiving situations may lead to caregiver burden and stress, such as the need for extensive assistance in daily activities, social isolation, and financial strain due to illness and caregiving responsibilities (Adelman et al., 2014). Clinicians should assess caregivers' overall well-being, their confidence regarding providing care, and any requirements for additional support. Sklenarova et al. (2015) examined unmet needs among caregivers for people with cancer and predictors of supportive care needs. The study classified supportive care needs as having four domains: healthcare system and information needs, emotional and psychological needs, work, social, and safety needs, and communication and family needs. One of their findings was that of 118 caregivers for cancer patients, 14.4% indicated that they experienced a low level of responsiveness from clinicians to the needs they expressed, 42% reported moderate responsiveness, and 13.6% reported no responsiveness at all. To enhance support for caregivers of cancer patients, healthcare systems must prioritise increased awareness and training for healthcare providers on caregiver needs, including communication skills and empathy. Establishing clear communication channels, such as regular check-ins and support groups, is crucial. Implementing standardised screening tools can help to identify caregiver burden and unmet needs, enabling the provision of tailored support services like counselling and respite care. Empowering caregivers with knowledge and resources, including disease education and coping strategies, is essential. Finally, fostering collaboration among healthcare providers, social workers, and community organisations can create a comprehensive support system for caregivers, ultimately benefiting both the caregiver and the patient (Molassiotis and Wang, 2022).

Younger caregivers were more likely to report moderate or high levels of unmet needs in psychological and emotional domains, as well as in work and social domains. The prevalence of unmet needs in healthcare systems and information domain varied depending on the type of cancer that the relevant patient had. Additionally, individuals experiencing anxiety or depression were more prone to report moderate or high levels of unmet needs across all domains compared to those who did not have these conditions (Girgis et al., 2011). A follow-up study by Girgis et al. (2013) examined the need for supportive care and the correlating factors among caregivers during the 24 months following a patient's epilepsy diagnosis. The study noted a decrease in supportive care needs over time, but nearly one-third of caregivers still had ongoing needs at the 24-month mark. Factors that emerged as being correlated with reduced supportive care needs were addressing concerns related to cancer recurrence, reducing the stress of living with cancer, comprehending the patient's experience, and addressing logistical needs, such as needing to park at the hospital.

Furthermore, a study by Zhu et al. (2021) highlighted the increasing need for information about end-of-life care among caregivers and emphasised a patient-centred approach for addressing organisation, education, emotions, and communication. Caregiver burden was observed, particularly among male, well-educated, and long-term caregivers of cancer patients. Psychological symptoms were prevalent, necessitating focused management within palliative care.

Nurses must evaluate and cater to caregivers' quality of life needs, while caregivers require comprehensive information about caregiving practices and the patient's condition that encompasses health education regarding the disease, medications, diet, rehabilitation, and exercise.

Both patients and caregivers present a range of supportive care needs, including needs relating to disease management and information about treatment, emotional support, communication with healthcare professionals, and practical assistance with daily activities. Patients might require symptom management, pain control, and palliative care services, while caregivers may benefit from respite care and information about caregiving. The healthcare team's systematic assessment and addressing of these needs are crucial for providing comprehensive and patient-centred care.

In conclusion, caregivers have a range of information needs that are tied to their caregiving duties. Addressing these needs can enhance caregiving experiences and alleviate burdens. Healthcare professionals should acknowledge these needs and offer education, support, and resources to empower caregivers to comprehend their loved one's condition and provide effective care.

1.4.4 Providing information: timing

Several studies have explored patients' satisfaction with receiving information at different time points during the treatment period (Cheng and Chen, 2023, Durnin et al., 2021, Lütscher et al., 2022). However, there is no consensus on the ideal timing for providing information. It has been observed that information needs and information-seeking behaviours of patients tend to evolve over time. The prevailing consensus is that patients' information needs should be frequently assessed and personalised information should be provided throughout the course of RT (Lütscher et al., 2022).

Information needs change over time, so it is evident that a dynamic approach, rather than a fixed strategy, is more appropriate. Revisiting and reinforcing information provision at different time points might enhance how effective a person’s comprehension of that information can be. Regarding the optimal timing for delivering cancer-related information, inconsistent data have been noted, emphasising that therapeutic radiographers should not assume that their information priorities align with those of their patients. Each patient possesses distinct and specific information needs (Durnin et al., 2021).

1.4.5 Information format

The information format pertains to the structure and organisation of the information relayed by healthcare professionals to patients and their caregivers. Ensuring effective communication of information in this context is crucial to enable patients and caregivers to comprehend the treatment plan, potential side effects, and strategies for managing any symptoms that arise. A study examined information format preferences and found that patients and caregivers favoured two shorter consultations supplemented with written and online information over a single lengthy consultation or written information alone when making decisions about cancer treatment. This outcome reinforces the idea that providing information to cancer patients is an ongoing process (Herrmann et al., 2018).

Effective communication in cancer care necessitates a dynamic, two-way exchange of information between healthcare professionals, patients, and caregivers. This collaborative approach ensures patients and caregivers fully comprehend treatment plans, potential side effects, and symptom management strategies. A study found that patients and caregivers preferred shorter consultations supplemented with written and online resources for ongoing information delivery (Herrmann et al., 2018). By actively asking questions, confirming their understanding and providing feedback, patients and caregivers contribute to a more effective information exchange, leading to greater satisfaction and improved adherence to treatment plans.

The way information is presented can significantly influence a patient's ability to remember and understand it, particularly when information is delivered in a single instance. In the contemporary technological landscape, patients and caregivers often turn to the internet and other sources for information.

Telephone hotlines and online support are also emerging as convenient methods for obtaining information. However, the utilisation of these resources can vary based on factors like age. Younger patients tend to seek more detailed physiological information online, while older patients place greater emphasis on face-to-face or telephone communication (Durnin et al., 2021).

While external sources like the internet are valuable, studies suggest that patients may be more hesitant to trust information from sources other than their healthcare providers (Robertson et al., 2023). Information formats such as brochures and guidance from healthcare professionals are particularly influential in encouraging patients to adhere to risk-minimisation behaviours. Healthcare providers also have a role to play in guiding patients toward reliable online information sources and clarifying the appropriateness of the information they find (Durnin et al., 2021).

Alternative information formats have been explored as well, such as virtual reality systems for conveying treatment information. For instance, a study by Stewart-Lord et al. (2016) demonstrated that patients who received information about RT through a virtual reality system exhibited better comprehension of their treatment and its potential side effects. However, such methods may have limitations due to factors like cost and time consumption. Despite the emergence of innovative information formats, patients and caregivers still value information provided by healthcare providers and prefer face-to-face interactions.

In conclusion, the effective communication of information in the context of lung cancer RT necessitates healthcare professionals considering both the format and the content of the information they provide. By tailoring information to the specific needs and concerns of patients and caregivers and offering it in diverse formats, healthcare professionals can empower patients and caregivers to make informed decisions and navigate the treatment process more confidently.

1.4.6 Information content

In the context of communication between caregivers and patients undergoing lung cancer RT, information content pertains to the specific details that healthcare professionals convey to patients and their caregivers concerning patients' treatment, possible side effects, and strategies for managing symptoms. Ensuring effective communication of information content is essential to ensure that patients and caregivers comprehend the treatment plan and are empowered to actively engage in patients' care.

Research consistently highlights the importance of providing lung cancer patients and their caregivers with specific information to enhance their understanding and satisfaction with RT treatment. Studies in cancer survivors emphasise the value of clear communication about the treatment process itself, potential symptoms, and possible side effects (Palmer et al., 2020). This knowledge empowers patients to actively participate in shared decision-making and fosters a greater sense of control during their cancer journey.

Patients undergoing palliative radiation for advanced lung cancer may also require information about effectively managing symptoms and side effects, including pain, fatigue, and nausea. Furthermore, information regarding coping strategies and available support-related resources are important (Lütscher et al., 2022). An earlier study by Wilcock et al. (2013) observed that patients in this category had substantial information needs concerning symptom management, and a lack of understanding in this area induced significant anxiety and distress among patients. Ensuring that patients and caregivers have adequate information, encompassing the side effects of treatment and symptom management, is crucial for obtaining valid informed consent and fostering patient involvement in treatment-related decision-making.

In summary, effectively communicating information content within the context of lung cancer RT necessitates healthcare professionals considering the unique needs and concerns of patients and caregivers. By offering accurate, current information encompassing potential side effects, symptom management techniques, logistical details, treatment objectives, and potential long-term impacts, healthcare professionals can contribute to patients and caregivers feeling better informed and actively engaged in the treatment process.

1.4.7 Factors influencing the information needs of patients with lung cancer

Information needs encompass the specific details that individuals seek to comprehend about a particular subject or issue. Effective communication of these details is crucial to ensuring that individuals possess the necessary information to engage in informed decision-making and appropriate actions. Numerous factors can shape an individual's information needs, including age, gender, disease stage, ongoing treatment, educational background, employment status, and parental responsibilities (Hsieh et al., 2018). Unmet needs regarding supportive care are prevalent among lung cancer patients, with certain individuals exhibiting a disproportionately high number of unmet needs. This trend is more pronounced among younger patients, those with advanced disease, and those experiencing a lower quality of life (Giuliani et al., 2016).

The biggest concern of lung cancer patients was the cancer itself and access to recovery information. Additionally, information regarding food selection and social welfare resources are of considerable importance to them. However, the means of information needs for each domain significantly decreased over time. Demographic information for example, age, gender, disease stage, current treatment, education, work status, and having children significantly influence information needs over time (Hsieh et al., 2018). The need for “disease-related information” remained high regardless of disease stage (Hsieh et al., 2018). Both advanced lung cancer patients and their caregivers have trends in concerns that change over time, perhaps due to changes in disease progression, treatment, or other factors (Sato et al., 2021).

In conclusion, comprehending the myriad factors that created information needs is pivotal for healthcare professionals who want to effectively engage with patients and furnish them with the requisite information and support. By customising communication strategies and information delivery to individualised needs and preferences, healthcare practitioners can empower patients to feel more informed, bolstered, and adept at managing their health and overall well-being. Access to accurate and up-to-date information, as well as support resources, is crucial for lung cancer patients and their caregivers throughout all stages of the disease.

1.5 The Thai reality of being treated with palliative radiotherapy for advanced lung cancer for the patient and the caregiver

In Thailand, treatment of advanced lung cancer follows the international guidelines. Over the past decade, significant advancements have been made in this field. However, in Thailand, critical issues such as limited access to drugs and a shortage of essential medical professionals including medical oncologists, radiation oncologists, thoracic surgeons, molecular pathologists, oncology nurses, and oncology pharmacists pose major obstacles. Implementing a multidisciplinary approach to lung cancer management can greatly benefit both patients and healthcare providers (Reungwetwattana et al., 2020). Palliative RT for advanced lung cancer is currently performed mostly in the academic and university hospitals. The use of advanced technologies in the treatment of advanced lung cancer has been increasing rapidly since its adoption in the last decade.

Radiation therapy (RT) plays a considerable role in the palliative management of lung cancer, both non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). In Thailand, the evolution of RT techniques has significantly improved treatment outcomes. Initially, RT in Thailand relied on a two-dimensional technique (2D-RT). The advent of three-dimensional conformal RT (3D-CRT) and intensity-modulated RT (IMRT) marked a significant leap forward. They allow for better tumour targeting and contouring to minimise damage to healthy tissue. Stereotactic body RT (SBRT) and image-guided RT integrate real-time images during treatment to ensure that the tumour is accurately targeted and that errors are minimised (Reungwetwattana et al., 2020).

Several studies involving patients with advanced cancer In Thailand that focused on symptom clusters revealed differences in the prevalence, frequency, and severity of symptoms depending on the type of cancer (Chaiviboontham et al., 2011, Pudtong et al., 2014, Khamboon et al., 2015). Chaiviboontham et al. (2011) found that pain was the most common symptom, followed by feeling bloated, lacking energy, shortness of breath, and a symptom that was described as “I don’t look like myself.” Four symptom clusters were identified: “pain, sickness-behaviour and psychological”; “anorexia-cachexia”; “gastro-intestinal and elimination”; and, “cutaneous and other”. Pudtong et al. (2014) identified an average of 14.65 symptoms, with coughing being the most common, lack of appetite the most frequent, and pain the most severe and distressing symptom. Conversely, Khamboon et al. (2015) found that lack of appetite was the most prevalent and severe symptom, urination problems were the most frequent, and constipation was the most distressing. Studies of symptom experience during advanced cancer (Get-Kong et al., 2010) showed that the most commonly reported symptom prevalence and distress was pain. Difficulty swallowing was reported as the most frequent symptom, while “I don’t look like myself” was the most severe symptom (Get-Kong et al., 2010). Thai patients with advanced cancer sought ways to cope with their suffering. Three themes emerged from the interview data: adopting religious doctrine, maintaining hope, and being surrounded by the love and care of their family (Nilmanat et al., 2015). Studies on Thai cancer survivors also found that symptom experiences were similar across the five cancer groups, except for pain, which was significantly higher in lung cancer survivors. The most frequently reported symptoms across all groups were numbness in the hands/feet, sleep disturbances, fatigue, and pain (Pongthavornkamol et al., 2019). There is a lack of research on patients with advanced lung cancer undergoing RT, a group that has been overlooked by Thai researchers.

Fumaneeshoat and Ingviya (2020) a cross-sectional study regarding caregiving for patients with lung cancer in southern Thailand found that there was a link between younger caregivers and a lower quality of life, while factors linked to a better quality of life were a higher income and being a child of the patient. The primary factor among caregivers associated with a lower caregiver burden was being Muslim, and the main factor associated with a higher caregiver burden was a lower income. Patient-related factors affecting caregivers' burden included being female, the relative patient having a high score on Barthel's Activities of Daily Living (ADL) index, and caregiving for ≥2 years. In conclusion, caregivers' quality of life and caregiver burden were influenced by their respective patients' ADL and the duration of the illness. It's recommended that caregiver training is provided to help maintain patients' ADL. Health authorities should facilitate opportunities for patients to share their experiences of managing the symptoms of lung cancer (Fumaneeshoat and Ingviya, 2020).

Key factors contributing to elevated levels of caregiver burden remained consistent, such as caregivers' physical and psychological health, financial strain, social isolation, and limited family and social support. Additionally, less acknowledged factors associated with increased burden were caregivers' self-esteem, having a male gender, and the evolving nature of cancer treatment. These findings provide us with an updated understanding of the caregiver burden in the context of caring for patients with solid tumour cancers, offering insights for future interventions aimed at alleviating this burden (Thana et al., 2021a). Sixty-three percent of caregivers reported no burden, with guilt emerging as the primary variable influencing burden. Factors linked to high burdens included being a sole caregiver, having a sibling relationship with the patient, experiencing migraines, and the type of cancer the patients had. In conclusion, the caregiver burden among caregivers for Thai cancer patients appears to be minimal. This unexpectedly low figure could be attributed to sociocultural perspectives (Chindaprasirt et al., 2014). While this study reports a relatively low level of caregiver burden among Thai cancer patients, it's important to interpret this finding cautiously, considering potential sociocultural influences and methodological limitations. Further research is needed to gain a comprehensive understanding of caregiver burden in this population.

In summary, caregiver burden pertains to the multifaceted stress endured by individuals who provide care to those grappling with chronic illnesses or disabilities, such as cancer. Caregivers have a paramount role as the primary support for patients. Despite their indispensable role, the emotional and personal needs of caregivers are often insufficiently addressed, although they significantly suffer due to their supportive roles. Caregivers play a vital role in the health and well-being of individuals they care for. As patient well-being hinges on the quality of home-based care, healthcare providers must comprehend the significance of caregivers. Clinicians should identify the caregivers of their patients, inquire about their caregiving experiences, and conduct caregiver assessments. Inclusion of caregivers as proactive care partners, recognition of caregiver burden, and prompt interventions to alleviate this burden are essential.

1.6 The knowledge gap

In the area of palliative thoracic RT, there is not a comprehensive understanding regarding the symptom burden, the caregiving burden, or the information needs of patients regarding the self-management of symptoms, especially in the Thai context. Additionally, the factors that might influence these burdens and needs are not well-defined. To bridge this knowledge gap, further research and studies are needed to provide insight into these areas and contribute to the improvement of care for patients undergoing palliative thoracic RT in Thailand.

The existing research on symptom experience often focuses on symptom prevalence and tends to overlook other critical dimensions such as symptom severity and frequency and distress (Chen et al., 2022, Sung et al., 2017). Understanding these dimensions is essential for effective symptom management and patient care. Despite the prevalence of psychological symptoms such as “I don’t like myself”, depression, anxiety, and distress among patients with advanced lung cancers, clinical settings may not always recognise or address these issues (Chen et al., 2022, Cheng and Chen, 2023, Lütscher et al., 2022, Sung et al., 2017). There is a limited understanding of how symptom experiences change during treatment. And a gap exists regarding comprehending the enduring symptom experiences that some cancer survivors face after treatment completion (Fraser et al., 2019, Kolsteren et al., 2022). Our knowledge is limited concerning the symptoms experienced and the predictors of those symptoms regarding people with advanced lung cancer who undergo palliative RT internationally and in Thailand.

Because of the knowledge gap regarding the caregiver burden that is caused by the unexplored long-term impact of it, more research is needed to comprehend the prolonged effects of caregiver burden throughout the treatment journey and in relation to caring for survivors (Becquéa et al., 2019, El-Jawahri et al., 2017, Sun et al., 2019), because of the limited scope of this study, I cannot explore this point. There's a need to explore how cultural and contextual elements impact caregiver burden within various populations and in Thailand. Although supportive interventions for caregivers such as psychosocial support and multimedia self-management have been studied, more research is required to develop and evaluate effective interventions (Fu et al., 2017). It remains uncertain whether current resources, like written materials and online platforms, meet patients' and families' information needs and constitute optimal information delivery

The knowledge gap concerning information needs partly relates to not catering for patients with multicultural backgrounds, so research should address the unique information needs of such patients, considering factors like language and cultural differences (Durnin et al., 2021, Kim et al., 2023, Webb et al., 2021). Whether the delivery of information and whether these written materials and online resources are effective in meeting information needs to be assessed. One study reported that there was an unmet need regarding information on sexual health, and this topic was not only significant for patients but also for partners and spouses (Llamas-Ramos et al., 2022). This subject cannot be found in Thai research in relation to patients with advanced lung cancer so there is a limit to our knowledge concerning implementation of supportive care in this area. Healthcare providers should prioritise meeting these needs by providing accurate, current information and ongoing support. Bridging these knowledge gaps will facilitate more effective communication and improved patient care. Information needed for research regarding radiotherapy was also poorly available, and some patients got treatment-related and self-care information from other healthcare providers, for example a clinician or radiotherapist.

1.7 Background to personal motivation and the rationale for study

My professional background and hands-on experiences of caring for patients and their families, particularly in the context of Thailand, further underscore my commitment to this research. Having worked as a radiation oncology nurse for over a decade, I have been a witness to the diverse array of symptoms that patients encounter throughout their treatment journeys. These symptoms profoundly affect patients' lives and create ripple effects on those closest to them, particularly caregivers.

While I was working on this thesis, I was granted a unique perspective by becoming a patient myself, having been diagnosed with breast cancer. My personal experience shed light on the multitude of symptoms that manifest during treatment. The psychological symptoms were especially eye-opening for me. The most prevalent symptoms among cancer patients undergoing SACT are fatigue, changes in taste perception, appetite loss, peripheral numbness, and insomnia. The shock of losing my cherished hair after SACT and the changes in my skin tone due to radiation field exposure were stark reminders of the challenges patients face. These experiences fortified my resilience and instilled a deep understanding of life's purpose and true significance.

Furthermore, this journey exposed the gap between healthcare providers and the patients they serve. The disconnect highlighted the limited comprehension that healthcare providers often have about the patient experience. As key players, healthcare providers play a crucial role in supporting patients, and patients look to them for information to navigate their symptoms at home. Thus, discerning the specific sources and types of information patients require and identifying the symptoms that patients prioritise for self-management become pivotal points of focus. Additionally, understanding the frequency of symptoms faced by both patients and caregivers is instrumental in managing the substantial symptom load.

Consequently, my research interest centres around investigating patients' symptom burden, the associated caregiving burden, and the informational needs of patients and caregivers in terms of symptom self-management during palliative RT for lung cancer. The outcomes of this study have the potential to guide healthcare professionals when they are devising tailored services and care strategies for both patients and caregivers. Furthermore, by exploring predictive factors, this research can help pinpoint patients and caregivers who are at risk of facing distress during their journey through this treatment process.

1.8 Research objectives and research question

1.8.1 The research objective of this study

One of the research objectives is to bridge the gap in the literature to provide an incidence of symptom experiences and to monitor changes in symptom experiences, the burden on caregivers, and information needs throughout the treatment journey for both patients and their caregivers. Another research objective is to enhance patient care by addressing knowledge gaps related to symptom experience, caregiver burden, and information needs; healthcare providers will then be able to offer more targeted and effective care. Improved symptom assessment and management can enhance patients’ outcomes during cancer treatment and improve survival rates. Tailored support for caregivers that understands the caregiver burden will lead to development of tailored interventions to support caregivers. In Thailand, where family plays a crucial role in caregiving, addressing caregiver needs can positively impact both patients and their families. Conducting this study in Thailand ensures that the findings are culturally relevant and applicable to the local context. It provides insights into how cultural factors influence symptom experience, caregiver burden, and information needs. Closing research gaps by bridging knowledge gaps contributes to the overall body of cancer research. Thailand-specific data can complement international studies, leading to a more comprehensive understanding of cancer care. In summary, this study has the potential to transform cancer care by informing clinical practice, supporting caregivers, and meeting patients’ unique needs in Thailand.

Insights from this study will inform clinicians about under-recognised symptoms; it's essential to address symptoms during treatment, to address the late effects of treatment, and to have a detailed follow-up after RT. Even after treatment ends, patients need ongoing follow-ups. Residual symptoms and side effects can persist, and close monitoring is essential. Regular check-ins allow clinicians to address any new symptoms promptly and provide necessary interventions. Effective communication between clinicians and patients plays a vital role in managing symptoms and ensuring optimal outcomes. It is also important for healthcare providers to create individualised care plans and establish an information repository for patients and their caregivers to effectively manage symptoms at home.

Despite the average survival period of approximately 8 months for lung cancer patients and the absence of a cure, palliative care remains essential to enhance patient support and mitigate symptoms as effectively as possible (Johnston et al., 2009, Rueda et al., 2011). In line with this, integrating the principles of palliative care, which encompass comprehensive symptom management and effective communication, into early oncological care could offer a cohesive and coordinated approach to symptom assessment and treatment (Reinke et al., 2016).

This study aims to investigate the evolving spectrum of patients' symptom burden, the corresponding burden on caregivers, and the important informational needs of both patients and caregivers regarding self-managing symptoms at home during palliative RT for lung cancer. By consistently evaluating the weight of these burdens and informational needs, healthcare practitioners can create tailored services and care plans to address the unique needs of both patients and their caregiving family members. Additionally, this study will delve into psychosocial and clinical factors that serve as predictors for the manifestation of these burdens and information needs among patients and caregivers. These predictive factors have the potential to equip healthcare providers with the foresight to identify patients and caregivers who may be susceptible to distress during palliative RT for lung cancer

1.8.2 The research questions of this study are

- What is the symptom experience of patients with advanced lung cancer in Thailand during a full course of palliative radiotherapy? How does it change?
- What is the caregivers' burden when they are caring for a patient with advanced lung cancer who is receiving palliative radiotherapy in Thailand?
- What are the patients' and caregivers' information needs at home?
- What are the predictors associated with an increased symptom experience of patients with advanced lung cancer who are receiving palliative radiotherapy, caregiver burden, and information needs of both patients and caregivers in Thailand?

1.9 Overview of chapters

This chapter offers readers an introduction to the structure of the thesis, outlining the scope of the investigation. The subsequent chapters delve into distinct facets of the research process.

Chapter 1: Introduction

In this chapter, the research's foundation is laid, encapsulating the research problem, the context, and precise definitions of key concepts relevant to this study.

Chapter 2: Background to the Research Topic

This chapter embarks on two pivotal paths. Firstly, it presents a comprehensive systematic review that explores the prevalence of symptom experiences among patients with advanced lung cancer undergoing palliative thoracic radiation therapy. Simultaneously, it delves into a literature review that surveys the existing evidence landscape concerning caregivers' burden and information needs. This dual exploration identifies both existing knowledge and the gaps that remain.

Chapter 3: Methodology

A thorough examination of the research methodology is carried out in this chapter. It sheds light on the theoretical underpinnings guiding the chosen approach to knowledge acquisition. Additionally, it delineates the reasoning behind the methodology adopted for this study.

Chapter 4: Research Methods

This chapter expounds on the practical execution of the research methods. It provides an encompassing overview of the methodologies employed in each distinct phase of the research. Furthermore, it offers insights into the rationale driving the selection of these methodologies. The researcher's step-by-step operationalisation of each research phase is articulated in detail.

Chapter 5: Research Findings

The fifth chapter unveils the heart of the research – its findings. A synthesis of these findings is presented, and their implications are discussed within the context of the existing knowledge base elaborated upon in the subsequent chapter.

Chapter 6: Discussion and Synthesis

This chapter serves as a platform for the comprehensive discussion and synthesis of the findings. The insights unearthed by this research are woven into the existing body of knowledge, illuminating avenues for further exploration.

Chapter 7: Conclusion

The concluding chapter serves as the culmination of this research journey. Key findings are distilled, leading to the articulation of conclusive statements. Recommendations stemming from the research are outlined, and the potential for future research endeavours is illuminated.

Chapter 2 Systematic review

2.1 Introduction

This chapter presents a systematic review of international evidence on patients' experiences of symptoms and side effects during palliative thoracic radiotherapy (RT). The systematic review was developed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses quality requirements (Moher et al., 2009). The protocol is registered on PROSPERO, the International Prospective Register of Systematic Reviews (CRD42018109765). PROSPERO maintains a persistent record of the review protocol's essential characteristics. It is recommended that systematic reviews be registered at the protocol stage to prevent unintentional duplication and to permit comparison of reported review methods with what was anticipated in the protocol (PROSPERO, 2022).

A systematic review aimed to address the following research questions:

1) What is the prevalence and severity of patient-reported symptoms and side-effects during palliative thoracic radiotherapy for advanced lung cancer?
2) How do patient-reported symptoms and side-effects change during palliative thoracic radiotherapy for advanced lung cancer?
3) Do patient-reported symptoms and side-effects vary according to patients' demographic and/or clinical characteristics?

2.2 Search strategy

A systematic search strategy was developed comprising search terms grouped in the following areas: a) lung cancer, b) palliative thoracic RT, and c) symptoms. We used the Patient (advanced lung cancer), Intervention (palliative thoracic RT), and Outcome (prevalence of, severity of, and change in symptoms; and factors influencing symptoms) (PICO) framework to develop our search terms (Higgins and Green, 2008). The search strategy included a combination of Boolean operators, truncation markers, and MeSH headings, as well as keywords, phrases, and synonyms to increase the inclusiveness and sensitivity of the searches. The searches were devised and run separately on the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycINFO (accessed via EBSCO), MEDLINE, EMBASE (accessed via Ovid), and Cochrane. A university librarian was consulted to validate the search strategies. Initial electronic searches from 2000 were run in 2022 and updated on 31 December 2023 to capture more recent publications. An example database search is provided in appendix 1.

2.2.1 Eligibility criteria

Reports were included if:

- They were conducted with patients treated with palliative thoracic RT for advanced lung cancer (stage III or IV), including primary lung tumours and other tumour types that had spread to the lung, irrespective of treatment duration, dosage, or the time point in the illness trajectory.
- They investigated patient-reported disease-related symptoms and treatment-related side-effects (prevalence, severity, and distress), and possible moderating factors of the patient's symptom experience (demographic and/or clinical).
- They employed quantitative and/or qualitative methods, irrespective of study design.
- They reported on primary or secondary research.
- They were conducted with male and female adult patients (18 years old and over)
- They were published in English with readily available abstracts.
- They were published as original articles in peer-reviewed journals between January 2000 and December 2023.

Reports were excluded if:

- They were conference abstracts, tool development studies, commentaries, and case studies.
- They involved participants with mixed cancer diagnoses or mixed treatment, except if analyses of subgroups were reported.
- They only involved clinician evaluation of symptoms and side-effects.
- They investigated RT for lung cancer with a curative aim.

2.2.2 Study selection and data extraction

An initial screening of titles and abstracts was conducted by one reviewer to identify potentially relevant studies. Three reviewers then independently evaluated the full text of these articles to determine their eligibility based on predefined criteria. Any disagreements were resolved through discussion and consensus. Data extracted from the final set of studies included search results, participant and clinical characteristics, symptom assessment tools, and information about symptom prevalence, severity, and associated distress.

2.2.3 Evaluation of the methodological quality of the study

An evaluation of each study’s methodological quality was performed by three reviewers independently and in parallel with the data extraction. Appraisal scores per study were finalised by consensus. We used the standardised QualSyst evaluation tool (Kmet et al., 2004) to do so. QualSyst provides two separate scoring systems: one is quantitative assessed across 14 criteria, including study objectives, design, subject selection, outcome measures, and statistical analyses, and one is qualitative, evaluated based on 10 criteria, such as clarity of research questions, appropriateness of study design, data collection methods, and analysis. All of final studies were quantitative, checklist for assessing the quality of quantitative studies was used. It contained 14 criteria to evaluate; 1. Question / objective sufficiently described? 2. Study design evident and appropriate? 3. Method of subject/comparison group selection or source of information/input variables described and appropriate? 4. Subject (and comparison group, if applicable) characteristics sufficiently described? 5. If interventional and random allocation was possible, was it described? 6. If interventional and blinding of investigators was possible, was it reported? 7. If interventional and blinding of subjects was possible, was it reported? 8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported? 9. Sample size appropriate? 10. Analytic methods described/justified and appropriate? 11. Some estimate of variance is reported for the main results? 12. Controlled for confounding? 13. Results reported in sufficient detail? 14. Conclusions supported by the results?

The score of 0 was assigned if the study did not meet the criteria, 1 when it partially met them, and 2 when it fully met them. Items not applicable to a particular study design were marked ‘not applicable’ and excluded from the summary of score calculations. Summary quality scores (SQS) were calculated and reported as percentages, indicating the overall methodological quality of the study, ranging from 0 to 100%. A higher SQS indicated better methodological quality, as follows: SQS >95% = high quality; SQS 90–95% = very good quality; SQS 80–89% = good quality; SQS 65–79% = moderate quality; SQS 40–64% = low quality. Disagreements were resolved by consensus as necessary.

2.2.4 Summary of findings

Data extracted from the included studies were organised into evidence tables, and the narratives, one for each research question, were integrated, linking the outcomes to the methodological quality of the underlying research. The evidence tables for each study were put into Excel, facilitating the description of study characteristics in terms of counts [N (%)]. Symptom/side-effect prevalence was graphically represented for each study, where a count of 0 indicated the absence of symptoms/side-effects, and a count of one indicated the presence of a symptom/side-effect. To calculate prevalence, the total number of participants who reported a given symptom/side-effect across all studies was divided by the total number of participants considered across all studies. Symptom/side-effect prevalence was presented both numerically and as a percentage for each period, i.e., before, during, and after treatment. In terms of severity of symptoms/side-effects, seven of the eight included studies used some European Organisation for Research and Treatment of Cancer (Arraras et al.) measure, thus allowing severity scores to be transformed and reported on a 0–100 scale (formula: [(average − 1)/ range] × 100), whereby labels assigned to specific score ranges were as follows: 0 = no symptom/side-effect, 1 to 34 = mild symptom/side-effect, 35 to 67 = moderate symptom/side-effect, 68 to 100 = severe symptom/side-effect. Application of the formula allowed for comparability across studies. The last study used a different measurement tool, for which no equivalent formula exists, and therefore this study was omitted from the comparison.

2.3 Search results, study characteristics, and methodological quality

Following an initial screening of 4988 references, 78 potentially eligible articles were selected and retrieved in full-text form. Subsequently, 70 articles were excluded (Appendix 1), and the detailed reasons for exclusion are depicted in Fig. 2.1. The final sample included eight studies (Bezjak et al., 2002, Lefresne et al., 2017, Langendijk et al., 2001, Langendijk et al., 2000, Eldeeb et al., 2014, McDermott et al., 2018, Senkus-Konefka et al., 2005, Sundstrøm et al., 2005). All eight studies employed a quantitative approach: six (75%)

are descriptive prospective repeated-measures studies, while the remaining two studies (25%) have a randomised controlled trial design. The sample sizes ranged from 30 to 407 participants, and the total number of participants across all 8 studies was 1156. Five studies were conducted in Europe (63%), two in North America (25%), and one in Egypt (12%). Five articles (63%) were published between 2000 and 2005, and three articles (37%) were published between 2014 and 2018 (Table 1). Methodological quality scores ranged from 86% to 96% with a mean SQS of 91% (Appendix 2)

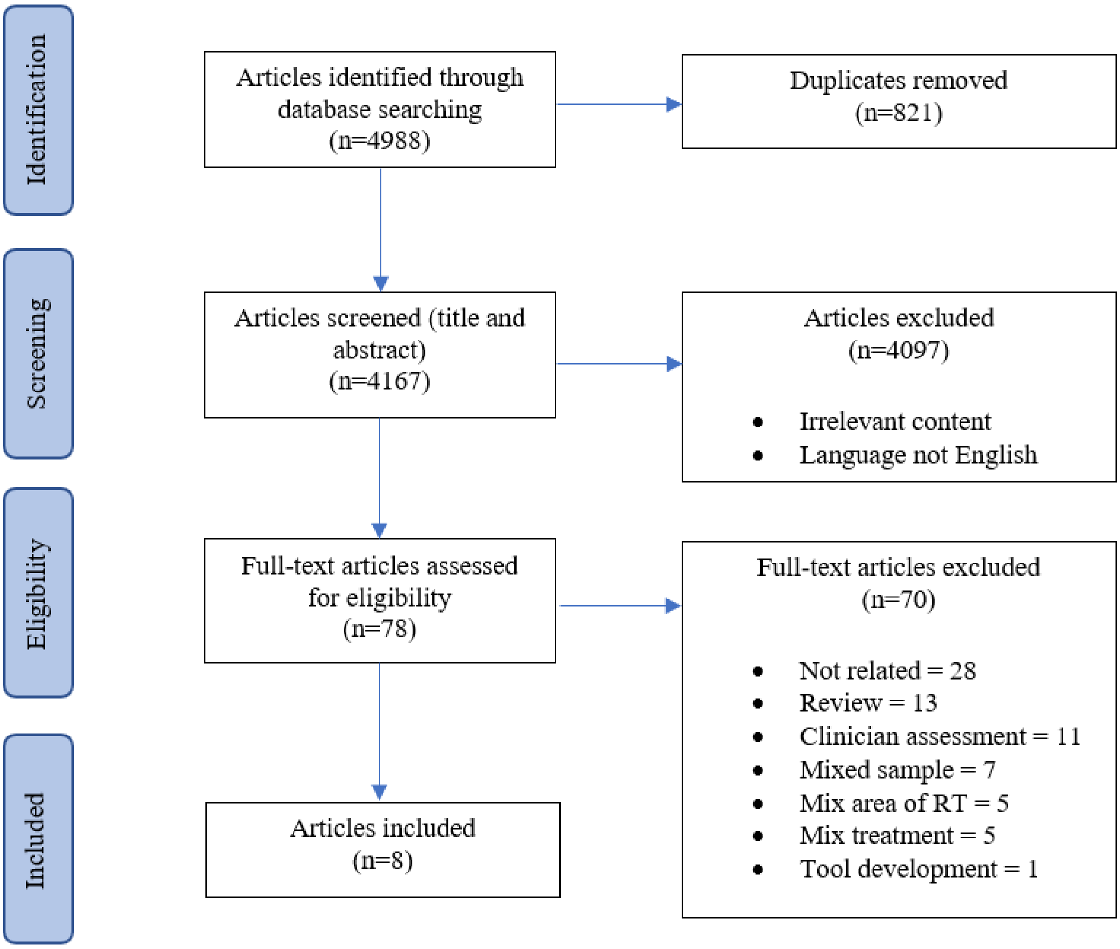


Figure 2-1 Literature databases and total number of relevant references.

2.3.1 Patient characteristics across the included studies

Across all studies, age ranged from 30 to 99 years, although most patients were in the 60-71 years age category. Over 70% of participants were male (73%, 847 individuals). Most participants had been diagnosed with stage III cancer 796 (69%), while 299 (26%) were reported with stage IV cancer. Four percent of all participants (41 individuals) had stage I or II cancer (tumours with a diameter larger than 4 cm and considered inoperable because of comorbid diseases and inadequate pulmonary function), while 19 participants (2%) were at an extensive clinical stage. Regarding tumour types, 1137 (98%) were non-small cell lung cancer (NSCLC) and 19 (2%) were small cell lung cancer (SCLC). In the NSCLC group, 397 (34%) were squamous cell carcinoma, 390 (34%) were unknown, 171

(15%) were adenocarcinoma, 114 (10%) were undifferentiated carcinoma, and 84 (7%) were large cell carcinoma. In the SCLC group, 19 (100%) of the patients were at an extensive stage. The most prevalent RT protocol was 20 Gy delivered in 5 fractions (24%). This was followed by 30 Gy in 10 fractions (18%), and 17 Gy in 2 fractions (18%) (Table 1).

Performance status varied depending on the measurement scale (see also Appendix 3):

- The World Health Organisation (WHO) performance status (PS) scale was used in three studies (Langendijk et al., 2001, Langendijk et al., 2000, Senkus-Konefka et al., 2005). Among 329 patients, 138 (42%) had a PS subscale of 1, 84 (25%) had a PS subscale of 2, 69 (21%) had a PS subscale of 0, 35 (11%) had a PS subscale of 3, and 3 (1%) had a PS subscale of 4.
- The Karnofsky Performance Status (KPS) scale was employed in two studies (McDermott et al., 2018, Sundstrøm et al., 2005). The range of KPS scores for patients was 70–80 in 254 (57%) patients, 90–100 in 141 (32%), and ≤60 in 47 (11%) patients.
- The Eastern Cooperative Oncology Group (ECOG) PS scale was used in two studies (Bezjak et al., 2002, Eldeeb et al., 2014). The ECOG PS scores indicated that 40% were graded as 1, 32% were graded as 2, 23 % were graded as 3, and 5% were graded as 0.
- Palliative Performance Status (PPS) was used by one study (Lefresne et al., 2017). A mean PPS of 50 was reported, with a range of 10 to 100.

Weight loss: Four studies involving 827 participants found that 367 individuals (44%) had a weight loss of less than 10%, 286 individuals (35%) had a weight loss exceeding 10%, and 174 individuals (21%) did not experience any weight loss (Bezjak et al., 2002, Langendijk et al., 2000, Lefresne et al., 2017, Sundstrøm et al., 2005).

Table 2-1 Characteristics and key findings of the 8 studies included in the analysis.

Author, country	Aim of the study	Study design, outcome measure and time points	Number of participants, demographic, clinical data, radiotherapy dose and area, symptomatic findings, and quality rating
Bezjak *et al*. (2002) **Country:** Canada	To compare 10 Gy/1F RT with 20 Gy/5F in the palliation of thoracic symptoms from lung cancer, and to add to the evidence comparing 10 Gy/1F with 20 Gy/5F in terms of palliation of thoracic symptoms, toxicity, QoL, and survival	**Design:** multicentre RCT **Outcome measure:** Daily diary card LCSS EORTC-QLQ-C30 **Time points:** two (baseline and week 5)	**Number of participants:** 230 **Demographic:** male/female 145/85, median age 70.4 **Clinical:** ECOG1 10 (45%) **Radiation doses:** 10 Gy/1F 20 Gy/5F **Area of RT:** Thoracic **Symptoms before RT:** cough 55 (24%), shortness of breath 69 (30%), chest pain 51 (22%), coughing up blood 25 (11%), fatigue 23 (10%), loss of appetite 7 (3%), difficulty swallowing 2 (1%) **Quality rating:** Very good
Eldeeb *et al*. (2014) **Country:** Egypt	To compare symptoms' control in patients with inoperable, locally advanced or metastatic NSCLC using two different regimens of palliative RT. To determine, toxicity profile, HRQOL, tumour control, and overall survival.	**Design:** prospective repeated measure **Outcome measure:** EORTC-QLQ-C30 EORTC-QLQ-LC13 CTCAE version 3.0 **Time points:** four (baseline, after 1 week. After 6 weeks. After 16 weeks)	**Number of participants:** 30 **Demographic:** male/female 28/2, median age 59.3-60.9(30-80) **Clinical:** Smoker 80-86.7%, ECOG3 (53.3-73.3%) **Radiation doses:** 30 Gy/10F 17 Gy/2F **Area of RT:** Thoracic **Symptoms before RT:** dyspnoea 30 (100%), cough 30 (100%), chest pain 20 (67%), haemoptysis 19 (63%) **Quality rating:** Good
Langendijk *et al*. (2000) **Country:** Netherlands	To investigate changes in respiratory symptoms and QoL in patients with locally advanced and metastatic NSCLC-QoL receiving thoracic RT, and the correlation between the level of symptom relief and	**Design:** prospective repeated measure **Outcome measure:** EORTC-QLQ-C30 EORTC-QLQ-LC13 **Time points:** four (before the start of RT, then 2 weeks, 6 weeks and 3 months post-RT)	**Number of participants:** 65 **Demographic:** male/female 59/6, mean age 65 (39–88) **Clinical:** stage IIIb 37 (57%), squamous cell 32 (49%), WHO PS3 22 (34%) **Area of RT:** Thoracic **Symptoms before RT**: fatigue 63 (94%), cough 60 (89%), dyspnoea 59

Author, country	Aim of the study	Study design, outcome measure and time points	Number of participants, demographic, clinical data, radiotherapy dose and area, symptomatic findings, and quality rating
	objective tumour response		(88%), pain 58 (86%), appetite loss 48 (71%), chest-wall pain 41 (62%), insomnia 38 (57%), haemoptysis 31 (46%), arm/shoulder pain 29 (43%), nausea and vomiting 23 (34%), constipation 21 (31%) and dysphagia 17 (25%) **Quality rating:** Good
Langendijk *et al*. (2001) **Country:** Netherlands	To investigate changes in respiratory symptoms and QoL in patients with NSCLC receiving radical RT (60 Gy) and the association between the level of symptom relief and objective tumour response, as well as with radiation-induced pulmonary changes	**Design:** prospective repeated measure study **Outcome measure:** EORTC-LC13 EORTC-QLQ-C30 CT for tumour response CXR for RT pulmonary changes **Time points:** six (pre-RT) then 2 weeks, 6 weeks, 3 months, 6 months and 12 months post-RT)	**Number of participants:** 164 **Demographic:** male/female 138/26, median age 68 (37–84) **Clinical:** stage IIIb 79 (48%), squamous cell 95 (58%), WHO PS1 79 (48%), median survival of patients 8.5 months **Radiation doses:** 45 Gy/20F boost 15 Gy/6F total 60 Gy/26F **Area of RT:** Thoracic **Symptoms before RT:** cough 149 (91%), fatigue 138 (84%), dyspnoea 128 (78%), insomnia 92 (56%), pain 87 (53%), appetite loss 72 (44%), chest pain 62 (38%), arm/shoulder pain 59 (36%), nausea and vomiting 39 (24%), haemoptysis 36 (22%), dysphagia 30 (18%), constipation 30 (18%) **Quality rating:** High
Lefresne et al. (2017) **Country:** Canada	To prospectively evaluate the outcomes of the patients assessed at the Vancouver Rapid Access clinic. Aspects of interest included performance status, patient-reported overall health, and palliation of symptoms requiring palliative RT.	**Design:** prospective repeated measure study and retrospective chart review. **Outcome measure:** the Edmonton Symptom Assessment System (ESAS) EORTC-QLQ-LC13 EORTC-QLQ-BM22	**Number of participants:** 125 *109 received palliative RT. **Demographic:** male/female 68/57, median age 71 (45-99) **Clinical:** stage IV 84 (67%), Median PPS 50(10-100) **Radiation doses:** 20 Gy/5F, 30Gy/10F, 8Gy/1F **Area of RT:** Thoracic (57%), Bone (37%), and Brain (20%) *Twenty-four patients received RT to more

Author, country	Aim of the study	Study design, outcome measure and time points	Number of participants, demographic, clinical data, radiotherapy dose and area, symptomatic findings, and quality rating
		EORTC-QLQ-BN20 **Time points:** two (baseline and 4 weeks)	than one anatomic site on their first visit. **Symptoms before RT:** cough 51 (47%), dyspnoea 45 (41%), pain 36 (33%), chest pain 23 (21%), haemoptysis 23(21%), dysphagia 12 (11%) **Quality rating:** High
McDermott *et al*. (2018) **Country:** Ireland	To assess whether more technically advanced treatment techniques result in equivalent symptom relief and reduce the side effect of symptomatic oesophagitis in patients with locally advanced lung cancer	**Design:** prospective repeated measure study **Outcome measure:** EORTC-QLQ-C15-PAL EORTC-QLQ-C30 EORTC-QLQ-L13 **Time points:** four (baseline, during treatment, 2 weeks and 1 month)	**Number of participants:** 35 **Demographic:** male/female 14/21 **Clinical:** stage III 17 (49%), KPS80 13 (37%) **Radiation doses:** 39 Gy/13F, 20 Gy/5F, 17 Gy/2F **Area of RT:** Thoracic **Symptoms before RT:** cough 5 (14%), dyspnoea 16 (46%), haemoptysis 6 (17%), pain 5 (14%), dysphagia 2 (6%), hoarseness 1 (3%) **Quality rating:** Very good
Senkus-Konefka *et al*. (2005) **Country:** Poland	To compare two palliative RT regimens in patients with NSCLC and to examine the degree and duration of symptomatic relief, treatment side effects, objective response rates and overall survival	**Design:** prospective RCT **Outcome measure:** Self-report by both patients and physician Four-point scale (none, mild, moderate and severe) **Time points:** minimum of twenty (once weekly until week 8, then monthly for 6 months, then bi-monthly for the next 6 months, and 3-monthly thereafter	**Number of participants:** 100 **Demographic:** male/female 90/10, median age 67 (47–81) **Clinical:** local advance 84 (86%), squamous cell 65 (66%), WHO PS2 45 (46%) **Radiation doses:** 20 Gy/5F 16 Gy2F **Area of RT:** Thoracic **Symptoms before RT:** cough 62 (63%), dyspnoea 61 (62%), chest pain 61 (62%), haemoptysis 32 (33%), dysphagia 9 (9%), SVCS 7 (7%) **Quality rating:** Good

Author, country	Aim of the study	Study design, outcome measure and time points	Number of participants, demographic, clinical data, radiotherapy dose and area, symptomatic findings, and quality rating
Sundstrøm *et al.* (2005) **Country:** Norway	To compare the course of symptoms and HR-QoL after immediate thoracic RT between symptomatic and non-symptomatic patients with advanced NSCLC	**Design:** prospective **Outcome measure:** EORTC-QLQ-C30 EORTC-QLQ-L13 Clinician symptom assessments **Time points:** nine (baseline, 2 weeks, 6 weeks, 14 weeks, 22 weeks, 30 weeks, 38 weeks, 46 weeks, 54 weeks)	**Number of participants:** 407 **Demographic:** male/female 305/102, median age: 69 (41–88) **Clinical:** squamous cell carcinoma 192 (47%), KPS70–80 233 (57%), stage IIIb 258 (63%) **Radiation doses:** 17 Gy/2F 42 Gy/15F 50 Gy/25F **Area of RT:** Thoracic **Symptoms before RT:** cough 249(61%), fatigue 232(57%), dyspnoea 168(41%), appetite loss 163(40%), chest pain 148(36%), haemoptysis 108(27%), Hoarseness 91(22%), nausea 31(8%), Dysphagia 26(6%), Vomiting 22(5%) **Quality rating:** High

Abbreviations: CCRT, Concurrent Chemoradiotherapy; CFRT, conventionally fractionated radiation therapy; CT scan, computed tomography scan; CXR, chest x-ray; CTCAE, Common Terminology Criteria for Adverse Events scale; ECOG , Eastern Cooperative Oncology Group; EORTC, European Organisation for Research and Treatment of Cancer; F, Fraction; Gy, Gray; HAD[S] , Hospital Anxiety and Depression Scale; HR-QoL, health-related quality-of-life; KPS, Karnofsky Performance Status; LC, Lung Cancer; ; LCSS, Lung Cancer Symptom Scale; NSCLC, non-small cell lung cancer; PS, performance status; QLQ, Quality of Life Questionnaire ; QoL, quality of life; RCT, randomised controlled trial; RT, Radiotherapy or radiation therapy; RTOG, Radiation Therapy Oncology Group; SBRT, stereotactic body radiation therapy; SVCS, Superior vena cava syndrome; WHO, World Health Organisation.

2.3.2 Instruments for symptom evaluation

All studies employed validated measures, with patient self-assessment being a universal approach (100%). The most prevalent data source was the European Organisation for Research and Treatment of Cancer (Arraras et al.) (79%). Various questionnaires created by this organisation were used; The EORTC-QLQ-C30 was used in 32% of the studies(Bezjak et al., 2002, Eldeeb et al., 2014, Langendijk et al., 2001, Langendijk et al., 2000, McDermott et al., 2018, Sundstrøm et al., 2005) , the EORTC-QLQ-LC13 in 32% (Eldeeb et al., 2014, Langendijk et al., 2001, Langendijk et al., 2000, Lefresne et al., 2017, McDermott et al., 2018, Sundstrøm et al., 2005) , and 5% employed the EORTC-QLQ-BN20,(Lefresne et al., 2017) EORTC-QLQ-BM22,(Lefresne et al., 2017) and EORTC-QLQ-C15-PAL (McDermott et al., 2018) was used in each of three studies. The rest of instrument for symptom assessment were the Lung Cancer Symptom Scale (LCSS)(5%)(Bezjak et al., 2002), daily diary cards (5%)(Bezjak et al., 2002) and a four-point scale (none, mild, moderate, severe) for symptom assessment.(Senkus-Konefka et al., 2005)

2.3.3 Symptom prevalence throughout palliative thoracic radiotherapy

a. Before RT

PREVALENCE

Thirteen distinct symptoms were self-reported across all reviewed studies prior to the start of palliative thoracic RT. Cough was the most prevalent symptom, affecting 62% of participants (721 out of 1,156). This was followed by fatigue at 58% (500 out of 866), insomnia at 56% (129 out of 229), dyspnoea at 51% (592 out of 1,156), pain at 47% (184 out of 389), chest pain at 40% (434 out of 1,091), pain in the arm or shoulder at 38% (87 out of 229), appetite loss at 35% (307 out of 866), haemoptysis at 26% (295 out of 1,156), hoarseness at 24% (106 out of 442)2, constipation at 21% (49 out of 229), nausea and/or vomiting at 19% (122 out of 636), and dysphagia at 9% (86 out of 1,001).

SEVERITY

The mean shows the severity of symptoms, and a high score on the scale represents a high level of symptomatology / problems. In six studies, the mean scores were transformed into a linear range of scores as set out in the EORTC Scoring Manual, from 0 to 100: 0 = nil, 1 to 34 = mild, 35 to 67 = moderate, and 68 to 100 = severe. Dyspnoea had the highest mean score, which was within the 41-63 range, followed by cough at 40–57, haemoptysis at 9-57, fatigue at 40–54, appetite loss at 27-48, chest pain at 17-47, and dysphagia at 5-35 (Langendijk et al., 2001, Langendijk et al., 2000, Lefresne et al., 2017, McDermott et al., 2018, Senkus-Konefka et al., 2005, Sundstrøm et al., 2005). Additionally, Sundstrom et al. (2005) demonstrated that 300 patients (74%) were classified as having moderate to severe symptoms.

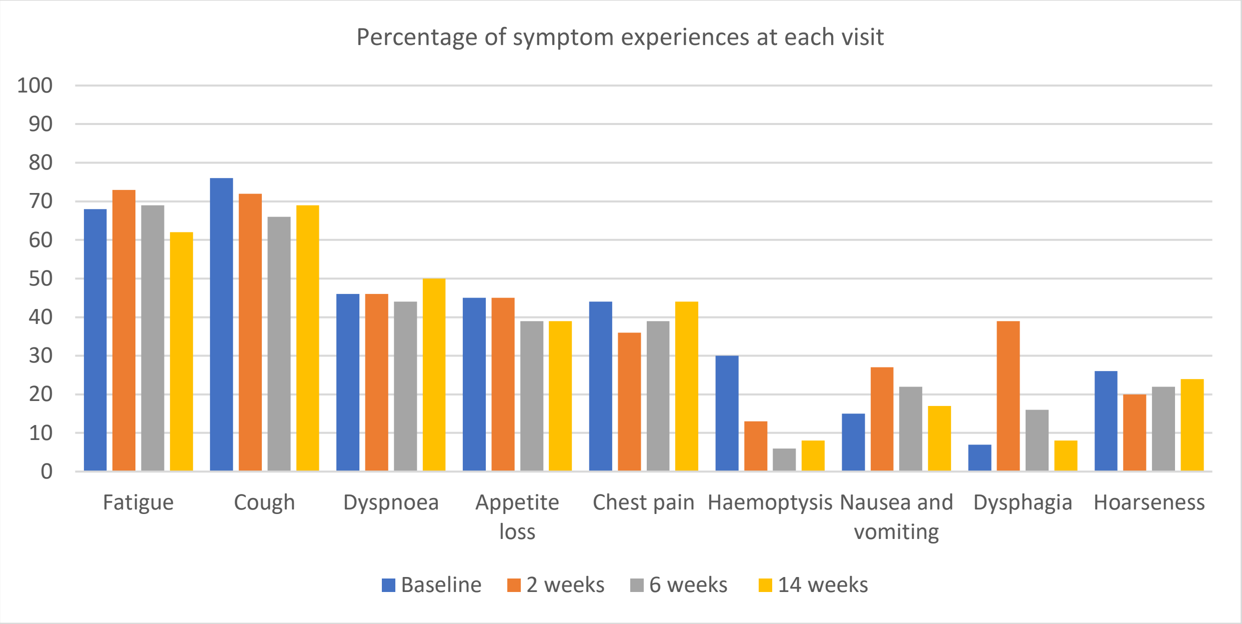


Figure 2-2 Percentage of patients who had symptoms at each visit by self-report.

b. During RT

PREVALENCE

Seven symptoms were evaluated across the eight studies, taking into account the duration of treatment. Five of these symptoms were associated with the chest (cough, dyspnoea, chest pain, haemoptysis, and difficulty swallowing), while the remaining two were disease symptoms (fatigue and loss of appetite). The number of patients who had symptoms was only shown in the study of McDermott et al. (2018), which found that fatigue was the most frequent symptom, at 37% (13 out of 35), followed by dyspnoea at 34% (12 out of 35), cough at 14% (5 out of 35), and dysphagia at 11% (4 out of 35). During palliative thoracic RT, patients experienced changed symptoms. Dyspnoea and haemoptysis reduced from the initial levels and cough occurrence remained steady, whereas dysphagia and fatigue increased compared to the baseline (McDermott et al., 2018).

SEVERITY

The mean severity score for respiratory symptoms included a score for cough, dyspnoea, haemoptysis, chest pain, and dysphagia. The score for the severity of cough in two studies showed opposing results: Sundstrøm et al. (2005) found that cough remained stable during treatment, while Langendijk et al. (2001) found an increase in severity during the RT period. Dysphagia severity showed a decrease from the baseline, as reported by Langendijk et al. in 2000, but a study mentioned by Senkus-Konefka et al. in 2005 did not show this decrease. Sundstrøm et al. (2005) observed a reduction in the severity of dyspnoea from the baseline, in contrast with Langendijk et al. (2001), who saw an increase from the baseline. A reduction in the severity of haemoptysis was observed by Sundstrøm et al. (2005) and Langendijk et al. (2001). And fatigue and appetite loss increased from the baseline in the study of Langendijk et al. (2001).

c. After RT

Symptom prevalence and severity and changes in prevalence and severity were evaluated in eight studies and across 14 different time points, i.e. 2, 4, 6, 14, 16, 22, 30, 38, 46, and 54 weeks after RT.

PREVALENCE

Two studies evaluated the prevalence of nine symptoms at the same time point, 2 weeks after RT was completed (McDermott et al., 2018, Sundstrøm et al., 2005). Fatigue was found to be the most common symptom experienced by participants, with 70% (249 out of 355) feeling fatigue, followed by cough at 67% (241 out of 355), dyspnoea at 46% (164 out of 355), appetite loss at 45% (147 out of 326), dysphagia at 38% (135 out of 355), chest pain at 36% (117/326), nausea and vomiting at 27% (88 out of 326), hoarseness at 19% (64 out of 324), and haemoptysis at 13% (42 out of 326).

SEVERITY

Table 3 show the mean score throughout RT, from the baseline to 54 weeks after RT. The mean scores for dyspnoea, cough, and haemoptysis showed a significant improvement in weeks 1, 6, and 16 after RT (Eldeeb et al., 2014). Notable reductions in mean scores for dyspnoea were demonstrated at week 4 after treatment (Bezjak et al., 2002; Eldeeb et al., 2014; Langendijk et al., 2000; Lefresne et al., 2017; McDermott et al., 2018), although there was a gradual worsening over time in one study (Langendijk et al., 2001).

There was a degree of reduction in chest pain at week 4, although this consistently did not reach statistical significance (Bezjak et al., 2002). Haemoptysis consistently improved, becoming significantly less prevalent at 4 weeks after RT (Bezjak et al., 2002; Eldeeb et al., 2014; Lefresne et al., 2017; Senkus-Konefka et al., 2005). Swallowing difficulties, or dysphagia, became more pronounced during RT but returned to their initial levels after 6 weeks (Bezjak et al., 2002, Langendijk et al., 2001, Senkus-Konefka et al., 2005, Sundstrøm et al., 2005).

Fatigue and appetite loss increased notably in severity 4 weeks after the course of RT (Bezjak et al., 2002). Sundstrom et al. (2005) reported a peak amount of fatigue at week 2 after RT that reduced to a level lower than the baseline at week 14, while a study by McDermott et al. (2018) found that fatigue rose from the baseline at week 4. Langendijk et al. (2001) reported that there was a significant rise in fatigue to above the baseline at 2 and 6 weeks and 3, 6, and 12 months after treatment. However, the decrease did not bring these symptoms back to their initial baseline levels. Similarly, appetite loss significantly increased during RT but then decreased to a level lower than the baseline value at both the 6-week and the 3-month marks after RT.

2.3.4 Percentage of improvement

When symptomatic improvement was being considered across all evaluated patients, the responses for symptom prevalence and symptom severity were considered. The data in three studies showed the percentage of improvement (Senkus-Konefka et al., 2005) (Langendijk et al., 2000) (Langendijk et al., 2001).

There was symptomatic improvement in cough ranging from 31% to 51%, as documented by Senkus-Konefka et al. (2005), Langendijk et al. (2000), and Langendijk et al. (2001). There was symptomatic improvement in dyspnoea in 36-60% of the assessed patients (Langendijk et al., 2000, Senkus-Konefka et al., 2005). Symptomatic improvement in chest pain was found in 60–83% of assessed cases, accompanied by a trend of mean score reduction from the baseline observed at various visits (weeks 2, 4, and 8 after RT), as reported by Senkus-Konefka et al. (2005), and Langendijk et al. (2000).

Conversely, the highest rate of improvement (79–86%) was reported in haemoptysis compared to other respiratory symptoms by Langendijk et al. (2001); Langendijk et al. (2000); Sundstrøm et al. (2005); and Senkus-Konefka et al. (2005). Senkus-Konefka et al. (2005) noted that 71% of the evaluated patients experienced relief from dysphagia symptoms after RT.

The percentages for improvement in fatigue and appetite loss were 21% and 33% respectively, as indicated in the study of Langendijk et al. (2000). The improvement rates reported for respiratory symptoms ranged from 36% for dyspnoea to 79% for haemoptysis (Langendijk et al., 2000).

2.3.5 Moderators of symptom prevalence/change

Three studies explored the factors that moderated the prevalence of symptoms in the context of cancer treatment, and they could not find any patient-related factors. These studies collectively identified several key moderators, including performance status, weight loss, cancer stage, objective tumour response (measured by changes in tumour size before and after RT via CT scans, with a response defined as complete tumour disappearance or a reduction of 50% or more of the two largest diameters), and radiation-induced pulmonary changes (assessed through chest radiographs obtained at 6 weeks and 3 months post-RT, categorised into five groups: no changes, minimal changes, patchy changes, dense changes, and severe changes) (Langendijk et al., 2001, Langendijk et al., 2000, Sundstrøm et al., 2005).

The poor performance status, weight loss, and lung cancer stage were linked to more frequent symptoms ($p < 0.0001$), as reported by Sundstrøm et al. (2005). Additionally, Langendijk et al. (2000) observed that patients with objective tumour responses experienced statistically significant improvement in dyspnoea ($p = 0.02$) and chest pain ($p = 0.03$). Similarly, Langendijk et al. (2001) noted that severe radiation-induced pulmonary changes were associated with increased dyspnoea post-RT ($p = 0.04$), and that patients with objective tumour responses reported greater relief from chest pain and arm/shoulder pain ($p < 0.01$).

2.4 Discussion

2.4.1 Summary and critique of evidence

It is important to identify the symptoms of lung cancer patients undergoing palliative radiation therapy. This will help clinicians, especially within a multidisciplinary team, to be proactive when assisting patients through a formalised pathway of information and intervention. It is particularly relevant where there is a clinical pathway across a timeline for specific interventions so that clinicians can support self-care activities that aim to maintain patients' quality of life despite the distressing symptoms of the disease and the treatment (Durnin et al., 2021). This systematic review helped the researcher to make decisions about empirical research. Also, the limited number of papers in this field made the researcher realise that it was necessary to conduct the studies.

The prevalence and severity of symptoms before, during, and after RT varied, with cough being the most prevalent symptom at baseline, followed by fatigue and insomnia. The most severe was dyspnoea, followed by cough and haemoptysis. During RT, fatigue emerged as the most frequent symptom, followed by dyspnoea and cough. Throughout RT, compared to baseline levels, dyspnoea and haemoptysis reduced, cough remained steady, and dysphagia and fatigue increased. Cough severity remained stable during treatment, while haemoptysis severity decreased from the baseline. Conversely, fatigue and appetite loss increased from the baseline. After RT, there was an initial increase in symptom prevalence at 2 weeks, followed by a subsequent decrease. Symptomatic improvement ranged from 21% to 86%. Fourteen weeks after the end of RT haemoptysis and dysphagia were not as severe as baseline levels. Cough and dyspnoea seem to recur quickly after the end of RT. Fatigue, appetite loss, dyspnoea and cough were present during RT, this still persisted 54 weeks after RT ended. Moderators including performance status, weight loss, cancer stage, tumour response, and radiation-induced pulmonary changes were identified across studies.

This systematic review explored the symptom burden of patients with advanced lung cancer receiving palliative thoracic RT in order to introduce the need for early, thoughtful symptom management for these patients. Assessment at the initial presentation of symptoms has been linked to improved self-care, emotional well-being, and functional status, better quality of life, and reduced morbidity in patients (Haun et al., 2017, Lindell and Danoff, 2021). To measure the impact of palliative care interventions for advanced lung cancer, repeated investigation of patients' symptom experience is essential, as symptoms fluctuate during and after RT (Deshields et al., 2014). The recommendation is to employ comprehensive self-reported symptom assessment systems using validated tools; In practice, most records regarding palliative RT in patients with advanced lung cancers showed that assessments were primarily based on clinician observations and reporting, rather than incorporating comprehensive patient-reported outcome measures (Eldeeb et al., 2014).

The review found no qualitative research that met the inclusion criteria. Incorporating qualitative research could provide additional insights into patients' lived experiences of symptoms. The reviewed literature showed significant heterogeneity regarding the prescribed dose of and fraction size for palliative thoracic RT (Metcalfe et al., 2010). The differences in patient characteristics, methods of symptom assessment, and measured outcomes further challenged the synthesis and comparability of the findings. While most of the studies included in the review are of a high quality.

The analysis recognised 13 symptoms at baseline that were documented in eight studies. This number of symptoms is not surprising considering the pathophysiology which is associated with obstructive pneumonia (Valvani et al., 2019). Initially, cough emerged as the most prevalent symptom, followed by fatigue, insomnia, dyspnoea, and pain. In line with earlier studies conducted by Metcalfe et al. (2010) and Walasek et al. (2015), it was found that between 47% and 70% of patients with advanced lung cancer undergoing palliative RT presented with cough. Lung cancer cells and respiratory secretions can act as foreign bodies, intensifying coughing in patients (Lin and Che, 2018). In cases of advanced lung cancer, patients might develop restrictive lung disease, leading to symptoms such as cough, breathlessness, and chest discomfort, along with notable reductions in diffusion capacity and respiratory volume (Majeed and Gupta, 2022).

Dyspnoea was found to be more severe than other symptoms, underscoring the significance of effective symptom management. A similar observation was made in a study by Hiratsuka et al. (2022) involving patients with advanced cancer in their final days of life, wherein dyspnoea was noted to be more severe in lung cancer patients compared to those with other types of cancer. Our review indicated a consistent reduction in haemoptysis from the baseline, and it improved notably; haemoptysis proved to be the most responsive symptom (King et al., 2022, Reinfuss et al., 2011), with improvement reported as early as 24 to 48 hours after radiation delivery (Johnstone and Rich, 2018). The reduction in haemoptysis from the baseline may stem from several factors, such as radiation specifically targeting the source of haemoptysis, for example a tumour or inflamed blood vessels, leading to its reduction (Singer et al., 2023).

There is still a lack of sufficient empirical evidence regarding the symptom experience in this population during palliative RT, indicating a need for further investigation into the onset of symptoms and the distress they cause (Martin et al., 2022). Conducting research that tracks symptoms during and after palliative RT can provide valuable insights for tailoring interventions and delivering personalised care to patients. Further investigation is warranted to identify effective self-management methods that can lead to better treatment adherence and health outcomes. Patient education materials, mobile apps, and telehealth programmes provide accessible and personalised support. These methods improve health literacy and empower patients to make informed decisions. Furthermore, they facilitate care coordination and monitoring (Bashi et al., 2018).

It is also essential to delve into how cultural and demographic factors influence symptom experience and management, with the goal of ensuring equitable care for all patient groups. Moreover, exploring the benefits of interdisciplinary collaboration among healthcare providers has promise regarding enhancing holistic symptom management approaches. Multidisciplinary teams in healthcare collaborate by establishing common objectives to guide patient care, maintaining open channels for communication and for sharing information and insights, defining the roles and responsibilities within the team, and coordinating efforts to ensure seamless patient care (Morley and Cashell, 2017). Relevant research emphasises the significance of cooperation, role perception, and interdisciplinary learning within such teams (Rosen et al., 2018).

The incorporation of these research areas into future studies has the potential to deepen our understanding of symptom management in patients with advanced lung cancers undergoing palliative thoracic RT, ultimately leading to improved patient outcomes and a higher quality of care. Dynamic assessment focusing on real-time symptom assessment allows for an ongoing evaluation of patients' conditions. It ensures that healthcare providers receive real-time data, enabling timely interventions (Jin et al., 2020). Self-reported symptoms play a significant role in identifying and monitoring symptoms. However, dynamic assessment methods, such as electronic symptom self-reporting systems, can improve symptom management and patient outcomes, particularly for conditions like advanced lung cancer (Cho et al., 2021). By prioritising dynamic assessment via remote patient monitoring (RPM), healthcare providers ensure proactive and personalised care, ultimately improving patient outcomes and safety.

Moreover, it is important to implement remote monitoring, or electronic patient-reported outcome measures (ePROMs), in practice to ensure accurate symptom assessment and management, especially when patients can't access traditional healthcare services. ePROMs operate through technology-driven methods and work remotely by tracking and gathering information regarding medication adherence, activity levels, and other vital health metrics. Patients often use health applications for scheduled follow-up visits, aiding in diagnosis and treatment (Jin et al., 2020). Remote monitoring enhances patient outcomes by providing real-time insights, enabling prompt interventions. Studies show reduced costs and better outcomes, especially for chronic conditions like hypertension, when this type of monitoring is done.

While ePROMs offer valuable real-time insights for improved patient care, successful implementation requires careful consideration of HCP workload. The potential for increased data volume, alert fatigue, and workflow disruptions requires strategies to optimise HCP time. Assigning dedicated staff to manage ePROM data, utilising prioritisation algorithms, and implementing automated responses can help to alleviate burden. Furthermore, integrating secure messaging systems and providing comprehensive training to HCPs is essential for efficient and effective use of ePROMs. By proactively addressing these challenges, healthcare systems can harness the benefits of remote monitoring without overburdening providers.

Remote monitoring thus contributes significantly to healthcare efficacy, particularly during crises, by facilitating proactive care and timely interventions. It allows healthcare providers to track patients’ conditions from a distance, enabling early intervention and reducing the risk of disease transmission. Remote monitoring, or ePROMs, also helps allocate resources efficiently and provides valuable data for epidemiological research and the public health response. In summary, it has the potential to improve outcomes and support effective healthcare for those patients who are able to utilise it effectively (Abejas et al., 2023, Payne et al., 2023).

The key to addressing the symptoms discussed earlier lies in self-management. Studies have shown that self-management offers various benefits, including improved health status, reduced hospital admissions, and reduced pain and reduced distress caused by symptoms (Dongen et al., 2020, Girgis, 2020, Hout et al., 2021, Hout et al., 2020). Patients need to actively participate in and take responsibility for their care so that they can cope positively with adversity. Self-management guidance is available online for people with cancer and their caregivers and covers dyspnoea and other symptoms (for example: https://www.bc-cpc.ca/publications/symptom-management-guidelines/symptom-management-guidelines-printable/). Remote monitoring and ePROMs also exist for patients at home (Abejas et al., 2023, Payne et al., 2023).

2.4.2 Strengths and limitations of the review

This is the first systematic review of the symptom experience of patients with advanced lung cancer who are receiving palliative thoracic RT, thus filling a gap in the existing literature. A comprehensive search strategy was employed using a broad operational definition of symptom experience to include as many relevant studies as possible. Understanding responses from patients with this type of cancer and undergoing this treatment is important. It is widely acknowledged that conducting patient-reported studies in palliative care populations is challenging, primarily due to patients' declining physical condition and limited prognosis (Kaasa et al., 2018, Hui and Bruera, 2020, Reid et al., 2015). The symptoms associated with this form of palliative treatment can be both physically and emotionally distressing, particularly for patients with advanced disease (Davis and Hui, 2017).

While conducting patient-reported studies in palliative care can be challenging due to patient vulnerability, cognitive impairment, short life expectancy, and ethical considerations, it remains crucial for advancing patient-centred care. These studies provide valuable insights into symptom management, advance care planning, and the overall needs of palliative care patients. To facilitate such research, adaptations like shorter questionnaires and flexible scheduling should be considered, alongside close collaboration with palliative care specialists and the use of appropriate outcome measures. By thoughtfully addressing these challenges and providing adequate training and support to research staff, valuable patient-reported studies can be conducted, ultimately contributing to improved care and quality of life for this vulnerable population.

The review is limited to English-language articles so may have missed studies in languages other than English that could have explored symptom experiences in different cultural contexts. Heterogeneity in symptom measurement instruments that use various scales and scoring systems presented challenges in synthesising results and drawing conclusive findings. A study missing some data will no longer be able to access the study database.

Standardising symptom measurement instruments and scales across studies would help to achieve more robust conclusions. According to the evidence presented in this systematic review, the researchers provided a solid review of the available evidence, even though only eight articles could be included. As previously stated, the relatively small number of articles included is normal and is one of the difficulties of undertaking patient-reported research in palliative care areas.

2.4.3 Conclusions and implications for practice

Thoracic RT may offer adequate palliation of lung cancer-related symptoms, but the degree of symptom control is a possible variable; symptom frequency and severity can vary significantly over time. The studies included in this review indicate that symptoms can fluctuate, highlighting the need for close monitoring. This review identified what symptoms seem to be more susceptible to being controlled, as well as those that persist. Our findings will be useful to multidisciplinary lung cancer teams for directing symptom assessment efforts and developing symptom management strategies for patients at home, such as electronic patient-reported outcome measures (ePROMs) (Abejas et al., 2023, Payne et al., 2023). This review consists of a concise report on the synthesised evidence.

2.5 Summary of chapter

This chapter provides a comprehensive examination of the existing knowledge related to symptom experience, caregiver burden, and informational needs. The incorporation of lung cancer information adds context to the discourse on palliative radiation. The exploration of symptom patterns, symptom experience attributes, and informal caregiving offers valuable insights into the impact of palliative RT on both patients and caregivers. In essence, the chapter offers a consolidation of the current evidence landscape, employing a methodical approach to literature review and a discerning evaluation of gaps in the evidence. Essentially, the findings from this review helped the researcher to indicate decisions that have to be made about how to design the study based on some findings of this systematic review. More detail can be found in the next chapter.

Chapter 3 Literature pertaining to the selected methodology

3.1 Introduction

This chapter will focus on decisions concerning the selected methodology of quantitative descriptive research design for the symptom experiences, side effects, and predictors of symptoms in Thai patients with advanced lung cancer who are receiving palliative radiotherapy (RT), as well as the caregiver burden and the information needs of patients and caregivers in Bangkok, Thailand and will explore the reasoning behind it. After meticulously outlining and dissecting each phase of the research in terms of the methodologies employed, this chapter culminates in a comprehensive overview of the ethical considerations that underpin the research. The examination specifically targets healthcare and nursing research, which aligns with the study's context. Notably, this research predates the COVID-19 pandemic, which allowed us to execute the data collection as originally planned and in a timely manner. Key points covered in this chapter are shown in Table 3.1.

Table 3-1 The key components of the research methodology.

Components	Descriptions	Reasons
Paradigm	Postpositivism	The researcher relied on postpositivism. It highlights that an objective reality exists, but it is based on the premise that humans can never know reality perfectly. Knowledge comes from observations, but also from the fusion of subjective interpretations and comprehensions. This approach uses scientific methods, structured research processes, and quantitative data collection like surveys, experiments, and statistical analysis. The significance of interpretation, reflexivity, and context in research means that a fluid and adaptable approach to research methodologies is best. (Moon and Blackman, 2014).
Theoretical framework alignment	The symptom management theory	This is a conceptual framework used in nursing research to understand and manage symptoms experienced by individuals, particularly those with cancer.It focuses on three key dimensions: symptom experience, symptom management strategies, and symptom outcomes. This study focuses on symptom experience: it examines how individuals perceive and live with symptoms. This framework helps researchers organise complex relationships within the symptom experience, especially in the context of cancer, with the most common focus being on understanding the symptom experience. This theory underpins the theoretical framework that guides this study. Specifically, this thesis draws from Dodd et al.'s (2001) work to explore symptom experiences.

	The Supportive Care Needs Framework	The supportive care theory serves as a comprehensive framework, ensuring patients receive holistic care tailored to their individual needs in the context of cancer treatment. The Supportive Care Needs Framework was proposed by Bonevski (2000) and Fitch (2008). Information needs subsets and unmet supportive care needs were discussed within the concept of caregiver burden.
Ontological position	Naïve realism	These study aimed to find the one reality that exists that can be understood using an appropriate method to assert the existence of an objective reality which is distinct and self-contained, thereby demonstrating a causal connection through empirical events. The ontological position aligns with naïve realism (Moon and Blackman, 2014).
Epistemological position	Objectivism	This knowledge comes from observations and empirical evidence and is based on facts rather than speculation or intuition. I specify that my stance on knowledge acquisition is positivist (Moon and Blackman, 2014).
Research design	Questionnaire survey design and explored predictors of symptoms	I thoroughly deliberated over the design of the questionnaire survey employed in this study. This approach serves as a crucial data collection method. The general principles of theoretical thinking are cognition, perspective, and self-awareness, all of which are used to obtain knowledge of reality and to design, conduct, analyse, and interpret research and its outcomes. These fit within the methodological decisions taken in this study
Research methodology	Data analysis approach	The specific research method employed was a survey. The research team outlines the chosen approach used for the data analysis and justify its application. This step ensures that the findings are robust.

Methods of data collection	Questionnaires	The method used to gather data is questionnaires.
Methods of data analysis	Descriptive and inferential analysis	This research analyses the collected data by conducting quantitative analysis and statistical tests.

3.2 Research design

The methodology in research, along with a set of supporting methods and guidelines, provides a framework for conducting that research (Blessing and Chakrabarti, 2009). In the realm of nursing research methodology, the current landscape can best be described as pluralistic and is marked by the coexistence of various methodologies (Corry et al., 2019). Two prominent research methods stand out: qualitative and quantitative methodologies. Quantitative studies align with the positivist paradigm, while qualitative studies are rooted in the naturalistic paradigm (Polit and Beck, 2022). These methodologies each possess unique attributes and trace their origins to distinct scientific traditions and bodies of knowledge. Quantitative research operates on the assumption that the universe is stable and predictable, lending itself to an experimental quantification of events. It is rooted in the positivist tradition stemming from the biomedical sciences. Qualitative research, on the other hand, prioritises the interpretation of meaning and the comprehension of human activities and behaviours through an interpretivist lens. This tradition stems from the social sciences' approach to qualitative inquiry (Polit and Beck, 2022).

Both of these methodologies are relevant in nursing research, with the selection hinging upon the nature of the research question at hand. A productive approach is to view research not as a dichotomy but as a continuum, with hybrid methodologies bridging the gaps between different approaches. It's a common assumption that qualitative approaches align with interpretive and critical social theory paradigms, while quantitative methods are grounded in positivist and postpositivist ontologies. An emerging paradigm, critical realism, acknowledges the potential for observation errors, and the revisability of theories is based on positivist and postpositivism ontologies. An emerging paradigm is the critical realist paradigm, in which the researcher acknowledges that all observations are susceptible to error and all theories are subject to revision (Parahoo, 2014).

For the scope of this study, quantitative methods would likely encompass surveys. In the medical and health sciences, surveys are frequently and effectively utilised in psychological research (Gray et al., 2016). Because existing quantitative evidence on health-seeking behaviours and consideration of the research questions focuses on exploring and describing both patient and caregiver perceptions, a quantitative design became a compelling choice. The systematic review guided the research towards a quantitative descriptive design due to its alignment with the research questions and existing evidence. The focus on exploring and describing patient and caregiver perceptions of health-seeking behaviours lends itself to quantitative surveys that can analyse patterns and trends.

Additionally, this design allows for building upon existing quantitative evidence, enabling comparisons and identification of knowledge gaps. For example, a quantitative survey could examine the relationship between caregiver burden and information-seeking behaviours by utilising validated scales and analysing correlations. While a quantitative approach is well-suited to measure and quantify aspects of health-seeking behaviours, a mixed-methods approach could provide a more holistic understanding by incorporating qualitative data to explore the reasons behind those behaviours, personal experiences, and challenges faced. The selection of methodologies is fundamentally steered by research questions, which are shaped by a thorough literature review and a reflective process that centres around the research topic (LoBiondo-Wood et al., 2017).

3.3 The overall paradigm

Table 3.2 show the summaries of four paradigms usually applied in nursing research and the ontological, epistemological, and methodological approach for each paradigm.

Table 3-2 Summaries of the four paradigms discussed in this research: positivism, post positivism, interpretivism, and critical social theory.

	Ontology	*Epistemology*	*Methodology*
Positivist	Within positivism, the ontological stance asserts the existence of an objective reality that is distinct and self-contained, demonstrating causal connections through empirical events.	Epistemologically, knowledge is derived from observations and empirical evidence and is grounded in facts rather than speculation or intuition.	Methodologically, this paradigm relies on the systematic employment of scientific techniques, structured research processes, and quantitative data collection methods such as surveys, experiments, and statistical analysis.
Post positivism	Social phenomena transcend mere objective measurements and are also shaped by subjective perceptions and interpretations.	Knowledge emerges not solely from objective observation but also from the fusion of subjective interpretations and comprehensions.	This paradigm underscores the significance of interpretation, reflexivity, and context in research, advocating a fluid and adaptable approach to research methodologies.
Interpretivism	Interpretivism places emphasis on subjective experiences and meanings and is rooted in the belief that reality is forged through interactions and interpretations within a social context. Social phenomena are regarded as intricate and multilayered and as	Knowledge is generated by delving into the subjective meanings and behaviours of individuals, which are filtered through the researcher's own perspective.	Interpretivism embraces qualitative methods to procure rich, intricate data on subjective experiences, contexts, and the distinct facets of each research scenario. Flexibility and reflexivity are endorsed to ensure transparency and accountability.

	resisting simplification through quantitative measurement.		
Critical social theory	The ontological standpoint of critical social theory posits that reality is socially constructed but there is an acknowledgement that power dynamics and social inequalities intricately meld social phenomena together.	Epistemologically, knowledge is far from neutral; it is instead shaped by power relations and societal disparities.	Methodologically, this paradigm leans towards qualitative research methods to explore social phenomena profoundly, and it strives to understand the subjective experiences and perspectives of individuals and groups within the wider societal context.

Kuhn (1996) introduced the term 'paradigm' to describe the theoretical framework of normal science. In the realm of research, paradigms encompass the theoretical frameworks, concepts, and assumptions that provide guidance for the formulation, execution, and interpretation of research endeavours. These philosophical foundations give rise to specific research approaches, such as qualitative or quantitative methods (Weaver and Olson, 2006). Research paradigms play a pivotal role in shaping researchers' perspectives on reality and knowledge, influencing the framing of research questions, methodologies, and outcomes. The landscape of research paradigms is characterised primary categories: positivism, interpretivism, post positivism, and critical social theory, each offering distinct lenses through which to comprehend reality and knowledge (Burrell and Morgan, 2017).

Nursing research is an expansive domain encompassing inquiries into the improvement of nursing practice novel care models, the expansion of nursing theories and concepts, and evaluations of policy and role impacts on nursing practice (Moule et al., 2017). In nursing research, the selection of research paradigms is of paramount importance. This choice facilitates the development of research methodologies while accounting for the researcher's own values (axiology) and aligning with their perception of truth (ontology) and their understanding of knowledge (epistemology) within their specific area of interest. Therefore, the selection of a research paradigm constitutes a fundamental aspect of any research undertaking. The progression of nursing as a professional discipline necessitated the establishment of a scientific research foundation to augment the discipline's credibility (Weaver and Olson, 2006).

3.3.1 Positivism: Exploring the empirical paradigm

Positivism is a paradigm that places a strong emphasis on empirical evidence and the utilisation of scientific methodologies to grasp the essence of reality. This paradigm operates under the assumption that an objective reality exists and that it can be observed and quantified through empirical investigations (Moule et al., 2017). Adherents to positivism contend that knowledge can be obtained through the avenues of observation, experimentation, and quantitative analysis. Within this research paradigm, hypotheses are rigorously tested, leading to the establishment of causal connections (Weaver and Olson, 2006). The positivist framework upholds a commitment to well-defined concepts and variables, tightly controlled conditions, precision-based instrumentation, and the validation of hypotheses through empirical assessments. The postpositivist paradigm, an extension of positivism, proves particularly suitable for delving into nursing subjects that demand comprehensive data collection and analysis of representative samples. It is also well-suited to exploring technically intricate clinical knowledge pertaining to specific treatments and constructing predictive theories aimed at at-risk individuals and communities (Weaver and Olson, 2006).

Central to the foundation of positivism is the principle of empiricism, which dictates that only those phenomena perceptible by human senses can be regarded as factual. Positivists embrace the concept of cause and effect (determinism) and seek explanations grounded in empirical data (Corry et al., 2019). They employ a hypothesis-deductive methodology reminiscent of disciplines like physics and chemistry. This entails subjecting hypotheses and theories to deductive testing during experiments (Parahoo, 2014). In the realm of research, positivism is not always employed in isolation. The combination of positivist and naturalist perspectives can furnish a more comprehensive understanding of the phenomenon at hand.

3.3.2 Postpositivism: Beyond the boundaries of positivism

Postpositivism emerged as a theoretical framework in response to the limitations inherent in positivism, showcasing both commonalities and distinctions between the two (Corry et al., 2019). Shared assumptions between positivism and postpositivism include the utilisation of a scientific method to explore cause-and-effect relationships within both the natural and the social realms, the indispensability of systematic and consistent empirical observation for knowledge acquisition, the recognition that causation is established through the consistency of conjunctions, and the understanding that science should incorporate value judgments. However, disparities exist between these two approaches. These divergences manifest in their perspectives on the scientific process such as whether it relies on induction or on hypothesis testing, whether the objective is theory verification or falsification, whether absolute truth can be unearthed by science or whether it is constrained by its own nature, and whether scientists should predominantly depend on observations or exercise their creative faculties (Corry et al., 2019).

Post positivism is a philosophy rooted in empirical observation, emphasising the importance of studying phenomena that can be directly observed through the senses. While this might initially seem to limit the study of abstract concepts like worry, well-being, and life satisfaction, post positivism recognises the value of self-reported data in capturing these experiences. This approach relies on the assumption that the measurement tools used to assess these intangible concepts are both valid and reliable, ensuring that the data collected accurately reflects the experiences being studied (Parahoo, 2014). Research conducted within the postpositivist framework upholds the tenets of the scientific method. This entails the formulation of research questions or hypotheses in advance, the operationalisation (definition) of key concepts, the selection of data collection methods prior to data-gathering, and a primarily quantitative approach to data analysis. It is possible to integrate qualitative methodologies into this framework and to adapt them to suit its processes. Predominantly, postpositivist research designs encompass surveys and experiments (Weaver and Olson, 2006).

3.3.3 Interpretivism: Unveiling the depths of subjective understanding

Interpretivism is a paradigm that places a profound emphasis on subjective experiences and the importance of working out the underlying meanings inherent in social phenomena. This paradigm has its roots in qualitative research methodologies (Corry et al., 2019). It involves studying phenomena from the perspective of individuals within the context of their daily lives. This perspective is grounded in the notion that reality is a product of social construction and that individuals interpret the world through the lens of their unique experiences and viewpoints. Within the interpretivist framework, knowledge is sought through qualitative research techniques such as interviews, observations, and textual analysis. This research paradigm is dedicated to the exploration of the meanings and experiences of both individuals and groups.

Interpretivists distinctly reject the principles of both positivism and post positivism, with interpretivism being posited as an alternative to positivism (Parahoo, 2014). Central to this paradigm is the concept that humans actively contribute to the shaping of the social world, engaging in an ongoing process of sense-making and interpretation of their social surroundings. Interpretivists have the philosophical belief that comprehending human behaviour necessitates an examination of the context in which it unfolds and an exploration of the cognitive processes that underpin it. This approach also recognises that researchers inevitably carry preconceived notions that must be "bracketed" or critically considered because of their potential influence on the collected data. Interpretivists accord great importance to subjective experience, perception, and language as keys to unlocking the intentions and motivations that underlie behaviour. It's acknowledged that individuals' behaviours are inextricably linked to their internal thought processes, and the impact of being studied must be acknowledged to reach a holistic understanding of their actions.

3.3.4 Critical social theory: Challenging injustice and empowering change

Critical social theory is a way of thinking that aims to fight unfairness and create a more equal society where everyone has a fair share of power and resources. It includes movements like feminism, community activism and efforts to free people from oppression. This theory believes that what we consider "truth" is shaped by social, political, cultural, gender, and economic factors. It sees research as a tool for change and exploring different, better ways of living. A key idea is "praxis," which means combining thinking and action to create real change. The focus is on the process of making change, not just the results (Weaver and Olson, 2006).

At its core, critical research is all about questioning the way things are and uncovering hidden social injustices. It believes that power shapes our reality, and research should be used to help people who are pushed to the edges of society. It also challenges the ideas of those in charge. Researchers use many different methods, from in-depth interviews to statistical surveys, to explore power, inequality, and how to create a fairer world (Collins, 2019).

In summary, the researcher’s perspectives and beliefs fit the postpositivist paradigm, and this can be tested when working with established facts about symptom experience, information needs, and caregiver burden. The methodology used is quantitative research, which can be conducted to objectively measure how big each concept is and what factors affect symptom experience, information needs, and caregiver burden. The research is based on the analysis of numerical data and is directed at establishing relationship between patients’ and caregivers’ characteristics and symptom experience in patients, information needed in patients and caregivers and caregivers’ burden.

3.4 Conceptual framework

In this study that involves Thai patients with advanced lung cancer undergoing palliative radiotherapy (RT), the integration of the Symptom Management Model (SMM) by Dodd et al. (2001) and the Supportive Care Framework by Fitch (2008) provides a robust conceptual foundation. These frameworks collectively offer a comprehensive perspective on symptom experiences, management strategies, and the multifaceted needs of patients and caregivers.

The researcher draws on the symptom management model proposed by Dodd et al. (2001). This model serves as a foundational framework, whether the aim is to alleviate the symptom's impact or alleviate the distress associated with the symptom. The model also recommends that all dimensions of a symptom should be assessed, such as prevalence, frequency, severity, and distress caused. The model helped the researcher to decide which symptom questionnaire is best suited to this study. The notion of symptom management contributes essential insights, guiding symptom assessment and treatment strategies within nursing practice. Moreover, it shapes the formulation of research inquiries and hypotheses in the field of nursing (Humphreys et al., 2013). Operating as a middle-range theory, this model offers a valuable structure for interconnecting clinical variables, symptom status, and patient outcomes. By integrating this framework into this research, this study’s authors sought to hypothesise causal links connecting demographic factors, physiological characteristics, treatment parameters, and symptoms in patients undergoing palliative RT for advanced lung cancer. In alignment with the symptom management model, we formulated hypotheses that interlink individual attributes like age, gender, lung cancer subtype, and disease stage with treatment variables such as radiation technique, dose, and treatment area.

Additionally, we incorporated the supportive care framework as proposed by Fitch and Steele (2010). This model adopts a person-centred approach that aims to provide comprehensive services to individuals grappling with advanced lung cancer. The intent is to address their informational, emotional, social, and physical needs throughout their cancer journey.

3.4.1 The symptom management theory

This theory suits this research because it includes many concepts that link to symptom experiences, as described in the next section. This middle-range nursing theory provides an all-encompassing structure for comprehending and handling symptoms encountered by individuals living with chronic illnesses. This theory underscores the significance of tackling the multifaceted elements of symptom experiences and underscores the requirement for tailored, situation-specific strategies for symptom management (Mathew et al., 2021).

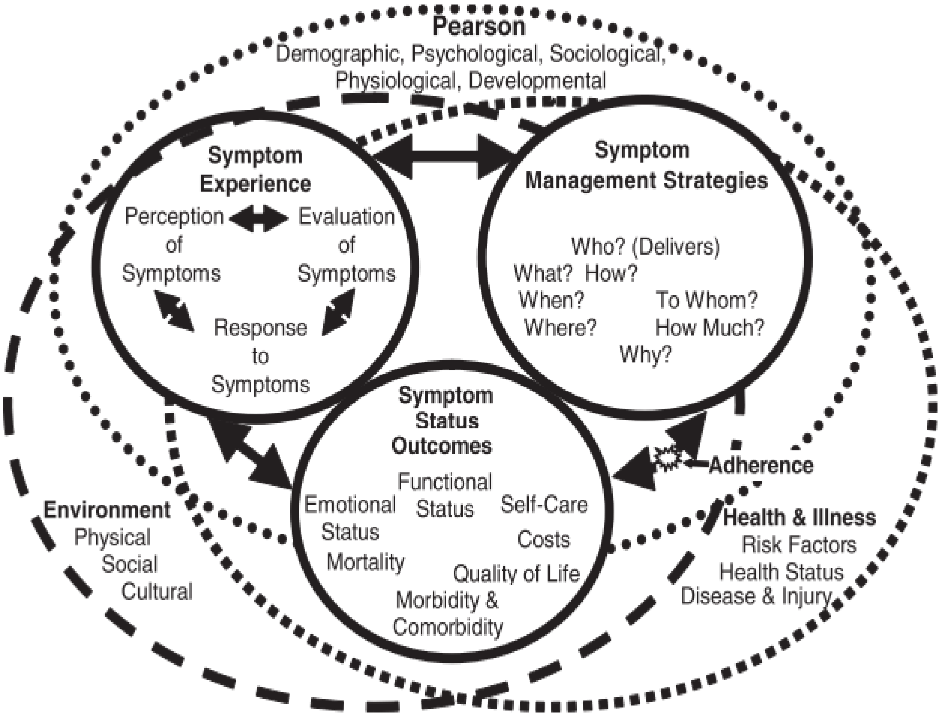


Figure 3-1 Symptom management theory.

Source: (Humphreys et al., 2013).

This study was grounded in the symptom management framework developed by the University of California School of Nursing Symptom Management Framework Group. The symptom management model encompasses three core elements: symptom experiences, symptom management strategies, and symptom status outcome, as proposed by Dodd et al. (2001). Nonetheless, Humphreys et al. (2013) made revisions to the framework with the aim of offering guidance for symptom assessment and treatment in nursing practice, along with proposing inquiries and hypotheses for nursing research. The foundation of the symptom management model is employed in patient care, where patients acquire the skills and capabilities needed to effectively handle their symptoms. Central to symptom management concepts are the evaluation of symptom experiences, devising symptom management strategies, and assessing the impact of implementing this theory, all of which contribute to alleviating patient symptoms. The integration of symptom management concepts into nursing practice calls for the role of a case manager or patient-focused nurse to strategies suitable care interventions that cater to the patient's needs.

3.4.1.1 Symptom experience

Symptom experience entails perceiving an anomaly in the body's performance of a particular function. Grasping the constituents of symptom experience is vital for effective symptom management. This encompasses the three subconscious consensuses that accompany perceived symptoms. Symptom assessment involves gauging the impact of symptoms and reacting to their recognition, where individuals sense changes or aberrations in their body or behaviour (Dodd et al., 2001). People typically evaluate symptoms by determining their severity, causes, and potential remedies. The influence of daily activities on symptom perception varies depending on the symptom experience, rendering the evaluation of and responses to symptoms distinct (Humphreys et al., 2013).

Symptom evaluation encompasses scrutinising the nature of the experience and assessing the severity of the symptom and the frequency of its occurrence. This assessment considers physical, psychological, and sociocultural responses to symptoms. It acknowledges the reciprocal association between symptom assessment and response, which is activated when individuals sense bodily or behavioural changes. This heightened awareness may hinge on individual and treatment-related factors. Once symptoms are recognised, they are subjected to assessment (Humphreys et al., 2013).

Factors such as severity, location, temporariness or persistence of symptoms, and the frequency with which they impact daily life, as well as their amenability to treatment, shape the assessment process. This assessment is founded on the experience of symptoms. Subsequently, individuals respond to the assessed symptoms, which encompasses physical, mental, and sociocultural facets.

People then endeavour to find avenues for managing these symptoms, considering both the physiological and the contextual dimensions (Dodd et al., 2001).

Symptom management strategies

The approach to symptom management is a fluid and adaptive process that responds to changing contexts. Its objective is to mitigate issues or mitigate symptom progression. The process commences with symptom assessment to identify emerging challenges. Goals are then established to address problems and effectively navigate symptoms. The components of symptom management methods are "who" (the party responsible for symptom management), "what" (the methodology employed for symptom management), "when" (the timing of symptom management), "where" (the location for symptom management), "why" (the rationale behind symptom management), "how" (the strategies used for symptom management), and "what" (the specific approach used). Once an individual comprehends how to handle and alleviate symptoms, their confidence in managing the situation increases. If the applied management approach yields positive outcomes and symptoms diminish, this instils a sense of efficacy. Conversely, if the initial approach is ineffective, individuals will explore alternative methods. Persistence in consistent symptom management, unhampered by obstacles, leads to effective symptom control (Dodd et al., 2001, Humphreys et al., 2013).

Symptom Status Outcomes

The culmination of symptom management is the resultant reduced impact of symptom experiences and their subsequent management. The symptom status outcomes' can be categorised as fitting within one of eight quality-related indicators: symptom status, bodily functionality, emotional well-being, cost implications of symptom management, potential adverse outcomes or complications stemming from symptom management, mortality rates, overall quality of life, and individual capacity for self-care. These different symptom management outcomes are intertwined and interconnected, often influencing each other. Furthermore, the outcomes of symptom management are intricately linked to other diverse aspects, ranging from social characteristics to physiological attributes. This study comprehensively explores symptom experiences and their interconnectedness with various facets of symptom management outcomes (Dodd et al., 2001, Humphreys et al., 2013).

3.4.1.2 Operational definition

Symptom experience

The term "symptom experience" encompasses a range of activities, including perceiving symptoms, evaluating their presence, and responding to changes in bodily functions, perceptions, or thoughts. This concept is quantified through the utilisation of the Memorial Symptom Assessment Scale (MSAS), originally developed by Portenoy et al. (1994) and initially applied to patients with metastatic cancer. In cases when patients were filling out the relevant questionnaires and confirmed that they had been symptom-free the previous week, they were allowed to skip subsequent questions. Conversely, patients who reported that they had experienced symptoms were asked to provide additional responses regarding symptom frequency and severity and the associated distress. The translated Thai version of this questionnaire was introduced by Suwisith et al. (2008).

Symptom experience is a broader, more encompassing concept. It includes not just the frequency of a symptom but also its intensity, distress, and impact on the individual's life (Armstrong, 2003). Symptom frequency is a component of symptom experience that was assessed on a four-level scale: "rarely", "occasionally", "frequently", and "almost constantly". Similarly, symptom severity was measured using a four-level scale: "slight", "moderate", "severe", and "very severe". In terms of distress, responses were graded on a five-level scale: "not at all", "a little bit", "somewhat", "quite a bit", and "very much". The design of the symptom management model delineates a two-way relationship among the three central concepts, represented in a diagrammatic format. This correlation, substantiated through research and experimentation, contributes to a more comprehensive conceptual framework that is endorsed by the Centre for Disease Control at the University of California Symptom Management faculty group (Figure 3.1).

3.4.1.3 Model hypothesis

The symptom management model is underpinned by five primary principles:

1. Individual Perception of Symptoms: This model is founded on the principle that the evaluation of symptoms is rooted in the unique perception of an individual. Symptom identification and interpretation stem from the person experiencing the symptoms themselves.
2. Collective Experience: Unlike models solely derived from a single person's encounter, this model acknowledges the diverse range of experiences of different individuals. This recognition is crucial to account for variations in symptom experiences that can be influenced by factors like environment, social dynamics, and personal circumstances.
3. Early Intervention: A cornerstone of this model is the recommendation that symptom management initiatives should be initiated prior to the onset of symptoms. This preventive stance aims to enhance preparedness and minimise the impact of symptoms on individuals and their well-being. To truly operationalise early intervention in symptom management, proactive assessment is essential. This involves regularly evaluating individuals for risk factors associated with specific symptoms, considering their medical history, lifestyle, environment, and genetic predispositions. Based on these assessments, preventive measures can be implemented, including lifestyle modifications, prophylactic medications, counselling, or educational programs. For example, cancer patients undergoing RT could benefit from proactively managing potential side effects like nausea, fatigue, and skin reactions through anti-nausea medication, energy conservation education, and skincare recommendations. This proactive approach aims to minimise symptom impact and enhance patient well-being.
4. Representation by Others: Caregivers or family members often relay and interpret the symptoms of patients who may be unable to

communicate their symptoms directly – such as young children or individuals recovering from a stroke. This model underscores the validity of such communication, as management strategies are frequently tailored not only to individuals but also aim to be suited to family units, groups, workplaces, or broader contexts.

5. Dynamic Nature of Symptom Management: This model acknowledges that symptom management is a dynamic process that evolves over time. It is influenced by a spectrum of factors encompassing personal outcomes, nursing consensus, individual attributes, and the interplay between health and the environment.

These assumptions collectively shape the symptom management model, offering a comprehensive framework that accommodates the diverse and evolving nature of symptom experiences. This study focuses on the first hypothesis, which is about individuals' perception of symptoms.

3.4.1.4 The relation of nursing concepts to the model

In the most recent iteration of the model, the integration of nursing concepts which relate to person, health, and environment – is acknowledged as crucial. These concepts act as variables that influence the model's three core components: symptom experience, symptom management strategies, and outcomes.

Concept of person

Personal variables can be seen in individualised data encompassing physical, psychological, and social aspects. Dodd et al. assert that each person experiences symptoms in a unique way. This notion is further enriched by the inclusion of variables such as developmental stage or individual maturity. When applying the model, a thorough and detailed explication of individual variables is often necessary. The relevance of these variables depends on the specific symptoms under consideration and the population of interest (Dodd et al., 2001)

Concept of health

Health variables encompass dynamic factors that can shift depending on individuals’ health status and can escalate individuals’ susceptibility to symptoms. These variables include injuries, partial dysfunction, and other health-related aspects. Dodd et al. reveal that health and illness variables, either directly or indirectly, impact the trajectory of symptom experiences, management strategies, and outcomes. Every individual harbour specific risk factor tied to symptoms; these risk factors arise from diverse environmental influences such as occupational hazards or treatment side effects. Symptom management programmes, encompassing education concerning suitable, safe, and effective work practices, are pivotal in foretelling, preventing, or mitigating such symptoms, especially those related to musculoskeletal issues. Furthermore, the model included an evaluation of factors that influence the perception of, appraisal of, and response to potential risk factors for various symptoms (Dodd et al., 2001).

Environmental concepts

The environment in this context signifies the contextual backdrop that is linked to symptom occurrence. It encompasses a spectrum of factors, including physiological parameters, societal norms, cultural practices, physical surroundings (e.g. homes, workplaces, hospitals), social support networks, and interpersonal relationships. The cultural environment extends to include an individual's adherence to ethical principles, which is influenced by factors like race, religion, beliefs, and values. Dodd and colleagues observed that the environment influences two core facets of the model: symptom management strategies and resultant outcomes. This expansion of the nursing, person, health, and environmental concepts has notably enriched the model's theoretical foundation, which builds upon prior research (Dodd et al., 2001).

3.4.1.5 Research in this field

Symptom management theory has been explored and compared with other theories, exhibiting its applicability across diverse patient cohorts (Cwiekala-Lewis et al., 2017, Jablonski and Wyatt, 2005, Mathew et al., 2021). Mathew et al. (2021) systematically assessed the symptom management theory's scope and its utilisation for comprehending research and practical applications among adult cancer patients. Their findings illuminate that the dimension of symptom experience has been the focal point of intensive research regarding adults grappling with cancer. The article also sheds light on certain limitations inherent in symptom management theory, pinpointing their implications for both cancer-afflicted adults (Mathew et al., 2021) and individuals nearing the end of life (Jablonski and Wyatt, 2005).

Within the Thai context, symptom management theory has been robustly explored and applied across an array of patient populations (Chaiviboontham et al., 2011, Get-Kong et al., 2010, Khamboon et al., 2015, Suwisith et al., 2008), including individuals with lung cancer (Pudtong et al., 2014).

This model underscores the importance of assessing all dimensions of a symptom, including prevalence, frequency, severity, and the distress it causes. By applying this model, this study can systematically examine how demographic factors, physiological characteristics, treatment parameters, and symptoms interrelate in patients undergoing palliative RT for advanced lung cancer

3.4.2 The supportive care theory

Our hypotheses are grounded in the supportive care model and propose associations between individual attributes – such as age, gender, and lung cancer type – and information needs. Individuals with lung cancer may grapple with a spectrum of unmet needs, necessitating tailored support interventions. Rapid identification of these needs is pivotal to ensure timely allocation of appropriate resources. These needs span physical challenges like fatigue and discomfort, as well as emotional, psychological, social, spiritual, practical, and informational aspects. Crafting interventions to address this diverse array of demands is essential for aiding patients as they navigate their cancer experiences.

Supportive care entails an individual-focused approach to caregiving that aims to cater to the diverse needs of cancer patients, encompassing informational, emotional, social, and physical dimensions, across the trajectory of their illness

(Kotronoulas et al., 2017). While these supportive care needs are particularly relevant for lung cancer patients, many of them apply to individuals facing other types of cancer as well. For instance, comprehensive information about diagnosis and treatment, guidance for decision-making, empathetic support and reassurance from healthcare providers, the consistent presence of family members during diagnosis and treatment, assistance for managing fatigue, nutrition, depression/anxiety, and pain, online support resources, access to counselling and support groups, insights into palliative care and provision of spiritual support (Fitch and Steele, 2010).

3.4.2.1 Definition of supportive care

Definition establishes supportive care as the provision of essential services to those living with or affected by cancer that have the aim of addressing their physical, emotional, social, psychological, informational, spiritual, and practical needs throughout their cancer journey (Fitch, 2008).

The National Institute for Health and Care Excellence characterised supportive care in 2019 as a term that encompasses a spectrum of services. It involves advocating for the care of cancer patients and their caregivers as well as for the care of individuals with cancer. The approach involves equipping patients with essential knowledge and information, including about psychological support, symptom management, social support, rehabilitation, and spiritual support. This multidisciplinary approach involves not only the healthcare team but also family, friends, and volunteer groups (NICE, 2019).

Implications for supportive care for patients with cancer

Consistent findings from various studies emphasise that, beyond effective medical treatments, patients seek to be treated with empathy, dignity, and respect and desire their preferences to be considered when treatment and care decisions are made. The vast majority of patients express a strong need for comprehensive information about their condition and about available treatment options and available services (NICE, 2019).

Effective interpersonal communication is held in high regard, while seamless coordination of care services is highly valued and expected by patients, achieving this in practice can be challenging due to systemic and logistical barriers. Patients have an expectation that symptom management will be proficient and that psychological, social, and spiritual support will be available should the need arise. Many wish to spend their last days in a place of their preference, often their own homes (Hannon et al., 2015). They also seek assurance that their loved ones and caregivers will receive support throughout their illness and, in the event of their passing, during the bereavement period (NICE, 2019).

Supportive care is an integral facet of cancer treatment which has profound implications for cancer patients who receive such care. Delivering the highest-quality care necessitates interdisciplinary collaboration, integration of technology, and ongoing assessment and enhancement of supportive care interventions. By adopting evidence-based supportive care strategies, healthcare professionals can potentially augment patient outcomes and quality of life and can alleviate the burden of cancer for patients and their families even in the midst of challenging circumstances, such as the ongoing pandemic (Aapro et al., 2021).

Definitions of supportive care needs

a) Definition of the supportive care needs of patients

Supportive care needs encompass the requirements expressed by patients for assistance with managing symptoms and mitigating side effects, help with rehabilitation and coping strategies, with the fostering of informed decision-making and knowledge acquisition, and with minimising functional deficits (Ream et al., 2008). These needs denote the necessary patient care in terms of addressing symptoms and side effects, aiding with adapting and coping, facilitating making informed decisions through knowledge enhancement, and lessening functional limitations (Maguire et al., 2013). The need for supportive care pertains to seeking assistance with or fulfilment from support sources, where the assistance is aimed at attaining goals and a state of satisfaction with the situation (Sanson-Fisher et al., 2000). Sklenarova et al. (2015) posit that the need for supportive care means aspiring to attain what is deemed desirable or essential or seeking a response from diverse sources of support to maintain well-being.

Bonevski et al. (2000) delineate the supportive care needs of cancer patients as encompassing accessing psychological health information and care, physical and routine caregiving systems, support and assistance, and guidance regarding how to navigate life when confronted with challenges or difficult circumstances. The unbalanced needs of cancer patients entail a desire to receive care from multidisciplinary healthcare teams as well as family, friends, and volunteer groups.

b) Definition of the supportive care needs of caregivers

The supportive care needs of caregivers are defined as the requisites linked to the physical, emotional, and practical aspects of caring for individuals with chronic conditions or life-limiting illnesses (Chen et al., 2016). Unmet supportive care needs denote the discrepancy between the services or support that are required to address specific challenges and the actual services or support received.

3.4.2.2 Elements of supportive care needs

a) Elements of the supportive care needs of patients

This study adopts the Supportive Care Needs Framework which encompasses five distinct areas (Bonevski et al., 2000):

- Psychological Needs: Addressing emotional distress and encouraging the development of the coping skills required by the patient.
- Healthcare System and Information Needs: Seeking assistance from healthcare staff to navigate the healthcare system, manage the illness, and comprehend treatment side effects. This includes seeking information on diagnosis, treatment, and routine care.
- Physical and Daily Living Needs: Coping with physical symptoms, managing treatment side effects, and maintaining regular physical activities.

- Patient Care and Support Needs: Recognising the importance of healthcare providers' empathy, physical support, and mental support and offering treatment choices.
- Supportive Care Needs Related to Intimacy: Acknowledging the need for patient support in relation to changes in relationships and sexual desire, which encompasses shifts in the changes in how patients experience sex during their illness.

b) Elements of the supportive care needs of caregivers

Caregivers face a diverse range of challenges and needs while caring for patients. According to the framework developed by Sklenarova et al. (2015), the supportive care needs of caregivers caring for someone with cancer can be categorised into four domains:

- Healthcare Service and Information Needs: Addressing caregivers' need to understand the disease, diagnosis, and treatment through having access to relevant information.
- Emotional and Psychological Needs: Catering to caregivers' need for assistance with managing emotions and developing effective coping mechanisms.
- Work and Social Security Needs: Recognising caregivers' need to understand work-related impacts and how to access financial aid and health insurance systems, while fostering communication within families.
- Communication and Family Needs: Meeting the caregivers' need for guidance on effective communication with the person they are caring for and family members, as well as utilising familial support.

Moreover, according to the supportive care needs of caregivers caring for someone with cancer can be grouped into four categories (Girgis et al., 2011):

- Healthcare Services: Acknowledging caregivers' need for support from healthcare personnels, access to health systems and benefits, and continuous provision of physical and psychological care for patients.

- Emotional and Psychological Needs: Recognising caregivers' demand for assistance with managing their emotions and with developing effective coping strategies.
- Work and Social Aspects: Addressing caregivers' need for training in caregiving skills, advice on how to access financial support, access to health insurance, and effective communication with the person they are caring for and family members.
- Informational Needs: Catering to caregivers' requirement for accurate and comprehensive information about the disease, treatment, and patient care.

In conclusion, this study adopts the supportive care needs framework of caregivers due to its comprehensive delineation of the supportive care needs of caregivers who are caring for someone with cancer. As noted, the framework categorises these needs into four main areas: healthcare service needs, emotional and psychological needs, work, and social aspect, and information needs (Girgis et al., 2011).

3.4.2.3 Information needs

In order to accurately determine the supportive care needs of lung cancer patients and their caregivers, nurses need comprehensive information regarding the patients' experiences of symptoms (Kiteley and Fitch, 2006) . Information needs encompass aspects related to diagnosis, diagnostic tests, psychological concerns, family dynamics, and financial considerations. In the dynamic and rapidly evolving landscape of healthcare, healthcare providers grapple with the ongoing challenge of discerning the specific and personalised information needs of patients and their families. Key questions arise, including what information is essential, the appropriate depth and breadth of information provision, the suitable format for disseminating information, and the optimal timing for healthcare professionals to deliver this information (Durnin et al., 2021). This study exclusively focuses on the aspect of information needs, building on the framework established by Bonevski et al. (2000) for patients and by Girgis et al. (2011) for caregivers. Additionally, this research incorporates inquiries such as whether participants desire information on symptom management for each symptom on the Memorial Symptom Assessment Scale (MSAS), their preferred information sources and types, and the specific nature of the information sought. By investigating these aspects, the study aims to gain a more comprehensive understanding of the specific information needs of both patients and caregivers than is currently available.

3.4.2.4 Assessment of supportive care needs

- The Cancer Needs Questionnaire (CNQ), developed by Foot and Sanson-Fisher (1995), comprises 71 questions organised into three main sections: 1) Needs, encompassing five domains: psychological needs, health system and information needs, physical and daily routine needs, patient care and support needs, and gender-related needs; 2) Aspects of disease and treatment; and 3) Aspects of personal characteristics of patients.

- The Supportive Care Needs Survey – Long Form 59 (SCNS-LF59), an adapted version of the CNQ by Bonevski et al. (2000), consists of 59 questions aimed at evaluating the impact of various cancer-related aspects. It identifies five domains of supportive care needs: 1) Psychological, 2) Healthcare systems and information, 3) Physical and routine activities, 4) Care and support, and 5) Sexual integrity. The internal consistency of the questionnaire ranges from 0.87 to 0.97, indicating acceptable reliability (Sanson-Fisher et al., 2000).

- The Supportive Care Needs Survey – Short Form 34 (SCNS-SF34), derived from the original SCNS-LF59, retains its five components (psychological, health system and information, physical and daily life, patient care and support, and sexuality needs). The questionnaire's psychometric properties are strong, with Cronbach’s alpha coefficients ranging from 0.86 to 0.96, indicating high internal consistency. The SCNS-SF34 demonstrates convergent validity when compared to various psychosocial well-being measures, with correlations ranging from 0.48 to 0.56. Furthermore, both the 34-item and 59-item surveys exhibit strong agreement regarding identifying patients requiring assistance, with Kappa coefficients of at least 0.83 for each domain (Bonevski et al., 2000). The SCNS-SF34 retains the original instrument's psychometric features and remains easily comprehensible to individuals with a seventh- or eighth-grade education (Boyes et al., 2009).

The Thai version of this tool, translated by Uujai and Somjaivong (2016), has been employed to assess the impact of various cancer-related aspects, including an assessment of the healthcare system and treatment effects. It identifies five supportive care needs domains: 1) Psychological, 2) Healthcare systems and information, 3) Physical and daily activities, 4) Healthcare, and 5) Sexual aspects. This version consists of 34 questions scored on a 5-point scale, ranging from 1 to 5, with higher scores indicating greater need. A total score of between 34 and 36 points is interpreted as indicating a need for supportive care (Boyes et al., 2009). The Thai version demonstrates semantic and linguistic equivalence to the original form, with a Cronbach alpha of 0.95 and domain scores ranging from 0.52 to 0.93.

- The Supportive Care Needs Survey for Partners and Caregivers (SCNS P&C), with Cronbach's alpha values ranging from 0.88 to 0.94, identifies four domains of needs: healthcare service needs, psychological and emotional needs, employment and social needs, and information needs. The SCNS-P&C exhibits good construct validity and comprehensively assesses caregivers' supportive care needs throughout an illness. This tool's reliability and validity were established through analyses. It consists of 44 items and uses a 5-point scale for scoring (1 to 5) (Girgis et al., 2011).

The Thai version of this tool, translated by Sangruangake et al. (2022), demonstrates good reliability and validity for assessing caregivers' unmet needs in Thailand. It aids healthcare professionals to provide tailored care to address caregivers' specific needs. The T-SCNS-P&C displays satisfactory internal consistency, with a Cronbach's alpha of 0.82 for the total scale and 0.75 to 0.89 for each domain. Construct validation confirms the measurement model's fit and overall psychometric properties (Sangruangake et al., 2022).

To assess the unmet supportive care needs of lung cancer patients, the Supportive Care Needs Survey for Patients (SCNS-SF34) and the Supportive Care Needs Survey for Partners and Caregivers (SCNS P&C) were employed. Six questions from the information needs subscale were selected to evaluate information needs during palliative RT. Participants rated their level of need for assistance during treatment for each item.

3.4.3 Caregiver burden

Caregivers are individuals who offer physical, emotional, and/or financial assistance to those unable to care for themselves due to illness, disability, or other conditions. The role of caregiving can be demanding and emotionally taxing, often leading to unmet supportive care needs that can significantly affect both the caregivers' well-being and the quality of care they provide. Among the top unmet needs are those related to information about the relevant illness, healthcare professionals and services, and daily living. A positive correlation exists between patient anxiety and caregivers’ need for healthcare professionals/services, interpersonal communication, and psychological/emotional support. Additionally, caregivers' unmet information and healthcare professional/service needs are linked to their experience of fatigue. Sleep disturbances among caregivers are associated with their overall caregiving demands, daily living needs, and psychological/emotional needs (Chen et al., 2016).

Caregivers with unmet needs or those facing high levels of burden might struggle to fulfil their supportive role effectively, potentially compromising the ongoing support they offer to patients. The strain on caregivers could potentially lead to patients experiencing unmet needs (Deeken et al., 2003). Another potential consequence of unmet supportive care needs is a decline in the quality of care provided by caregivers. In research by Girgis et al. (2013), caregivers who reported higher numbers of unmet supportive care needs also reported providing lower-quality care. This is particularly concerning for caregivers of patients with chronic illnesses or disabilities who require continuous care and assistance. While the prevalence of unmet needs has diminished over time, approximately one-third of caregivers still report unmet needs at the 24-month mark. The most significant unmet needs are tied to caregivers' health and relationships. They are linked to increased disruptions in caregiving-related activities, anxiety, depression, a lack of coping strategies, and out-of-pocket expenses. This aligns with the earlier discussion on the link between lower income and higher caregiver burden, highlighting the need for financial assistance and support for caregivers. Reduced engagement in caregiving duties and improved physical health and social support are associated with fewer reported unmet needs. The connection between certain characteristics (e.g. anxiety and depression) and unmet needs tends to strengthen over time.

Unmet supportive care needs can lead to significant negative effects on caregivers' well-being and the quality of care they provide. The main consequences of unmet needs for supportive care can encompass caregiver burden, compromised care quality, and emotional exhaustion. Implementing supportive care interventions and resources to address these needs can help mitigate the adverse impacts of caregiving and enhance the well-being of both caregivers and care recipients.

An important outcome resulting from unmet supportive care needs is known as caregiver burden. This refers to the adverse effects that caregiving has on the physical, emotional, and social well-being of the caregiver. Caregiver burden often takes the form of conditions such as depression, anxiety, fatigue, and various physical and psychological symptoms (Liu et al., 2020b). Research conducted by W. Fu et al. (2021) discovered a correlation between higher levels of unmet supportive care needs and elevated levels of caregiver burden among caregivers. This burden can contribute to a reduced quality of life for the caregiver, heightened utilisation of healthcare services, and an increased likelihood of the care recipient needing institutionalised care. Notably, being older, having a lower educational attainment, and being married have been associated with a lower likelihood of experiencing caregiver burden. Additionally, the challenges faced by caregivers are exacerbated by increased expenditure related to essential items for the treatment of the relevant illness and decreased family income, both of which act as secondary stressors. The involvement of formal medical support systems has been shown to have a positive impact on alleviating caregiver burden.

3.4.2.1 Elements of caregiver burden

The selection of questions was guided by both clinical insights from caregivers and previous research (Lowenthal, 1964). This research covered the most frequently cited areas of concern by caregivers, including caregivers’ physical health, psychological well-being, financial situation, social interactions, and the relationship between the caregivers and the person they were assisting (Zarit et al., 1980). The Zarit Burden Interview (ZBI) addresses various aspects such as health, finances, social life, emotional state, personal life, and interpersonal relationships (Zubaidi et al., 2020).

It guides our understanding of caregiver burden by emphasising the interconnectedness of self-perception (Association), multifaceted strain (social and practical), and evolution over time (biological and disease-related factors)." the burden experienced by caregivers of cancer patients has been segmented into three distinct domains (Liu et al., 2020b):

- Self-perception: This pertains to how caregivers perceive their personal journey throughout the caregiving process. Naturally, within a similar caregiving context, the perceived level of burden can differ among caregivers.
- Multifaceted strain: Caregiver burden is multidimensional and can result in caregivers neglecting their own health due to the long-term care demands they face. This often leads to health issues. A caregiver burden can strain family relationships, disrupt caregivers' routines and lifestyles, limit their social engagement, and foster feelings of isolation. Economic difficulties of varying degrees are also frequently encountered by caregivers.
- Evolution over time: Caregiver burden is not a constant state; it evolves over time and is influenced by factors such as the duration of caregiving,

the support available from the social/family network, and the progression of the underlying disease.

These three categories collectively provide a comprehensive understanding of the various dimensions and dynamics of caregiver burden.

3.4.2.2Assessment of caregiver burden

- Caregiver Strain Index (CSI): The CSI offers a concise evaluation of caregiver burden, assessing the degree of strain experienced due to caregiving responsibilities. Comprising 13 questions with binary yes or no responses, the total score ranges from 0 to 13, with higher scores indicating a greater caregiver strain. Research has validated the reliability and validity of the CSI (Robinson, 1983).

- Modified Caregiver Strain Index (MCSI): The MCSI is a refined version of the CSI and gauges caregiver strain across multiple dimensions such as emotional, physical, and financial aspects. Comprising 15 questions with yes or no responses, the total score ranges from 0 to 15, with higher scores indicating an increased caregiver strain. The MCSI has demonstrated excellent reliability and validity (Thornton and Travis, 2003). However, it is worth noting that the CSI and the MCSI might not encompass the full breadth of caregiver burden experiences, which could be considered a limitation. It could be argued that they may not adequately capture caregivers' subjective feelings, including emotional distress and the impact on their personal identity. Additionally, the binary response format of yes/no in the CSI might not fully capture nuanced responses, potentially leading caregivers to believe that their experiences are not fully represented.

- Zarit Burden Interview (ZBI): Widely used to assess caregiver burden, the ZBI delves into the caregiver's emotional stress and strain and the burden related to caregiving. Consisting of 22 items, responses are rated on a scale from 0 (never) to 4 (nearly always), with a total score range of 0 to 88. Higher scores correspond to a greater caregiver burden. The reliability and validity of the ZBI have been established through multiple studies (Zarit et al., 1980).

The Zarit Burden Interview was employed in this study to identify caregiver burden as the ZBI has undergone extensive validation across diverse populations and settings (Seng et al., 2010).

3.5 Exploring alternative theoretical frameworks

This study's main objective was to determine what the symptom experiences of patients with advanced lung cancer are, the extent of caregivers’ burden, and what the information needs are of both patients and caregivers. Prior to deciding to use the symptom management theory, other theories were considered and evaluated in depth, such as Orem's Self-Care Model, the Patient Health Engagement Model, and the self-determination principle. While the theory of unpleasant symptoms provided a foundation for understanding symptom experiences, other frameworks, such as Orem's Self-Care Model and the Patient Health Engagement Model, were also considered to provide a more comprehensive perspective.

3.5.1 Orem's Self-Care Model

Orem's Self-Care Model focuses on the capacity of patients to practice self-care, which is described as the practice of activities that individuals initiate and undertake on their own behalf for the purpose of preserving life, health, and well-being (Williams et al., 2006). While this model introduces valuable concepts related to self-care, it also has limitations. Its application might be constrained in various contexts, it could appear complex, and it might not account adequately for social determinants of health, cultural variations, and the diverse needs of patients with limitations. Notably, it could be less accommodating for patients who are unable or unwilling to perform self-care tasks (Orem, 2001).

3.5.2 The Patient Health Engagement Model

The Patient Health Engagement Model is rooted in patients' experiences and preferences regarding their involvement in treatment. This framework can guide healthcare providers and policymakers when they are fostering patient engagement in care management (Graffigna et al., 2017). Although this model offers insights into patients' experiences, it might not fully encompass the nuanced psychological aspects of patient participation, such as emotional responses to waiting for test results or navigating online health forums. This limitation is especially evident when compared to the comprehensive approach of the supportive care framework.

3.5.3 Self-determination

The principle of self-determination (SDT) emphasises the importance of individual competence, autonomy, and relatedness for psychological well-being (Deci and Ryan, 2000). This psychological framework investigates human motivation and personality development. While it underscores personal motivation, it might not adequately address this circumstance and could be too complicated. Additionally, its alignment with this study's focus on symptom prevalence and supportive care might not be seamless.

3.5.4 The theory of unpleasant symptoms

The theory of unpleasant symptoms elucidates how symptoms of illness can lead to adverse health outcomes, potentially affecting quality of life and healthcare utilisation (Lenz et al., 1997). It suggests that distressing feelings might prompt harmful behaviours, like avoiding exercise or excessive medication use. Although this theory acknowledges the interaction between symptoms and the multiplicity of symptoms, it might not comprehensively capture the intricate nature of the symptom experience (Mikšić et al., 2018). Furthermore, it might not effectively account for the role of healthcare providers in symptom management.

While the alternative frameworks considered offer valuable perspectives on patient care and engagement, the Symptom Management Model and the Supportive Care Framework were ultimately selected for this study. These models provide a comprehensive approach to understanding and addressing the symptom experiences and information needs of patients with advanced lung cancer undergoing palliative radiotherapy, as well as the caregiver burden and information needs of their caregivers. Their holistic and multidimensional focus aligns closely with the study's objectives, making them the most suitable frameworks for this research.

3.6 Research methodology

Given the study's aim to numerically evaluate the frequency and severity of self-reported burdens, a descriptive quantitative research design is appropriate. This approach allows for the definition of respondent characteristics, facilitates comparisons, traces data trends, and validates existing conditions. Utilizing structured questionnaires enables the collection of numerical data on symptom burden, information needs, and caregiver burden, which can be analysed statistically to identify relationships and patterns.

The postpositivist paradigm aligns with this methodology, acknowledging that while social phenomena are influenced by subjective perceptions, they can still be measured and evaluated objectively. This perspective supports the use of deductive reasoning for hypothesis testing and theory development, ensuring that the research findings are grounded in empirical evidence.

The primary aim of this study is to numerically evaluate the frequency and severity of the burden that is self-reported, so descriptive research is an appropriate and suitable choice. This approach serves well to define respondent characteristics, facilitate comparisons, trace data trends, and validate existing conditions. Additionally, the research measures two variables concerning patients, characteristics of caregivers and symptom experiences of patients, information needs, and caregiver burden and scrutinises the statistical connections between them. These connections can be positive or negative and have diverse degrees of strength. The survey instrument, questionnaires, enables the researchers to capture perceptions accurately and to subsequently present findings in a precise manner.

The researchers' intention is to convert the issue of symptom burden and information needs in Thai patients with advanced lung cancer and their caregivers into quantifiable terms by generating numerical data concerning symptom burden and information needs alongside predictors that can be transformed into applicable statistics, fostering generalisations to a broader population. Given that the research problem and questions centre on the identification and comprehension of outcome predictors, a quantitative approach emerges as the most suitable path.

The data collection process involves surveys being administered to both patients and caregivers, enabling the quantification of burden measurements through structured questionnaires. My personal inclination leans towards numbers as they provide exact frequencies, aligning with my preference for objectively measurable elements. Engaging with numbers and quantifiable entities during research is a gratifying process, aiding in advancing comprehension and offering explanations about the natural world through experimental investigation. This research delves into and sheds light on the symptom experiences of patients with advanced lung cancer throughout palliative RT. Thus, it is pivotal that the chosen paradigm aligns with the concerns and needs of both patients and caregivers.

Consequently, the foundational approach for this study should be the postpositivist paradigm. The research questions are amenable to measurement, and thus much of the foundation rests on an ontology acknowledging that social phenomena are not solely objectively quantifiable; they are also influenced by subjective perceptions and interpretations. This view asserts that the object of study is measurable, accessible, and evaluable at any given instance (Raadschelders, 2011). As a researcher, I maintain a degree of independence from the subjects under investigation, acknowledging inherent biases while valuing objectivity – this defines my epistemological stance. Employing deductive reasoning for hypothesis testing and theory development aligns with this paradigm. The chosen methodology within the positivist framework is quantitative, involving the analysis of numerical data to establish relationships.

Within the realm of health research, quantitative methodologies are frequently harnessed for the collection and interpretation of numerical data. These approaches leverage statistical analysis to scrutinise hypotheses and derive conclusions from the amassed data. The adoption of quantitative methodologies facilitates systematic data evaluation, identification of patterns, and the ability to draw informed inferences from the outcomes. Particularly in health research, these methods prove invaluable when the objectives encompass the identification of risk factors, assessment of treatment efficacy, and examination of outcomes (Gray et al., 2016). A range of quantitative methodologies are applicable in health research, encompassing experimental and quasi-experimental designs, surveys, and observational studies. Experimental and quasi-experimental designs manipulate factors to discern their impact on specific outcomes. In contrast, surveys serve as tools to amass data on attitudes, behaviours, and beliefs, while observational studies document spontaneous events without intervening in their occurrence (LoBiondo-Wood et al., 2017).

Many studies spanning various health domains – ranging from disease prevalence and incidence to risk factors, treatment effectiveness, and health disparities – have extensively employed quantitative methodologies. These approaches confer distinct advantages, facilitating hypothesis testing and enabling the generalisation of findings to broader populations. However, they come with limitations (Gray et al., 2016). Relying solely on quantitative data might overlook nuanced qualitative dimensions that defy quantification. Moreover, quantitative methodologies might not be universally suitable; certain research questions might find better alignment with alternative methods such as qualitative approaches. In summary, quantitative methods are an indispensable asset for health researchers. They facilitate meticulous exploration of numerical data and enable conclusions to be drawn through statistical analysis. Nonetheless, it's crucial to recognise their boundaries and to complement them with other research methods when the need arises (Gray et al., 2016).

3.6.1 Quantitative approaches

Employing a longitudinal study design allows for an in-depth investigation of changes over time, capturing the dynamics of symptom experiences and caregiver burden throughout the course of palliative RT. This design provides a more complex and scientifically rigorous approach than a simple cross-sectional survey, enabling the examination of temporal patterns and causal relationships.

Quantitative methods entail an approach that is aimed at assessing objective theories by exploring the interconnections between variables. These variables are typically subjected to measurement, often by employing instruments that yield numerical data that is suitable for statistical analysis (Creswell and Creswell, 2018). These methodological designs align with post positivist philosophical foundations, as previously discussed. The realm of quantitative designs encompasses diverse forms: experimental designs as well as non-experimental structures like surveys and longitudinal studies.

Within the context of this study, where the focal point is examining symptom experiences, information needs, caregiver burden, and the intricate web of relationships among these variables, surveys take on a paramount role. Investigating these aspects through surveys constitutes a central strategy for addressing the research questions and hypotheses.

3.6.2 Survey methodology

Survey research, utilising both cross-sectional and longitudinal designs, is instrumental in collecting data on attitudes, behaviors, and beliefs within a population. By administering structured questionnaires to patients and caregivers, this study can gather comprehensive data on their experiences and needs. This methodology facilitates the extrapolation of findings to a broader population, enhancing the generalizability and applicability of the research outcomes.

In summary, the integration of the Symptom Management Model and the Supportive Care Framework provides a comprehensive conceptual foundation. The adoption of a descriptive quantitative research design within a postpositivist paradigm ensures a rigorous and systematic examination of the symptom experiences and needs of Thai patients with advanced lung cancer undergoing palliative RT (Creswell and Creswell, 2018).

3.7 Patient and public involvement in the research

Patient and public involvement means examining the implementation of the PPI principle within the research context. PPI has played a pivotal role in shaping the structure and design of each investigation in this thesis. It is worth noting that I am an active participant in the PPI research group under the guidance of Professor Bridget Johnston.

At the University of Glasgow's School of Medicine, Dentistry and Nursing, fostering public engagement in nursing and healthcare research is a central tenet. In the palliative, end of life and bereavement care studies group, PPI forms a foundational element of every PhD thesis. For this study, I enlisted the participation of two individuals who volunteered to engage in PPI.

The two members of the public I recruited contributed to shaping the designs of the studies in this thesis. They provided insights into the objectives they believed each study should pursue and the advantages that participants should gain from taking part in this research. Moreover, they offered guidance on the structure and presentation of documents such as participant information pages, ensuring that the content was clear and accessible and used everyday language.

This section will delve into the process of recruiting PPI representatives, introduce these individuals, and elucidate their contributions to the designs and studies outlined in this section. The representatives are called Orando and Joy. They took part in the PPI group for this PhD thesis and have granted their consent for their identities to be revealed and for their experiences to be discussed in this thesis. Please refer to Appendix 4 for documented consent.

3.7.1 Recruitment of patient and public involvement representatives

When choosing PPI representatives, it was essential to establish a clear understanding of the role, the anticipated contributions, and the overall process, as well as how to facilitate meetings and establish a rapport with the PPI representatives. A series of steps was taken to set up the recruitment process. Specific criteria were formulated to identify individuals who might be interested. A flyer was crafted outlining the role and the subject matter. Potential candidates were informed that their involvement could encompass activities such as devising recruitment strategies, aiding in interviews, reviewing writing styles, attending conferences, contributing insights and opinions to support research, and collaborating with other public involvement advisors in research. The flyer was disseminated on Twitter.

3.7.2 Contribution to this research

Joy was recruited through Twitter, and her experiences as a caregiver for patients with cancer aligned with the eligibility criteria. As Joy resided in Southampton, an in-person meeting was not possible even prior to the COVID-19 pandemic. Consequently, Skype emerged as the preferred mode of communication. Joy's contributions to this research entailed reviewing questionnaires and offering suggestions to enhance their accessibility.

Orando, on the other hand, was recruited during a structured PPI event at the University of Glasgow. He met the eligibility criteria. Initially, PPI meetings with Orlando were held face to face, but due to geographical constraints, these shifted to phone and email interactions after the pandemic limited in-person meetings. Orando's role in this research, driven by his nursing background, provided valuable context on symptom experiences, information needs, and caregiver burdens which significantly influenced the design of the studies.

Jeerawan was recruited during the data collection period. She met the eligibility criteria. Initially, PPI meetings with Jeerawan were held face to face. She was a caregiver of an advanced lung cancer patient. She made the following comment, on behalf of her husband “This study explores the challenges faced by patients with advanced lung cancer and caregivers during radiation. It aims to understand the burden of symptoms of patients and caregivers, as well as factors influencing symptom management and information needs. Using surveys, Saeng collected data from patients and caregivers, focusing on symptoms and information needs, for example information source and type. The findings reveal that patients undergoing radiation have various symptom burdens, including pain, fatigue, and cough, [the] same as my husband. Caregivers also face challenges in providing care. The study also identifies predictors affecting symptom and information needs, [and] caregivers' burden. Overall, the research highlights the importance of targeted interventions to improve symptom management and provide support to patients and caregivers, ultimately enhancing the quality of care and life for those dealing with cancer in Thailand. Also, because of the cultural context, patients and caregivers in Thailand seem to need different information and have a different burden from the rest of people affected by lung cancer worldwide. Saeng's work has provided us with an opportunity to reflect on our experiences, understand ourselves better, alleviate tension, and navigate through treatment. Despite my husband's departure, I am confident he would express gratitude to the doctors, nurses, and the entire team for their care during his challenging battle with cancer".

3.8 Chapter summary

The chapter discusses the research design choices, including whether to use quantitative or qualitative methods. It explains why a quantitative descriptive research design was chosen, with a questionnaire survey as the primary data collection method. The chapter also introduces and evaluates the theoretical framework that is used to investigate symptom management and supportive care needs.

In summary, the chapter aims to present the decisions made during the development of the research design. It explains the rationale behind choosing quantitative methods and outlines why questionnaires are used for data collection. The next chapter will detail how these decisions were implemented.

Chapter 4 Methods

4.1 Introduction

This chapter delves into the "where", "what", and "how" questions, in contrast to the previous chapter, which primarily focused on the "why" questions surrounding the current research. It explored the reasoning behind the main methodological decisions made. This chapter elucidates the process of translating the research into action and presents a comprehensive breakdown of the research methodologies applied. This study follows a sequential research design, and this phase represents the second stage of the research process.

4.2 A quantitative study

4.2.1 Study design

A longitudinal observational study was conducted involving patients with advanced lung cancer who were receiving palliative radiotherapy (RT) and their caregivers in Thailand.

4.2.2 Setting

The study was conducted across three hospitals in Thailand:

1. Chulabhorn Hospital: The hospital has a Cancer Excellence Centre with 100 beds. It was established by the HRH Princess Chulabhorn College of Medical Science in 2016, and its main aspirations are to help alleviate the suffering of Thai patients and to celebrate the auspicious occasion of His Majesty the King's 90th birthday in December 2017. Prof. Dr. HRH Princess Chulabhorn graciously initiated the construction of this 400-bed hospital that provides a comprehensive range of cancer treatments, including surgery, systemic anticancer therapy (SACT), RT, targeted therapy, and integrative medicine. Moreover, a palliative care team, a home visit care team, and a Lung, Colorectal, Cervix and Liver Excellence Centre covers both cancer and other types of diseases so that the Thai population,

especially the impoverished ones and those living in remote areas can have equal access to modern and highly technological treatments that meet international standards and are administered by professional and specialised physicians from multiple disciplines and with various subspecialties. The intention is to expand this hospital and to have five excellence centres in addition to the existing Cancer Excellence Centre. Study participants were recruited from this specialised cancer-care hospital.

2. Thailand National Cancer Institute: A specialised cancer hospital with 200 beds controlled by the Ministry of Public Health offering treatment for various cancer types. It is the leading national institution for cancer control and cancer patient care. The mission is to develop and manufacture knowledge of and technology for cancer and to create policy-oriented recommendations. This institute wants to provide anyone who needs help with the medical personnel and services that they need and wants better technology so that it can better serve the public. It was established in 1992.
3. Rajavithi Hospital: A general hospital with 1,200 beds offering cancer treatment services under the purview of the Ministry of Public Health. All settings were located within the RT outpatient department, which serves patients from across the country. It was determined to be the first special hospital for women and children in Thailand. Now serving medical services for both men and women of any age, it now boasts state-of-the-art technology and specialised medical teams, with six Centres of Excellence providing advanced treatments and skilled nursing care. The hospital aims to become a full-status international hospital that collaborates with ASEAN countries. Over the past six decades, it has become an international training hub for countries like Myanmar, Cambodia, Vietnam, Laos, Bhutan, and several West African nations, and it has established exchange programmes with Singapore. Notable programmes include ENT training, featured in *Reader's Digest* and on the Discovery Channel, various intensive training courses, and international programmes like Head and Neck Oncology, and these have received positive feedback from Southeast Asian medical professionals. Additionally, it runs a joint

critical patient nursing enhancement programme with Parkway University of Singapore (https://www.rajavithi.go.th/eng/_introduction.php).

4.2.3 Accessible population

The target population for this study consisted of patients with advanced lung cancer and their caregivers referred to the RT outpatient department in three cancer centres in Bangkok, Thailand, between 2019 and 2020, totalling 766 individuals. Each organisational setting was different, such as Rajavithi Hospital and the National Cancer Institutional, under the supervision of the Ministry of Public Health, and Chulabhorn Hospital, which is affiliated with the Office of the Prime Minister.

4.2.4 Sample

Individuals diagnosed with advanced lung cancer and scheduled to receive palliative RT were invited to participate in the study between 1 September 2019 and 31 January 2020. Selection was based on the following criteria.

Inclusion criteria for patients:

- Histologically confirmed diagnosis of lung cancer with stage III-IV (TNM classification).
- Aged 18 or older.
- Scheduled to undergo palliative RT.
- Scheduled to receive up to 10 fractions of palliative RT, following the criteria outlined by Stevens et al. (2015).

Exclusion criteria for patients:

- Inability to communicate in English or Thai.
- Diagnosis of severe cognitive or mental illness that significantly affects communication.

Inclusion criteria for caregivers:

- Caring for an eligible patient and having a pre-existing relationship with them, e.g. spouse, child, parent, friend, etc
- Aged 18 or older.

- Only one caregiver per patient if the patient has multiple family members.
- Involved consistently across all time points.

Exclusion criteria for caregivers:

- Inability to communicate in English or Thai.

4.3 Sample size

In 2015, 122, 107, and 259 patients with lung cancer were treated with RT at Chulabhorn Hospital, Thailand National Cancer Institute, and Rajavithi Hospital, respectively (THASTRO, 2017). Of these patients, 58% had advanced disease and received palliative RT, so the pool of potential participants was 55 patients. Our sample size calculation (obtained using nQuery Advisor v6.02) indicated that to detect an effect size of 0.40 in symptom experiences in patients with lung cancer , as measured by the MSAS (Hermann et al., 2016) at 80% power, assuming a standard deviation of 0.50, 56 patients would need to be recruited for the study.

Having this number of patients will show a clinically meaningful difference over time of 0.20 units with specific thresholds for the effects of palliative RT on symptom burden, allowing for a 10% drop out rate, resulting in analysable data being available at follow-up for 50 patients. It should be noted that for each patient recruited, their caregiver would also be recruited. These groups will be analysed separately. In the caregiver group, our calculation indicated that assuming a standard deviation of 12.5 and 56 caregivers (50 analysable subjects after allowing for 10% dropout), we expected to detect an effect size of 5.05 (Grunfeld et al., 2004) at 80% power. This difference represents a clinically meaningful improvement in caregiver burden, as a 5.05-unit change on the ZBI indicates a moderate reduction in strain.

4.4 Research ethics

4.4.1 Ethics approval

Ethical approval was secured from the School of Medicine, Dentistry & Nursing, College of Medical Veterinary & Life Science at the University of Glasgow, as well as from the Institutional Review Boards of Chulabhorn Hospital, Thailand National Cancer Institute, and Rajavithi Hospital in Thailand (Appendix 5).

4.4.2 Ethics and information governance

The researcher meticulously identified eligible participants who met the specified inclusion criteria, outlined the study details to them, and extended invitations for participation. Written informed consent was acquired from all enrolled patients. Participants retained the autonomy to withdraw from the study at any juncture and for any reason. Data analysis was conducted up to the point of any participant withdrawal. Data concerning participants who died were collected up to the point of their passing and included in the analysis. Regarding participants unable to physically attend for RT and survey completion, efforts were made to facilitate completion via phone communication. If this was not feasible, their data were documented as missing.

A unique participant identification number and participants' hospital number were logged in the participant identification log. This log was maintained in paper form and securely stored in a locked cupboard at Chulabhorn Hospital. The participant identification number and the corresponding case note information collected for the study were stored on an encrypted USB for analytical purposes. This USB was stored at the Nursing & Healthcare School of the University of Glasgow in a secure, locked drawer in a locked room. Follow-up survey responses were input into an Excel spreadsheet and stored electronically on an encrypted USB.

Throughout, adherence to the Data Protection Act 1998 was steadfast. The investigator committed to maintaining records, including participant identities, original signed consent forms, and questionnaires, for potential evaluations or audits by regulatory authorities. Electronic data were securely stored on university servers.

4.4.3 Gaining informed consent

Weekly interactions with radiologists and the hospital information system facilitated the identification of new patients and the assessment of their eligibility for participation. Initially, eligible patients were approached by a local clinical team member who introduced the study to them. If the patient expressed interest, the principal researcher engaged with them, elaborated on the study, and extended the invitation to participate. Patients were also encouraged to nominate their primary caregiver, whom the principal researcher directly approached regarding participation. Participants were provided with an information sheet detailing the study and were afforded the opportunity to seek clarifications from the principal researcher.

Potential participants, both patients and caregivers, were given a one-week window to decide whether to participate. Upon consenting, they were required to provide written informed consent. While the objective was to enrol patient-caregiver pairs, individual participation was also permitted if one party declined involvement. Participants had the right to decline participation or withdraw from the study without offering a reason, with no impact on their treatment or rights. In cases of withdrawal, data analysis was conducted up to that point. Data regarding deceased participants were collected up to their time of passing and integrated into the analysis.

4.5 Recruitment and participation procedures

4.5.1 Patients

All participants engaged in the study across four consecutive time points, as follows:

- Prior to the initiation of RT treatment (before the first fraction of RT)
- During the first week of RT (1st-5th fraction)
- During the second week of RT (6th-10th fraction)

- One month after the completion of the final RT fraction (covering a range of 4-30 fractions of RT)

The reason for these four time points was guided by the systematic review, which confirmed that symptoms can fluctuate throughout the treatment period. Regarding the studying period and the limit of Covid-19 pandemic which limit the extended of time to study for a long-term symptom experience. Information needs, and caregiver burden.

Efforts were made by the researcher to facilitate questionnaire collection within the hospital premises. In cases where participants were unable to physically attend the hospital for RT sessions or follow-up appointments, as well as to complete the questionnaire, the principal researcher-initiated phone communication. This approach aimed to minimise the occurrence of missing data attributable to attrition.

4.5.2 Caregivers

Eligible caregivers received an invitation to participate in the study through a caregiver information sheet. Caregivers were given a one-week period to decide whether to participate. Upon expressing an interest in participation, caregivers were involved in the study across the same four consecutive time points as patients – prior to, two points during the RT, and after the patient's treatment.

As with patients, the researcher tried to gather questionnaires from caregivers within the hospital environment, either before or after the patient's sessions. In instances where caregivers were unable to be present at the hospital or to participate in the completion of the questionnaire alongside the patient, the principal researcher reached out via phone to offer the option of completing the questionnaires over the phone. This strategy aimed to minimise the likelihood of missing data due to attrition. The progression of participants through the study is outlined in Figure 4.1.

To mitigate potential issues with phone follow-ups, researchers were trained to conduct interviews with sensitivity and empathy, actively listening and validating emotions. Flexibility was prioritised by offering alternative times or communication modes if caregivers expressed discomfort. Privacy was assured by emphasising confidentiality and allowing rescheduling if a private setting was unavailable. Clear communication was maintained through concise language, avoiding jargon, and ensuring understanding by repeating or rephrasing questions. The researcher also prioritised building rapport before administering the questionnaire, engaging in brief conversations to establish a connection. Finally, caregivers were reminded of their right to withdraw at any time without penalty.

In this study, to prevent any difficulties by phoning bereaved caregivers, the researcher checked beforehand whether the patient was still alive via the medical record or by liaising with the clinical team. Allowing an appropriate interval after the patient's death can reduce the potential for immediate distress. Nevertheless, the researcher recognised that distress was still to be anticipated. The researcher had training in compassionate communication techniques to ensure that conversations were conducted with empathy and respect for the caregiver's emotional state. Offering information about bereavement support services during the initial contact and after the conversation provided caregivers with immediate avenues for assistance if needed. Ensuring that caregivers are fully informed about the study's purpose, procedures, and their rights, including the right to decline participation without any repercussions was crucial. In one instance, we discovered that a patient had already died and so compassionate communication and offering follow up was useful in this case. Nonetheless, implementing these strategies aligns with ethical guidelines by minimising harm and respecting the autonomy and well-being of participants.

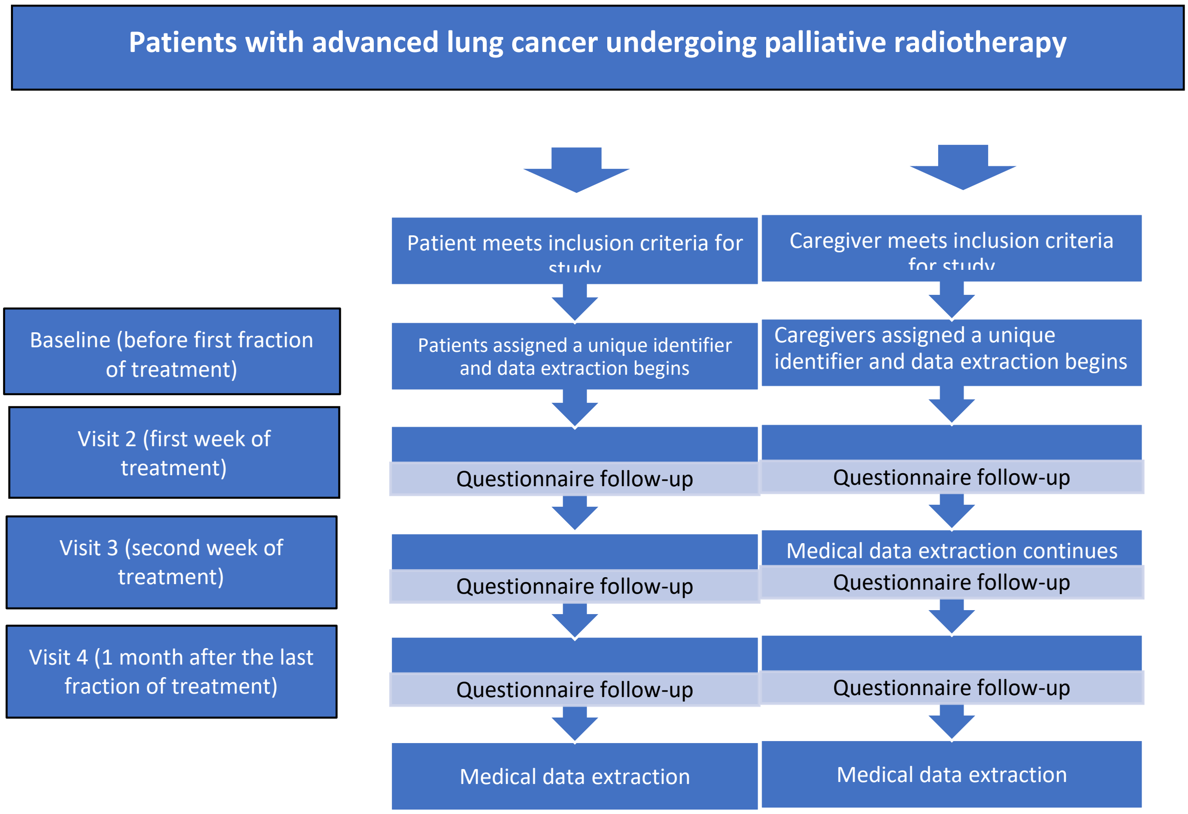


Figure 4-1 Participant journey through the study.

4.6 Measures

The Thai MSAS, the Thai modified MSAS regarding the need for information about symptoms, and the SCNS-P information needs subscale questionnaires were used for patients. The Thai modified MSAS regarding the need for information about symptoms, the SCNS-S&P information subscale, and the ZBI questionnaires were used for caregivers (Table 4.1). The participants completed all questionnaires at all time points (Appendix 6).

Table 4-1 Questionnaires in this study.

Questionnaires	**Patients**	**Caregivers**
MSAS-Thai symptoms	Yes	No
MMSAS-Thai need for information about symptoms	Yes	Yes
SCNS-P information needs subscale	Yes	No
SCNS-P&C information needs subscale	No	Yes
ZBI	No	Yes

MSAS: Memorial Symptom Assessment Scale; MMSAS: Modified Memorial Symptom Assessment Scale; SCNS-P: Supportive Care Needs Survey-Patient version; SCNS-S&P: Supportive Care Needs Survey – Partner & Caregiver version; ZBI: Zarit Burden Interview.

4.6.1 The modified Memorial Symptom Assessment Scale

The Thai version of the adapted Memorial Symptom Assessment Scale (MSAS) was employed to assess the prevalence, frequency, and severity of, and the distress caused by 37 symptoms associated with cancer and cancer treatment. This version included the original 32 symptoms from the MSAS and introduced five additional symptoms: chest tightness, cough, difficulty breathing, shortness of breath, and swelling of the arms or legs (Wong et al., 2017). Participants indicated whether they had experienced any of the symptoms during the preceding week (symptom occurrence). If applicable, they rated the frequency and severity of 29 symptoms and the distress they caused. For eight symptoms, only severity and distress were evaluated. If a symptom was not experienced, participants marked "did not have".

Frequency of symptoms was assessed using a four-point Likert scale: 1 = rarely, 2 = occasionally, 3 = frequently, and 4 = almost. Severity was rated on a four-point Likert scale: 1 = slight, 2 = moderate, 3 = severe, and 4 = very severe. Distress was measured on a five-point Likert scale: 0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, and 4 = very much. The reliability and validity of the MSAS and its subscales have been well established in studies involving cancer patients (Portenoy et al., 1994).

Symptom scores were aggregated into four subscale scores:

1. **Psychological Symptom Subscale (PSYCH):** Comprising the average symptom scores for six symptoms: feeling sad, worrying, feeling irritable, feeling nervous, difficulty sleeping, and difficulty concentrating.
2. **Physical Symptom Subscale (PHYS):** Averaging the symptom scores for twelve symptoms: lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness.
3. **Global Distress Index (GDI):** Averaging the frequency scores for feeling sad, worrying, feeling irritable, and feeling nervous, along with the distress scores for lack of appetite, lack of energy, pain, feeling drowsy, constipation, and dry mouth.
4. **Total MSAS Score**: Calculated as the average of the symptom scores for all 32 symptoms; each symptom score is an average of its dimensions.

The MSAS was adapted to include a question about patients' information needs (yes/no) for each symptom, which was aimed at aiding them to manage these symptoms at home. A score of 1 indicated an information need, while a score of 0 indicated no need. Participants identifying an information need were asked to specify the type of information required. Additionally, caregivers were provided with an adapted version of the MSAS and were asked to identify their own information needs regarding symptom management for the patient.

The validity of the MSAS questionnaire was established through strong correlations with the Functional Living Index for cancer patients, the Quality-of-Life Questionnaire, and the Karnofsky Performance Status Scale (Portenoy et al., 1994). The questionnaire's internal consistency was high when compared with the Symptom Distress Scale. The Thai translation of the questionnaire was conducted by Suwisith et al. (2008) using reverse translation techniques. In studies involving prostate cancer, colon cancer, breast cancer, and uterine cancer patients (with 246 individuals in total), the MSAS demonstrated high reliability. Cronbach coefficients were found to be 0.83 for psychological symptoms, 0.88 for common physical symptoms, and 0.58 for less common physical symptoms. The relative coefficient range upon repeated testing was 0.86-0.94. Mean values were highly correlated with clinical symptoms and quality of life (Portenoy et al., 1994). In Thailand, the MSAS was employed with breast cancer patients, yielding Cronbach coefficients of 0.85 for symptom frequency, 0.88 for symptom severity, and 0.94 for symptom distress (Suwisith et al., 2008). The questionnaire was evaluated in relation to cancer patients undergoing RT at the Radiological Oncology Department of Chulabhorn Hospital, where Cronbach coefficients were calculated to be 0.94 for internal consistency reliability (Appendix 3). In the present study, Cronbach coefficients were 0.98.

4.6.2 The Supportive Care Needs Survey for patients and caregivers

The Supportive Care Needs Survey – Patient version (SCNS) (Bonevski et al., 2000, Grunfeld et al., 2004) and the Partners and Caregivers version (SCNS-P&C) (Girgis et al., 2011) specifically focus on the Information needs subscale. The SCNS comprises 59 items categorised into five domains of need: psychological, health system and information, physical and daily living, patient care and support, and sexuality. The SCNS-P&C includes a 44-item tool that gauges caregivers' unmet needs within the information, healthcare services, daily living, and psychological domains. Both versions employ a 5-point Likert scale to rate items (ranging from 1 'No Need—Not applicable' to 5 'Some Need—High'). Cronbach's alpha coefficients ranged from 0.87 to 0.97 for the patient version and 0.88 to 0.94 for the partners and caregiver’s version. Analyses supported the tools' internal consistency and construct validity (Girgis et al., 2011). To minimise participant burden, only the information needs subscale of the SCNS (SCNS-INFO; 6 items) and SCNS-P&C (SCNS-P&C-INFO; 7 items) were utilised in this study.

The researcher employed the I-CVI (content validity for items) to assess, revise, delete, or substitute items (Polit and Beck, 2022). The I-CVI should ideally be 1.00 with five or fewer experts, or not lower than 0.78 (Polit and Beck, 2022). The English version has good internal consistency, with Cronbach’s alpha ranging from 0.88 to 0.94 for the four domains (Girgis et al., 2011). This thesis showed that the I-CVI result from the experts was 0.97. For language validity, the translation of the SCNS questionnaire from English to Thai was executed by a professional language expert using the following translation process (Pan, 2009): 1) the questionnaire was translated from English to Thai by two translators; 2) a back translation by two translators was conducted to ensure alignment with the original. Construct validity was assessed through Kaiser Meyer-Olkin analysis, resulting in 0.94, with Bartlett's test of sphericity also demonstrating a high level of significance (Schofield et al., 2012).

To assess reliability, a questionnaire regarding the supportive care needs of cancer patients was administered to a group of ten lung cancer patients who underwent the same treatment as the sample group. Internal consistency reliability was determined using Cronbach's alpha coefficient, resulting in a total of 0.96, with the following breakdown: supportive psychological care needs (0.95), supportive care needs regarding the healthcare system and information (0.79), supportive physical care needs (0.85), supportive care needs and assistance (0.81), and sexually supportive care needs (0.76). Reliability testing involving the SCNS questionnaire was performed on 20 caregivers with characteristics matching the study subjects who were caring for patients with advanced cancer being treated at Chulabhorn Hospital, Bangkok, Thailand. The Cronbach’s alpha coefficient was 0.83. Furthermore, reliability was deemed acceptable if r > 0.80. Internal consistency, measured through coefficient alphas for all subscales, ranged from 0.88 to 0.94 (Girgis et al., 2011). Considering these findings, the SCNS was established as reliable and suitable for identifying the supportive care needs of caregivers of advanced cancer patients in this study. Cronbach coefficients were 0.93 for patients and 0.95 for caregivers in this study.

Reliability testing for the SCNS questionnaire involved two distinct phases: initially, 20 caregivers, selected based on characteristics mirroring those of advanced cancer patient caregivers at Chulabhorn Hospital, were used to establish a Cronbach's alpha of 0.83, indicating acceptable reliability; subsequently, within the study itself, Cronbach's alpha coefficients of 0.93 for patients and 0.95 for caregivers were generated, suggesting robust internal consistency within the study population. The initial group was identified through hospital records and targeted recruitment, ensuring they met predefined criteria related to their patient's diagnosis and treatment location, while the study-specific reliability was derived from the data of the actual study participants.

4.6.3 The Zarit Burden Interview

The Zarit Burden Interview (ZBI) is designed to assess the extent of burden experienced by caregivers while providing care to their loved ones. Burden is defined as the caregiver's perception of their emotional and physical health, their social life, and financial implications that hinder their capacity to provide care effectively.

The Thai version of the ZBI (Toonsiri et al., 2011) consists of 22 items, each rated on a 5-point Likert scale: 0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, and 4 = nearly always. The questionnaire addresses various aspects of caregivers' well-being, encompassing health, psychosocial state, financial status, social interactions, and the caregiver-patient relationship.

Total scores for the ZBI can range from 0 to 88 and is determined by adding the scores of all endorsed items. The interpretation of scores is as follows:

0–21: Little or no burden
21-40: Mild to moderate burden
41-60: Moderate to severe burden
61–88: Severe burden

Higher scores for the ZBI denote a greater level of burden experienced by the caregiver (Zarit et al., 1987).

The ZBI is the most widely used instrument for assessing the burden experienced by the caregivers of persons with cancer (Higginson et al., 2010, Longacre et al., 2021). Burden Interview-22 (ZBI-22) has been shown to be effective in assessing caregiver burden relating to caring for patients with advanced conditions and oncological illnesses (Higginson et al., 2010) with a Cronbach's alpha of 0.88 [Bedard et al., 2001). The ZBI was translated into Thai by Toonsiri et al. (2011), and each question in this version correlates with the overall score at the moderate to high level, with correlation coefficients from 0.39 to 0.73. Analysis of the factors in the Thai version of the ZBI shows that it has a four-factor structure, and each element has a correlation with the Cronbach's alpha coefficients of 0.90, 0.86, 0.78 and 0.72 respectively.

The ZBI has good internal consistency (Cronbach's alpha) of 0.85 (Arai et al., 1997). The Thai ZBI for caregivers of patients with chronic illness has been validated with the Cronbach's alpha coefficient of 0.92 (Toonsiri et al., 2011, Chindaprasirt et al., 2014). In this study, Cronbach's alpha coefficient is 0.96.

4.7 Study variables

The data extracted in this study included many variables; initial data were extracted after the consultation in which the option of having palliative RT was discussed. Sociodemographic, treatment, and caregivers' characteristics were recorded. The variables collected at baseline were assigned a code to assist with categorisation and analysis (Table 4.1 and Table 4.2).

The socioeconomic descriptors are age, gender, marital status, education, employment status, income, and smoking history.

Table 4-2 Variables collected before treatment.

Variables		**Coding**
Patients	**Caregivers**	
Age		Age
Gender		Male/Female
Marital status		Married/Single/Divorce/Separate/Widowed
Highest level of education achieved		School/Further education
Employment status		Working/Not working
Income		≤30,000/>30,000
Smoking history		None/Light smoker/Moderate smoker/Heavy smoker/Second hand
-	Relationship	Spouse or partner/Child/Friend/Relative/Sister or Brother/Grandchild

Table 4-3 Treatment variables collected before treatment.

Variables	Coding
Diagnosis	CA lung/Mesothelioma
Pathology	Squamous cell/Adenocarcinoma/NSCLC/Unspecified/Neuroendocrine/SCLC/Malignant solitary fibrous tumour
Stage	IIIA/IIIB/IV
RT type	2D/3D/IMRT/VMAT/SRS
RT dose	20Gy/4F, 20Gy/5F, 25Gy/5F, 30Gy/10F, 35Gy/15F, 60Gy/30F
Other treatments	Systemic anticancer therapy/Hyperthermia/Strontium 89 chloride/Surgery/Targeted therapy/None
Area of RT	Chest/Mediastinum/Bone/Brain/Brain Bone/Liver

Abbreviations: CA, carcinoma; RT, radiotherapy; NSCLC, non-small-cell-lung cancer; SCLC, small-cell-lung-cancer; 2D, two dimensional; 3D, three dimensional; IMRT, intensity modulated radiotherapy; VMAT, volumetric modulated arc therapy; SRS, stereotactic radiosurgery; Gy, Gray; F, fractions.

Table 4-4 Variables created from the Memorial Symptom Assessment Scale.

The variables were created from the adapted MSAS for each symptom.

Variables	Coding
Information need	Do not need/Need
Information source	Internet/Health provider/Brochures or pamphlets/Cancer organisation/Another person with cancer/Books/Family/Newspaper/Magazine/Friend or co-worker/Complementary or alternative practitioner/Telephone
Information type	Internet/Brochures or pamphlets/Books/Talk/Online media/Video/Articles

4.8 Data collection process

Participants' medical records were reviewed at the time of the consultation to discuss palliative RT as an option one month after the last fraction of treatment. Caregivers who gave informed consent also completed follow-up surveys that were the same as the ones the patients completed. Participant anonymity was ensured by using a unique participant identification number. No identifiable information was collected in the data collection forms or survey. The required research data were collected from either self-reported information provided by the participants or extracted from medical notes. Patients’ and caregivers' characteristics were collected from self-reported information, and treatment characteristics were gleaned from medical records. The researcher reviewed the patients' medical notes, both hard and electronic copies.

The hard copies were accessed in the RT outpatient unit, and the electronic version was accessed with the permission of each hospital. Information about sociodemographic and clinical descriptors was either self-reported or collected from the hospital information system. Health record data were extracted for all 112 participants before RT, at the first and second weeks of palliative RT outpatient waiting time or in-patient stay, and finally at 1 month after palliative RT. In addition to extracting data, follow-up surveys were completed 1 month after palliative RT by those who had provided informed consent.

4.9 Data management and statistical methods

All variables were initially coded and entered into a Microsoft Excel spreadsheet, then transferred to SPSS version 27 for analysis. Descriptive statistics, including frequencies, means, medians, standard deviations, and ranges, were calculated separately for patient and caregiver characteristics and symptom experiences. To simplify the presentation of the data, only the top five symptoms at each time point are reported in this chapter, with comprehensive symptom data provided in Appendix 7. The number of patients and caregivers completing all four visits was also documented.

Exploring what data is missing can be done by identifying what is missing from the returned questionnaires and using descriptive statistics to understand the extent of missingness. Missing data within variables can be used to calculate scores. The distribution of the continuous variables can be assessed using statistical tests (Shapiro-Wilk) to check for normality. If data are normally distributed, parametric tests (e.g. t-tests, ANOVA) are appropriate. Otherwise, non-parametric tests should be considered (e.g. Mann-Whitney U test, Kruskal-Wallis). Data can be analysed in light of attrition by comparing the characteristics of participants who dropped out versus those who completed the study.

The comparison of continuous variables between two subgroups within the patient sample and within the caregiver sample used a Mann-Whitney test as a non-parametric test and an independent t-test as a parametric test. The comparison of continuous variables between subgroups at three levels used the Kruskal-Wallis Test as a non-parametric test and ANOVA as a parametric test. The comparison of categorical variables between subgroups used the chi-square or Fisher's exact test. The relationship between two continuous variables was assessed using Pearson Spearman as a non-parametric test and Pearson as a parametric test (see Appendix 7).

Some of the categorical variables had only a small number attached to them, for example teacher in the career category had only 1 participant in it, so I regrouped this category into three groups: Employee, None, and Others. These variables were regrouped for the purpose of the analysis.

Linear regression regarding the changes that had occurred from baseline in each outcome at each follow-up visit was used to explore any associations between patient characteristics and each outcome, first using a univariable method before extending to using a multivariable model. The statistical methods employed for each of the research questions are detailed in Table 4.5.

As noted earlier, contact with patients and their caregivers was attempted by telephone if required to try to minimise the risk of having missing data. Data were analysed as they were collected and no imputation for missing data was performed. All tests were done at the $p < 0.05$ level of significance. All statistical analysis was conducted following consultation with a statistician at the Robertson Centre for Biostatistics, University of Glasgow.

Table 4-5 The type of analysis conducted for each research question.

Research question		Type of analysis
1	What is the symptom experience of patients with advanced lung cancer in Thailand during a full course of palliative RT? How does it change?	Descriptive statistics were used to describe the symptom experience during each period. A non-parametric test (One-Sample Kolmogorov-Smirnov Test) was conducted regarding the changes that occurred between each visit and baseline.
2	What is the caregivers' burden when they are caring for a patient with advanced lung cancer who is receiving palliative RT in Thailand?	Descriptive statistics were used to describe the caregiver burden.
3	What are the patients' and caregivers' information needs at home?	Descriptive statistics were used to describe the information needs of patients and caregivers.
4	What are the predictors associated with the increased symptom experience of patients with advanced lung cancer who are receiving palliative RT, caregiver burden, and information needs of both patients and caregivers in Thailand?	Correlation analysis was used to describe the association between the continuous variables. Pearson's correlation was used as a parametric correlation, and the non-parametric test was Spearman's rank; r values were interpreted as follows: small (r=.10-.29); medium (r=.30-.49) or large (r=.50-1.0) (Cohen, 1988). For binary variables, an independent t-test was used as a parametric test, and Mann-Witney was used as a non-parametric test. For categorical variables, ANOVA was used as a parametric test and Kruskal-Wallis as a non-parametric test.
		Linear regression analysis was conducted to ascertain which, if any, variables had the most influence on changes in symptoms from baseline and on information needs at each of the second, third and fourth visits.

4.10 Summary

This chapter described the research methodology and methods. A longitudinal observation study was conducted with patients with advanced lung cancer who were receiving palliative RT and with their caregivers across three hospitals in Thailand from September 2019 to January 2020. Ethical approval was obtained from the university and three hospital review boards, and all participants gave informed consent. Measures were in place to ensure data protection and confidentiality. The study utilised various validated questionnaires, including the Thai version of the Modified Memorial Symptom Assessment Scale (MSAS), the Supportive Care Needs Survey (SCNS), and the Zarit Burden Interview (ZBI), to assess symptoms, information needs, and caregiver burden. Data on sociodemographic and treatment characteristics were collected, and the sample size calculation ensured that there was sufficient power to detect meaningful differences over time. The data collection process was planned to ensure participant anonymity and data integrity. The data analysis was conducted with expert guidance to ensure accuracy and appropriateness.

Chapter 5 Results

5.1 Introduction

This chapter presents the findings from a quantitative study focused on symptom experiences, caregiver burden, and information needs, along with their respective predictors. The primary objectives of this chapter are to address the four research questions: What is the symptom experience during a full course of palliative radiotherapy (RT) in patients with lung cancer in Thailand? How does it change? What is the caregiving burden experienced by family members caring for a patient receiving RT for lung cancer? What are the patients and caregivers' need for information on symptom self-management at home? And what are the predictors associated with increased symptom burden and information needed on symptom self-management in patients and caregivers?

5.2 Response, accrual, and withdrawal rates

During the study period from 1 September 2019 to 31 January 2020, a total of 112 participants took part, comprising 56 pairs of patients and caregivers. All patients and caregivers who were available during the study period were deemed eligible for participation and were thus invited to join the study. The response rate achieved was 100%, with no patients or caregivers declining to participate. The trajectory of their participation is visualised in Figure 5.1, and the distribution of patients and caregivers across the four visits is presented in Table 5.1.

Across visits 1 to 3, the retention rates demonstrated a notable level of consistency, ranging from 89% to 100% for both patients and caregivers (Table 5.1). However, during visit 4, the retention rate declined to 75%. This decrease in retention can be attributed to a comparatively higher dropout rate at this specific time point. An analysis of the factors contributing to discontinuation is detailed in Table 5.2, with the most prevalent factor being and the demise of the patient.

Table 5-1 Number of patients and caregivers at the four visits.

Patients				Caregivers			
1st	2nd	3rd	4th	1st	2nd	3rd	4th
N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
56(100)	54(96)	51(91)	42(75)	56(100)	56(100)	50(89)	42(75)

The participants were unable to complete the survey due to reasons such as being unable to talk or write or already being dead (Table 5.2).

Table 5-2 Reasons patients and caregivers were unable to complete the survey.

Reason	Patients (N = 56)				Caregivers (N = 56)			
	1st	2nd	3rd	4th	1st	2nd	3rd	4th
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Death	-	-	5(9)	14(25)	-	-	5(9)	14(25)
Drowsy (unable to talk or write)	-	2(4)	2(4)	2(4)	-	-	-	-
Gone abroad	-	-	-	-	-	-	1(2)	-

The attrition rate when comparing the patient/caregiver characteristics of those who remained in the study at each time point and the characteristics of those who remained and those who had dropped out by visit 4 were found not to be statistically significant different for the patient group and caregiver group between the four visits or for the caregiver group (Appendix 7).

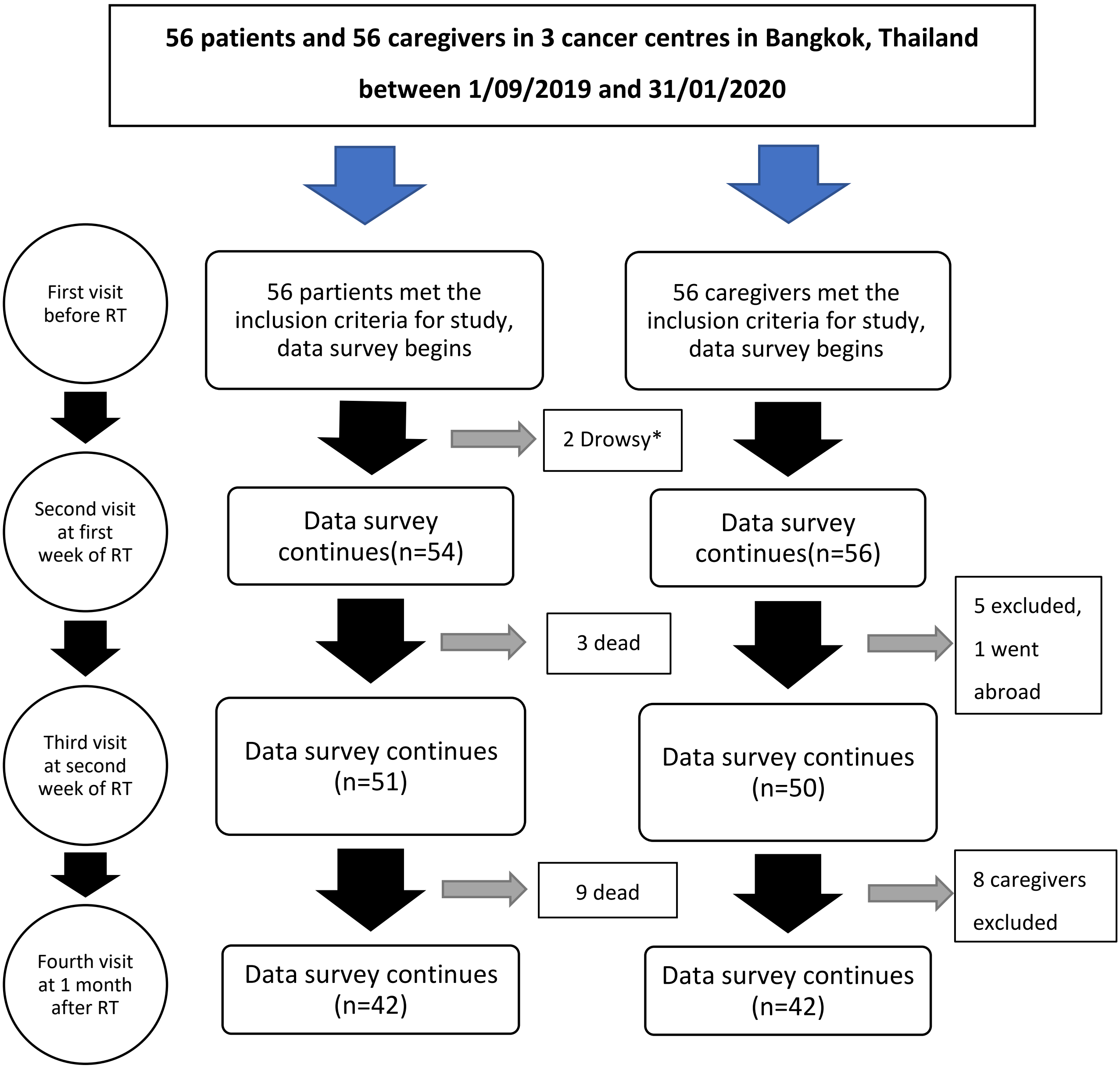


Figure 5-1 Participant journey through the study.

*2 drowsy people subsequently died

5.3 Description of study participants

Study participants will be described first in terms of the sociodemographic variables of patients and caregivers, and then according to the characteristics of the treatment each patient was receiving.

5.3.1 Demographic and sociodemographic characteristics of patients and caregivers

The data is presented in Table 5.3, showcasing the demographic and sociodemographic characteristics of both patients and caregivers. The patients' mean age was 59.4, with a higher representation of males (55.4%) than females. Most patients were married (82.1%) and had completed a primary school education, and 66.1% were still engaged in employment, primarily as employees (25.1%). About 39.3% of patients reported an income ranging from 10,001 to 30,000 baht, and 48.2% were heavy cigarette smokers.

Conversely, most of the caregivers were females (67.9%), with a mean age of 46.3. A significant portion of caregivers were also married (69.6%) and had bachelor's degrees (55.4%). The majority (85.7%) remained employed, with 33.9% being employees. About 41% of caregivers reported an income ranging from 10,001 to 30,000 baht. Notably, a larger percentage of caregivers had no history of smoking, and the majority of caregivers (44.6%) were identified as spouses or partners.

Table 5-3 Patients' and caregivers' characteristics at baseline.

	Patients (N = 56) **N (%)**	**Caregivers (N = 56)** **N (%)**
Age (years)[1]	59.4 (12.1)	46.3 (13.6)
Gender - Male	31 (55.4%)	18 (32.1%)
Female	25 (44.6%)	38 (67.9%)
Marital status - Married	46 (82.1%)	39 (69.6%)
Single	3 (5.4%)	17 (30.4%)
Divorced	2 (3.6%)	-

Widowed	5 (8.9%)	-
Marital status (regroup) - Married	46 (82.10%)	39(69.6%)
Not married	10 (17.9%)	17(30.4%)
Education level - Primary	22 (39.3%)	9 (16.1%)
Secondary	4 (7.1%)	-
High school	11 (19.6%)	14 (25.0%)
Bachelor’s degree	18 (32.1%)	31 (55.4%)
Master’s degree	1 (1.8%)	2 (3.6%)
Education level (regroup) - Primary	22 (39.3%)	9 (16.1%)
Secondary	15 (26.8%)	14 (25.0%)
University	19 (33.9%)	33 (58.9%)
Employment status - Working	37 (66.1%)	48 (85.7%)
Not working	19 (33.9%)	8 (14.3%)
Career - None	18 (32.1%)	8 (14.3%)
Employee	14 (25.1%)	19 (33.9%)
Business owner	2 (3.6%)	6 (10.7%)
Farmer	6 (10.7%)	5 (8.9%)
Police	2 (3.6%)	-
Official	5 (8.9%)	5 (8.9%)
Teacher	1 (1.8%)	1 (1.8%)
Vendor	6 (10.7%)	11 (19.6%)
Driver	1 (1.8%)	-
Technician	1 (1.8%)	-
Lawyer	-	1 (1.8%)
Career (regroup) - None	18 (32.1%)	8 (14.3%)
Employee	14 (25.0%)	19 (33.9%)
Other	24 (42.9%)	29 (51.8%)
Income (baht) - 0-1,000	6 (10.7%)	-
1,001-5,000	9 (16.1%)	3 (5.4%)
5001-10,000	8 (14.3%)	4 (7.1%)
10,001-30,000	22(39.3%)	23 (41.1%)
30,001-50,000	6 (10.7%)	12 (21.4%)
50,001-100,000	3 (5.4%)	12 (21.4%)
>100,000	2 (3.6%)	2 (3.6%)
Income (Bath)(regroup) - 0-10,000	23 (41.1%)	7 (12.5%)
10,001-30,000	22 (39.3%)	23 (41.1%)

>30,000	11 (19.6%)	26 (46.4%)
Smoking history - None	21 (37.5%)	49 (87.5%)
Light smoker	1 (1.8%)	2 (3.6%)
Moderate smoker	1 (1.8%)	-
Heavy smoker	28 (50.0%)	5 (8.9%)
Second hand	5 (8.9%)	-
Smoking history (regroup) - None	21 (37.5%)	49 (87.5%)
Some smoking	7 (12.5%)	2 (3.6%)
Heavy smoker	28 (50.0%)	5 (8.9%)
Smoking type - Cigarette	27 (48.2%)	6 (10.7%)
Tobacco	2 (3.6%)	1 (1.8%)
Cigarette and cigar	1 (1.8%)	-
Smoking type (regroup) - Cigarette	27 (48.2%)	6 (17.7%)
Other	3 (5.4%)	1 (1.8%)
None	26 (46.4%)	49 (87.5%)
Relationship - Spouse/Partner	-	25 (44.6%)
Child	-	20 (35.7%)
Relative	-	2 (3.6%)
Sister/Brother	-	6 (10.7%)
Grandchild	-	3 (5.4%)
Relationship (regroup) -Spouse/Partner	-	25 (44.6%)
Other	-	31 (55.4%)

Continuous variables are summarised using mean (standard deviation) or median (q1, q3) depending on the distribution of the data. – X missing

5.3.2 Treatment characteristics of patients

The data is described in Table 5.4 All patients had been diagnosed with stage IV lung cancer. Twenty-three had a diagnosis of adenocarcinoma. Twenty-nine patients were treated with 2-dimensional RT and twenty-seven patients were treated with 3-dimensional RT. Most patients received the 30 Gray 10 fractions regimen (83.9%) and a few were treated with targeted therapy (7.1%). The main area of treatment was the brain (46.4%).

Table 5-4 Treatment characteristics.

Diagnosis - Lung cancer	**56 (100%)**
Stage IV	56 (100%)
Pathology - Adenocarcinoma	23 (41.1%)
Unspecified	22 (39.3%)
Squamous cell	4 (7.1%)
NSCLC	3 (5.4%)
SCLC	2 (3.6%)
Other	2 (3.6%)
Pathology (regroup) - Adenocarcinoma	23 (41.1%)
Unspecified	22 (39.3%)
Other	11 (19.6%)
RT type - 2D	29 (51.8%)
3D	27 (48.2%)
RT dose - 20Gy/4F or 5F	5 (8.9%)
25Gy/5F or 7F	2 (3.6%)
30Gy/10F	47 (83.9%)
35Gy/15F	1 (1.8%)
60Gy/30F	1 (1.8%)
RT dose (regroup) - 30Gy/10F	47 (83.9%)
Other	9 (16.1%)
Other treatment - Targeted therapy	4 (7.1%)
Area of RT- Chest	6 (10.7%)
Mediastinum	4 (7.1%)
Bone	18 (32.1%)
Brain	26 (46.4%)
Other	2 (3.6%)
Area of RT (regroup) - Bone	18 (32.1%)
Brain	26 (46.4%)
Other	12 (21.4%)
Total SCNS at baseline (unit)	27.5 (15.0, 30.0)

5.4 Patients' symptom experiences and symptom scores

This study explored research question 1 in relation to symptom experiences: What is the symptom experience of patients with advanced lung cancer in Thailand during a full course of palliative RT? How does it change?

The symptom experiences were described across four time periods: baseline (visit 1), the first week of RT (visit 2), the second week of RT (visit 3), and one month after RT (visit 4).

5.4.1 Top five symptoms per assessment time point

The top five most frequently experienced symptoms at baseline included lack of energy, pain, cough, weight loss, and a feeling of not looking like oneself. The prevalence of these symptoms ranged from 57.1% to 71.4% (see Figure 5.2). During the second visit, patients continued to report lack of energy, weight loss, dizziness, cough, numbness/tingling in hands/feet, and lack of appetite as the predominant symptoms, with prevalence ranging from 53.7% to 75.9%. Moving to the third visit, patients' most common symptoms were lack of energy, lack of appetite, weight loss, difficulty sleeping, and pain, with symptom prevalence ranging from 60.7% to 86.2%. As for the fourth visit, the top five symptoms reported by patients were lack of energy, pain, weight loss, numbness/tingling in hands/feet, and difficulty sleeping, with prevalence ranging from 50.0% to 85.7% (see Figure 5.2).

Notably, pain was no longer among the top five symptoms at the second visit, while lack of energy and weight loss remained persistent across all four time points. Cough dropped out of the top five symptoms at visits 3 and 4. The symptom "I don't look like myself" was only present in the top five at baseline, while dizziness appeared in the second visit, numbness/tingling in hands/feet appeared at the second and fourth visits, and lack of appetite appeared at the third visit. Difficulty sleeping was a top five symptom reported at the third and fourth visits. Changes in symptom prevalence over time showed that lack of energy and difficulty sleeping increased consistently from baseline through all-time points. Pain, cough, and the feeling of not looking like oneself decreased in prevalence from baseline to each subsequent visit. Weight loss and lack of appetite had increased at visits 2 and 3 before declining from baseline at visit 4 (see Figure 5.2).

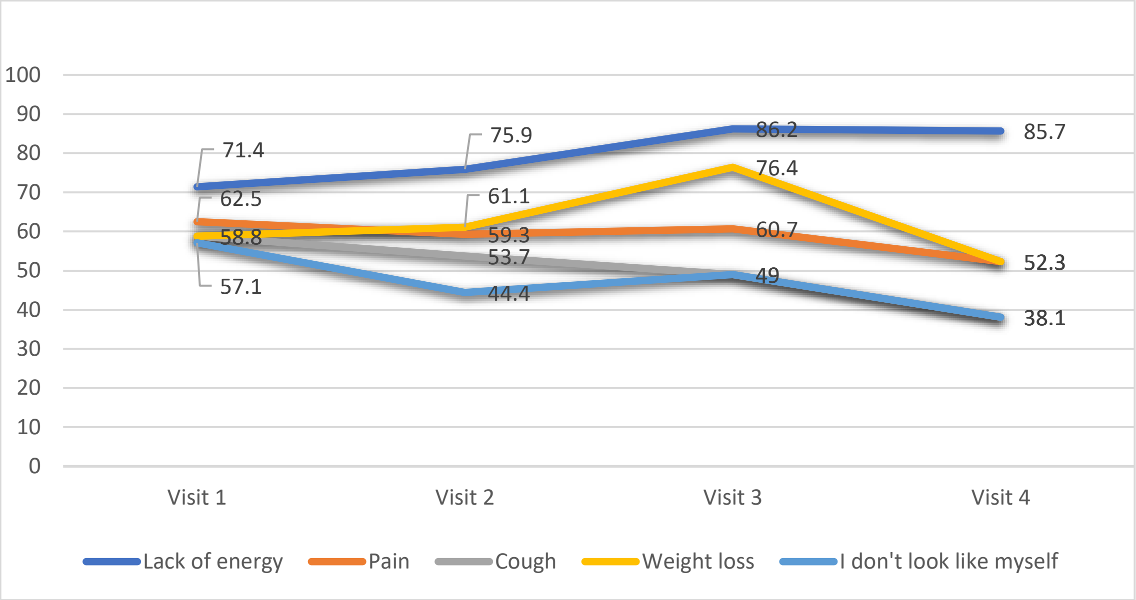


Figure 5-2 Top five symptoms experienced at four visits shown by the percentages of patients who reported having the symptoms.

The 5 most frequent symptoms illustrated that lack of energy were found in the first position in every visit, the second, third, fourth and fifth position difference in each visit (Table 5.5).

Table 5-5 Top five most frequent symptoms.

Baseline		Visit 2		Visit 3		Visit 4	
Mean(±SD)		**Mean(±SD)**		**Mean(±SD)**		**Mean(±SD)**	
Lack of energy	1.48(1.19)	Lack of energy	1.56(1.09)	Lack of energy	1.65(0.93)	Lack of energy	1.45(0.89)
Pain	1.38(1.26)	Pain	1.26(1.23)	Lack of appetite	1.33(0.86)	Numbness/ tingling in hands/feet	0.98(1.12)
Cough	1.32(1.27)	Numbness/ tingling in hands/feet	1.19(1.32)	Difficulty sleeping	1.24(1.09)	Difficulty sleeping	0.95(1.10)
Numbness/ tingling in hands/feet	1.30(1.43)	Cough	1.11(1.22)	Difficulty concentrating	1.04(1.02)	Pain	0.86(1.00)
Dry mouth	1.11(1.26)	Dizziness	1.06(0.98)	Pain	0.92(0.94)	Difficulty concentrating	0.81(0.99)

Pain was the most severe symptom at baseline, while lack of energy was the most severe symptom at the second, third, and fourth visits (Table 5.6). Difficulty sleeping was found on the third and fourth visits. What is the symptom experience of patients with advanced lung cancer in Thailand during a full course of palliative RT? How does it change?

Table 5-6 Top five most severe symptoms.

Baseline Mean(±SD)		Visit 2 Mean(±SD)		Visit 3 Mean(±SD)		Visit 4 Mean(±SD)	
Pain	1.29(1.14)	Lack of energy	1.26(0.92)	Lack of energy	1.33(0.74)	Lack of energy	1.10(0.66)
Lack of energy	1.20(0.92)	Pain	1.07(1.04)	Lack of appetite	1.08(0.72)	Difficulty sleeping	0.79(0.95)
I don't look like myself	1.05(1.09)	Lack of appetite	1.02(1.09)	Weight loss	0.98(0.68)	Numbness/ tingling in hands/feet	0.76(0.88)
Cough	1.02(1.00)	Numbness/ tingling in hands/feet	0.89(0.97)	Difficulty sleeping	0.96(0.87)	Pain	0.76(0.93)
Weight loss	1.02(1.05)	Cough	0.89(0.98)	Pain	0.90(0.90)	Weight loss	0.76(0.98)

Lack of energy was the most distressing symptom at every visit (Table 5.7). Interestingly, worry entered the top five distressing symptoms at the fourth visit, and further discussion of this provided in the next chapter.

Table 5-7 Top five most distressing symptoms.

Baseline Mean(±SD)		Visit 2 Mean(±SD)		Visit 3 Mean(±SD)		Visit 4 Mean(±SD)	
Lack of energy	1.85(1.00)	Lack of energy	1.72(0.85)	Lack of energy	1.68(0.58)	Lack of energy	1.54(0.45)
Pain	1.76(0.96)	Pain	1.61(0.82)	Lack of appetite	1.58(0.57)	Numbness/ tingling in hands/feet	1.51(0.95)
Difficulty sleeping	1.65(1.07)	Lack of appetite	1.56(0.93)	Weight loss	1.48(0.57)	Pain	1.43(0.88)
Cough	1.59(0.84)	Numbness/tingling in hands/feet	1.50(0.89)	Difficulty sleeping	1.48(0.76)	Difficulty sleeping	1.40(0.80)
Numbness/tingling in hands/feet	1.52(0.91)	Difficulty sleeping	1.45(0.86)	Pain	1.44(0.71)	Worrying	1.33(0.60)

5.4.2 The Memorial Symptom Assessment Scale

When the psychological subscale is analysed, the mean score appears to be highest during the third visit (last week of RT), while the mean score during the fourth visit (a month after RT) appears to be the lowest. As for the total physical subscale, there is a discernible downward trend from the baseline to the fourth visit. Similarly, the Global Distress Index implies a decrease from the first visit to the last visit. The total MSAS score also displays a reduction from baseline to the fourth visit. It is intriguing to observe that while the physical symptom burden for patients appears to decrease, the psychological symptom burden does not exhibit the same significant reduction.

Table 5-8 The Memorial Symptom Assessment Scale for patients across visits.

Descriptive Statistics	**Measure**	**Baseline**	**Visit 2**	**Visit 3**	**Visit 4**
		(N = 56)	**(N = 54)**	**(N = 51)**	**(N = 42)**
Total Psychological Subscale	Mean(±SD)	0.70(0.64)	0.67(0.52)	0.74(0.55)	0.63(0.64)
	Min, Max	0.00, 2.11	0.00, 1.66	0.00, 2.36	0.00, 3.28
Total Physical Subscale	Mean(±SD)	0.87(0.43)	0.77(0.47)	0.70(0.36)	0.59(0.57)
	Min, Max	0.21, 1.97	0.00, 2.67	0.20, 1.68	0.00, 2.53
Total Global Distress Index	Mean(±SD)	1.14(0.45)	1.08(0.45)	1.05(0.39)	0.97(0.54)
	Min, Max	0.48, 2.12	0.48, 2.38	0.48, 1.96	0.48, 2.80
TOTAL MSAS	Mean(±SD)	0.68(0.36)	0.60(0.36)	0.57(0.33)	0.50(0.47)
	Min, Max	0.14, 1.78	0.07, 1.91	0.15, 1.67	0.00, 2.16

The changes in the MSAS score depicted in Table 5.9, showing the fluctuation of total psychological symptoms over the course of the study, parallel the trends observed in the total Global Distress Index. In contrast, the total physical symptoms and total MSAS scores exhibit a consistent reduction from baseline across all visits. The changes in all dimensions of the MSAS rise are statistically significant except for total Psychological Symptoms. The total physical symptoms change 2 (p=0.036) and change 3 (p<0.001) rise is statistically significant. The global distress index changes 3 are statistically significant (p=0.045). The total MSAS change 1 (p=0.028) and change 3 (p=0.005) are statistically significant.

Table 5-9 Changes in the Memorial Symptom Assessment Scale for patients from baseline.

Descriptive Statistics	**Summary**	**Change 1**	**Change 2**	**Change 3**
Total Psychological Symptoms	Mean(±SD)	-0.06(0.48)	0.02(0.58)	-0.08(0.71)
	Min, Max	-1.01, 1.13	-1.11, 1.26	-1.60, 1.83
	p-value	0.531	0.739	0.506
Total Physical Symptoms	Mean(±SD)	-0.14(0.57)	-0.17(0.42)	-0.27(0.54)
	Min, Max	-1.35, 1.77	-1.51, 0.63	-1.41, 1.47
	p-value	0.053	**0.036****	**<0.001*****
Total Global Distress Index	Mean(±SD)	-0.10(0.46)	0.08(0.42)	-0.15(0.53)
	Min, Max	-0.94, 1.12	-0.90, 0.76	-1.16, 1.12
	p-value	0.231	0.324	**0.045****
TOTAL MSAS	Mean(±SD)	-0.10(0.40)	-0.10(0.35)	-0.15(0.45)
	Min, Max	-0.85, 1.34	-0.85, 0.70	-1.24, 1.19
	p-value	**0.028****	0.088	**0.005*****

Change 1 = Visit 2-Visit 1, Change 2 = Visit 3-Visit 1, Change 3 = Visit 4-Visit 1

*, ** Wilcoxon Signed Ranks Test

5.5 Caregivers' burden

To answer question number 2:

What is the caregivers' burden when they are caring for a patient with advanced lung cancer who is receiving palliative RT in Thailand?

When exploring the caregiver burden experienced by family members was explored, the question to which caregivers most frequently answered "Nearly always" was "Are you afraid of what the future holds for your relative?" (19.6%). More results for answers to individual questions can be found in the appendix 7.

The summarised ZBI scores for each visit are presented in Table 5.10, with the mean score indicating the highest burden at baseline and a subsequent reduction over the course of the study.

The levels of caregiver burden and the changes that occurred in those levels are outlined in Table 5.10, revealing a consistent trend of reduction in burden across all visits compared to the baseline. Throughout the study period, most caregivers reported experiencing little to no burden, ranging from 64.3% to 80.4%. On the other hand, 10.7% to 28.6% indicated a mild to moderate burden. The total burden score exhibited a decline from baseline, with the lowest score observed at the last visit.

Table 5-10 Total Zarit Caregiver Burden score and level of the caregiver burden at each of the four visits.

Descriptive Statistics	**Summary**	**Baseline**	**Visit 2**	**Visit 3**	**Visit 4**
		(N = 56)	**(N = 56)**	**(N = 50)**	**(N = 42)**
Total Zarit Score	Mean	14.48(10.72)	13.16(10.95)	11.78(10.46)	7.45(8.67)
	Min, Max	0,50	2,47	0,43	0,28
Level		**Baseline**	**Visit 2**	**Visit 3**	**Visit 4**
		N (%)	**N (%)**	**N (%)**	**N (%)**
little to no burden		40(71.4)	45(80.4)	41(73.2)	36(64.3)
mild to moderate burden		15(28.6)	10(17.9)	8(14.3)	6(10.7)
moderate to severe burden		1(1.8)	1(1.8)	1(1.8)	-
severe burden		-	-	-	-

Table 5-11 The changed Zarit Caregiver Burden score from baseline at each follow-up.

Descriptive Statistics	**Summary**	**Change1**	**Change2**	**Change3**
Total Zarit Score	Mean	-1.32(4.76)	-2.14(5.90)	-5.76(7.48)
	Min, Max	-15,12	-18,16	-23,8

Change1 = Visit 2-Visit 1, Change2 = Visit 3-Visit 1, Change3 = Visit 4-Visit 1

5.6 Descriptive analysis of patients’ and caregivers’ information needs

To answer question number 3

What are the patients’ and caregivers’ information needs at home?

The details concerning information needs regarding symptom self-management at home are presented in two parts, across four tables. The initial part highlights the information needs regarding symptom self-management at home, and this is categorised separately for patients (see Table 5.12) and caregivers (see Table 5.12). These data originate from the modified MSAS questionnaire on information needs concerning symptom self-management. The second part pertains to the information needs subscale derived from the Supportive Care Needs Survey – Patient version (SCNS) (see Table 5.13) and the Supportive Care Needs Survey – Partner and caregiver version (SCNS-P&C) (see Table 5.14).

Across all visits, the most prominent information needs for both patients and caregivers pertained to self-management strategies for dealing with lack of energy. The need for information depended on the prevalence of symptoms; if patients had symptoms, they and their caregiver's wanted information about them, but if patients did not have symptoms, information was not needed by either the patients or their caregivers. All patients' and caregivers' information needs regarding symptom self-management at home can be found in appendix 7.

Table 5-12 Patients' information needs regarding symptom self-management at home.

Baseline		Visit 2		Visit 3		Visit 4	
Symptom	**Mean(±SD)**	**Symptom**	**Mean(±SD)**	**Symptom**	**Mean(±SD)**	**Symptom**	**Mean(±SD)**
Lack of energy	0.66(0.48)	Lack of energy	0.63(0.49)	Lack of energy	0.76(0.43)	Lack of energy	0.79(0.42)
Pain	0.59(0.50)	Dizziness	0.57(0.50)	Lack of appetite	0.69(0.47)	Weight loss	0.48(0.50)
Numbness /tingling in hands/feet	0.55(0.50)	Weight loss	0.57(0.50)	Weight loss	0.67(0.48)	Difficulty concentrating	0.45(0.50)
Cough	0.54(0.50)	Pain	0.54(0.50)	Difficulty sleeping	0.55(0.50)	Numbness/ tingling in hands/feet	0.45(0.50)
Weight loss	0.52(0.50)	Numbness/ tingling in hands/feet	0.52(0.50)	Difficulty concentrating	0.53(0.50)	Worrying	0.45(0.50)

Table 5-13 Caregivers' information needs regarding symptom self-management at home.

Baseline		Visit 2		Visit 3		Visit 4	
Symptom	Mean(±SD)	Symptom	Mean(±SD)	Symptom	Mean(±SD)	Symptom	Mean(±SD)
Lack of energy	0.71(0.46)	Lack of energy	0.71(0.46)	Lack of energy	0.72(0.45)	Lack of energy	0.60(0.50)
Pain	0.63(0.49)	Weight loss	0.55(0.50)	Lack of appetite	0.56(0.50)	Lack of appetite	0.43(0.50)
Weight loss	0.63(0.49)	Lack of appetite	0.48(0.50)	Weight loss	0.56(0.50)	Weight loss	0.43(0.50)
Cough	0.55(0.50)	Pain	0.45(0.50)	Worrying	0.46(0.50)	Numbness/tingling in hands/feet	0.38(0.49)
Difficulty sleeping	0.55(0.50)	Cough	0.45(0.50)	Difficulty sleeping	0.44(0.50)	Difficulty sleeping	0.38(0.49)

At all visits, health providers were identified by 91.0% to 95.4% of patients as the primary information source. Patients' most preferred type of information was verbal communication, with preferences ranging from 34.6% to 44.9% (Table 5.14).

Table 5-14 Information sources and information types which patients preferred.

Information Sources	Baseline (%)	Visit 2(%)	Visit 3(%)	Visit 4(%)
Internet	6.1	8.9	4.5	7.5
Health provider	93.8	91.0	95.4	92.4
Information types	**Baseline (%)**	**Visit 2(%)**	**Visit 3(%)**	**Visit 4(%)**
Internet	1.8	0.0	0.0	0.0
Brochures or pamphlets	24.3	27.0	22.9	32.9
Books	26.3	23.3	24.5	9.9
Talk	44.4	34.6	42.4	44.9
Online media	6.4	9.8	4.4	8.4
Video	1.2	1.8	2.4	2.3
Article	1.3	3.5	3.4	1.6

At all visits, the information source which caregivers chose to use the most was the health provider (82.8–89.9%), and the information types which patients preferred the most were books, 30.5%) at baseline, and talking, with the level at 28.5% at the second visit and 37.5% at the fourth (Table 5.15).

Table 5-15 Information sources and information type which caregivers preferred.

Information Sources	Baseline (%)	Visit 2(%)	Visit 3(%)	Visit 4(%)
Internet	11.4	12.9	10.1	17.2
Health provider	88.6	87.1	89.9	82.8
Information types	**Baseline (%)**	**Visit 2(%)**	**Visit 3(%)**	**Visit 4(%)**
Internet	5.0	5.7	3.0	5.9
Brochures or pamphlets	17.0	14.4	23.7	18.4
Books	30.5	25.3	28.2	15.2
Talk	26.8	36.5	28.5	37.5
Online media	15.6	18.1	16.6	20.7
Video	5.1	0.0	0.0	2.3

Information about things that patients can do to help themselves get well was found in the SCNS – Patient version (Question 5), and this was the most preferred place for patients to find such information; the information needs reduced from baseline through to the fourth visit for every item (see Figure 5.3).

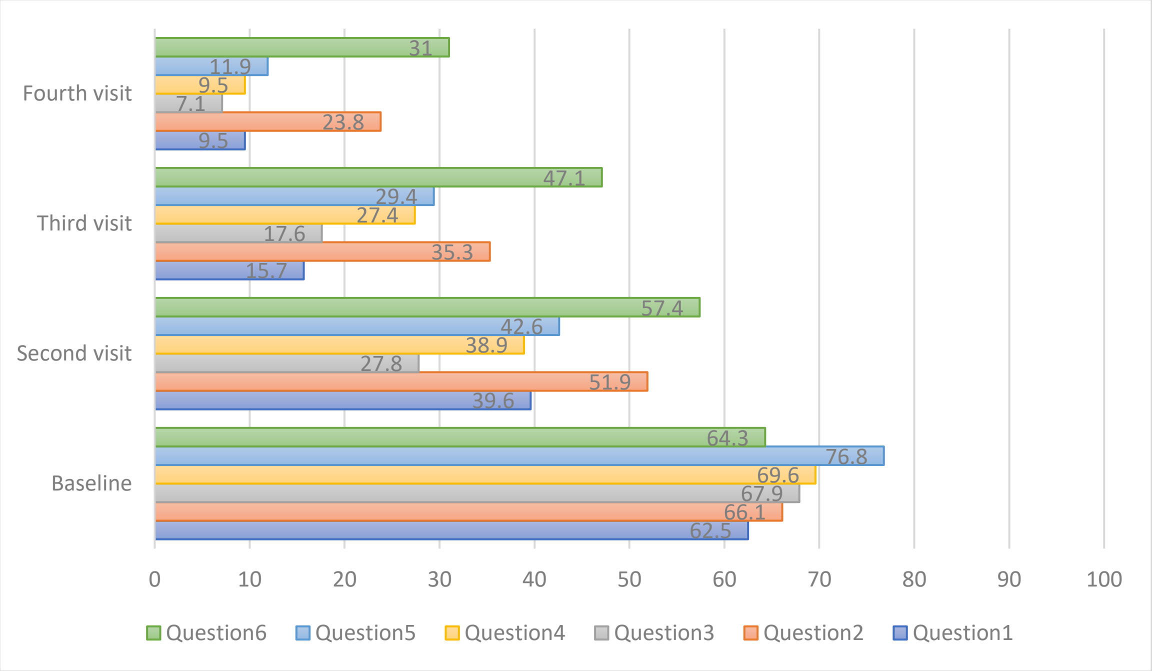


Figure 5-3 Percentages of information needs found via the Supportive Care Needs Survey - Patient version.

Question 1: To be given written information about the important aspects of your care. **Question 2:** To be given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home. **Question 3:** To be adequately informed about the benefits and side effects of treatments before you choose to have them. **Question 4:** To be informed about your test results as soon as feasible. **Question 5:** To be informed about cancer which is under control or diminishing (that is, in remission). **Question 6:** To be informed about things you can do to help yourself get well.

The information which caregivers wanted to have the most was information about complementary and alternative therapies (Question 4), and the information needs reduced from baseline in relation to every question across all visits (see Figure 5.4).

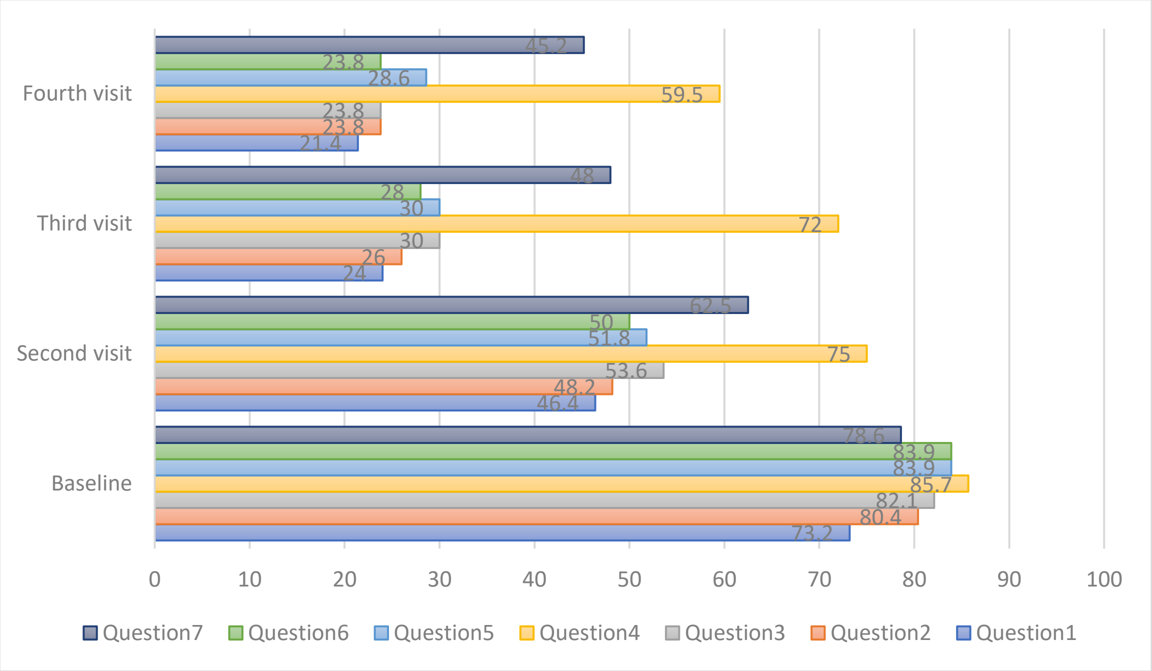


Figure 5-4 Percentage of information needs found via the Supportive Care Needs Survey - Partner and Caregiver version.

Question 1: Accessing information relevant to your needs as a caregiver/partner. **Question 2**: Accessing information about the person with cancer's prognosis, or likely outcome. **Question 3**: Accessing information about support services for caregivers/partners of people with cancer. **Question 4**: Accessing information about complementary and alternative therapies. **Question 5**: Accessing information about what the person with cancer's physical needs are likely to be. **Question 6**: Accessing information about the benefits and side effects of treatments. **Question 7**: Accessing local healthcare services when needed.

Regarding the scores for information needs from the MSAS and the SCNS, a high score means there is a high information need. The information needs score from the MSAS showed that caregivers need information more than patients at baseline and less than patients from that time. The information needs score for patients from the SCNS was less than that for caregivers at every visit. The score for information needs at visits 2 to 4 in both questionnaires was less than the score at baseline (Table 5.16).

Table 5-16 Scores for information needs and the change in information needs at the four visits.

	All patients (N = 56)	Caregivers (N = 56)
Information needs scores from MSAS	**Median [Q1, Q3]**	**Median [Q1, Q3]**
score at baseline	10.00[7.25, 14.00]	11.00[5.00, 16.00]
score at second visit	10.50[5.75, 15.00]	8.50[4.00, 13.75]
score at third visit	8.00[7.00, 14.00]	7.00[4.00, 12.00]
score at fourth visit	6.50[3.75, 12.50]	4.00[1.00, 10.50]
Information needs scores from SCNS	**Median [Q1, Q3]**	**Median [Q1, Q3]**
score at baseline	27.50[15.00, 30.00]	32.00[22.25, 35.00]
score at second visit	16.50[12.00, 23.00]	22.50[15.00, 31.75]
score at third visit	12.00[12.00, 19.00]	17.00[14.75, 23.00]
score at fourth visit	12.00[12.00, 15.00]	15.50[14.00, 20.25]
The change in information needs scores from MSAS from baseline	**Mean**	**Mean**
score at second visit	-0.81(5.73)	-3.55(8.17)
score at third visit	-0.94(6.63)	-3.64(9.24)
score at fourth visit	-1.50(8.98)	-4.14(8.86)
The change in information needs scores from SCNS from baseline	**Mean**	**Mean**
score at second visit	-5.54(7.61)	-5.61(7.74)
score at third visit	-6.94(8.24)	-8.68(7.88)
score at fourth visit	-8.98(7.25)	-10.38(8.17)

5.7 Predictors of burden and information needs: Multivariable analysis

To answer question number 4

What are the predictors associated with the increased symptom experience of patients with advanced lung cancer who are receiving palliative RT, caregiver burden, and information needs of both patients and caregivers in Thailand?

The tests that were run with actual variables were a non-parametric test with change scores. The multivariable analysis revealed that smoking history was a statistically significant predictor of change in several symptom scores. Heavy smokers experienced a greater increase in their total MSAS scores (indicating higher symptom burden) compared to non-smokers (p = 0.007). This finding highlights the importance of assessing and addressing the unique needs of patients with a history of smoking and detailed findings are provided in Appendix 7.

The univariate analysis correlations were tested, and relationships were identified before conducting a multivariable analysis. Details of the univariate analysis can be found in Appendix 7.

5.7.1 Predictors of change in patients' symptom scores

1) Smoking History: Multivariable analysis identified smoking history as a significant predictor of increased symptom burden in patients with advanced lung cancer undergoing palliative radiotherapy (RT). Specifically:
    - Total MSAS Score: Heavy smokers exhibited a greater increase in total MSAS scores compared to non-smokers (p = 0.027), indicating a higher overall symptom burden.
    - Physical Symptoms (PHYS): Heavy smokers had significantly higher PHYS scores compared to non-smokers (p = 0.021), suggesting more severe physical symptoms.
    - Global Distress Index (GDI): Heavy smokers had significantly higher GDI scores compared to non-smokers (p = 0.043), indicating more pronounced symptoms.
    - Psychological Symptoms (Association): Heavy smokers had significantly higher PSYCH scores (p = 0.041) reflecting increased psychological distress.
2) Gender: Males caregivers experienced a more significant reduction in symptom score compared to female caregivers (p = 0.011), indicating gender differences in symptom score.
3) Marital status: Being single indicated a significant reduction in symptom scores compared to those who were not single (p = 0.048).

4) RT type: Patients undergoing 3D RT having a greater increase in symptom scores than those undergoing 2D RT (p = 0.037) suggesting that RT type may correlate with heightened symptom score (see Appendix 7).

5.7.2 Predictors associated with caregivers’ burden

Multivariable analysis did not identify any statistically significant associations between caregivers’ characteristics and changes in Zarit Burden Interview (ZBI) scores. This suggests that individual demographic factors may not independently predict perceived caregiver burden, highlighting the multifaceted nature of caregiver experiences. (see Appendix 7).

5.7.3 Predictors associated with patients’ information needs

1) Smoking History: Heavy smokers reported a larger increase in information needs compared to non-smokers (p = 0.017), as measured by the Supportive Care Needs Survey (SCNS), indicating a greater need for information among this group.
2) Area of Treatment: Patients receiving radiation therapy to the bones exhibited a more significant reduction in information needs than those receiving brain radiation (p = 0.012), suggesting that treatment location influences informational need.
3) Education Level: Patients with only primary-level education experienced a greater increase in information needs compared to those with university-level education (p = 0.027), indicating that lower educational attainment may be associated with higher informational demands.
4) Radiotherapy Dose: Patients receiving doses greater than 30Gy/10F reported a larger increase in information needs (p = 0.009), suggesting that higher RT doses may correlate with heightened informational need (see Appendix 7).

5.7.4 Predictors associated with caregivers' information needs

1) Gender: Male caregivers experienced a more significant reduction in information needs compared to female caregivers (p = 0.041), indicating gender differences in informational needs.
2) Relationship to Patient: Spouses or partners reported greater information needs than caregivers with other relationships to the patient (p = 0.021), highlighting the influence of caregiver-patient relationship dynamics on informational needs (see Appendix 7).

5.8 Summary of research findings

The main research findings are summarised in relation to the research questions presented in Chapter 4, along with other noteworthy discoveries:

Primary research question:

1) **What is the symptom experience of patients with advanced lung cancer in Thailand during a full course of palliative RT? How does it change?**

The most prominent symptom across all four visits for both patients was fatigue. The scores for fatigue-related symptoms exhibited a consistent reduction from baseline throughout all visits.
According to the study, patients with advanced lung cancer in Thailand experienced various symptoms during a full course of palliative RT. Patients were asked about the symptoms at different assessment time points. Notably, pain was no longer among the top five symptoms at the second visit, while lack of energy and weight loss remained persistent across all four time points. Cough dropped out of the top five symptoms at visits 3 and 4. The symptom "I don't look like myself" was only present in the top five at baseline, while dizziness appeared at visit 2, numbness/tingling in hands/feet appeared at visits 2 and 4, and lack of appetite appeared at visit 3. Difficulty sleeping was a top five symptom at visits 3 and 4. Changes in symptom prevalence over time showed that lack of energy and difficulty sleeping increased.

2) **What is the caregivers’ burden when they are caring for a patient with advanced lung cancer who is receiving palliative RT in Thailand?**

Most caregivers felt burdened when they thought about the patient’s future, but most caregivers reported that generally they felt no burden or little burden. The trend in the scores for burden was a decrease from baseline.

3) **What are the patients’ and caregivers’ information needs at home?**

For both patients and caregivers, managing fatigue was the most frequently identified information needs across all visits. Both patients and caregivers sought information primarily from healthcare providers, with discussions being the preferred information format. Patients’ information needs regarding self-help methods for recovery decreased from baseline across visits. Caregivers' information needs regarding complementary and alternative therapies also decreased from baseline at all visits.

4) **What are the predictors associated with the increased symptom experience of patients with advanced lung cancer who are receiving palliative RT, caregiver burden, and information needs of both patients and caregivers in Thailand?**

a. *Predictors associated with patients having an increased symptom burden*

Smokers, men, single people, and patients on 3D RT reported a greater symptom burden overall. Psychological symptom scores were higher in patients with a smoking history and in those who were married. Physical symptom scores showed a positive correlation with smoking history. Moreover, smoking history was indicative of heightened Global Distress Index scores.

b. *Predictors associated with caregivers having an increased burden*

Gender and relationship status were associated with an increased symptom burden.

c. *Predictors associated with patients having an increased information need*

Smoking history, age, treatment area, education level, and RT dose were predictors of heightened information needs.

d. *Predictors associated with caregivers having an increased information need*

Gender and relationship status influenced information needs.

These findings provide valuable insights into the symptom experiences, caregiving burden, and information needs of patients and caregivers during palliative RT for lung cancer, offering potential directions for tailored interventions and care strategies.

Chapter 6 Discussion

This is the first study to explore the incidence and predictors of symptoms in patients with advanced lung cancer who are receiving palliative radiotherapy (RT), the incidence and predictors of levels of information needs regarding supportive care in the Thai context. The most important aspect of this study is that it measured the change from before RT to after RT regarding symptom burden, caregiver burden, and information needs.

6.1 Principal findings

In this study, the top five symptoms experienced at baseline were lack of energy (71.4%), pain (62.5%), cough (58.8%), weight loss (58.8%), and “I don’t look like myself” (57.1%). Other studies in different settings have found the same symptoms but differences in the way they are distributed (Kӧrner et al., 2017, Sharma and Purkayastha, 2017, Verhoef et al., 2022). While individual experiences vary, the high prevalence of fatigue reported in this study reflects a common challenge faced by patients undergoing cancer treatment, which I also experienced personally.

6.1.1 Symptom experience

The symptom experience of patients with advanced lung cancer who are receiving RT depends on the location and extent of the disease, the dose of radiation received, and individual patient characteristics. Breathing difficulty was experienced by 78.1% of patients, 70.3% experienced coughing, 60.9% shortness of breath, 60.2% of them had tightness in the chest, and sleep disturbance affected 62.5% (Kӧrner et al., 2017). Multiple symptoms are common in patients with advanced lung cancer (Shallwani et al., 2016, Mosher et al., 2015)

6.1.1.1 Fatigue

Fatigue was the top symptom at four visits during this study, which is the same as in many studies of patients with advanced lung cancer (Chen et al., 2016)

(Perpiñá-Galvañ et al., 2019, Wang et al., 2016). In these studies, the patients reported fatigue as the most frequent symptom, as well as the symptom most likely to interfere with their physical functioning or normal daily activities (Carnio et al., 2016). In 70% of lung cancer patients, this symptom is present occasionally, and in 30% of them, it is present all the time. Therapy for the fatigue should focus on both symptom relief and possible reversibility; causes of the fatigue could be water-electrolyte imbalances, depression, or other causes. Fatigue is not always diagnosed by doctors and is consequently inadequately treated (Carnio et al., 2016). It is the most often reported symptom in patients with lung cancer throughout the entire treatment, and all international guidelines (Mitchell et al., 2017) (https://www.ons.org/pep/fatigue?display=pepnavigator&sort_by=created&items_per_page=50) advocate early screening for cancer-related fatigue. The treatment of fatigue continues to be one of the most challenging aspects of oncology: little evidence supports pharmacological interventions, whilst emerging research suggests that complementary and alternative therapies and physical exercise are among the most effective techniques for cancer-related fatigue at any stage of lung cancer (Carnio et al., 2016, Hoffman et al., 2017). However, physical exercise must be tailored, as not all patients with lung cancer will be able to tolerate the same level of activity.

6.1.1.2 Pain

One of the most severe and prevalent symptoms is pain. With its proclivity for metastasis, lung cancer can cause pain locally by invading the parietal pleura, ribs, thoracic area, spinal cord, brachial plexus, or other places in the body. The chest and the lumbar spine are the most affected areas (Deshields et al., 2014), and 25–50% of lung cancer patients have pain due to tumour infiltration of the parietal pleura or the chest wall or because of a pulmonary embolism or pneumonia (Farbicka and Nowicki, 2013). Hermann et al. (2016) found that the pain levels initially decreased after diagnosis but that the mean overall score for pain was significantly higher at 4 months compared to at 2 months. Pain affects all dimensions of a patient’s life and the ability of patients to survive treatment and recover or achieve a peaceful death (Vuong et al., 2016).

Analgesic therapy is a treatment option, and pain management has become a priority in oncology. RT is recommended to relieve chronic pain (MacLeod et al., 2014). Although it has been reported that the incidence of inadequate pain management is decreasing, this may still indicate that cancer pain is still a difficult symptom to treat adequately. It may be advantageous to add a qualitative component to the pain management index assessment tool in order to provide a more precise evaluation of pain management (Vuong et al., 2016). This thesis found that pain and cough not being reported at follow-up may be the effect of RT reducing the amount of disease in the lung. The study of Körner et al. (2017) also found that at the end of RT, pain had decreased significantly (62.8%) and that the percentage of palliative patients with a clinically relevant symptom had increased significantly to 91.4%, with tiredness particularly increasing.

6.1.1.3 Cough

Cancer-related causes of chronic cough were airway/endobronchial lesion, lung parenchymal infiltration, pleural disease effusion, mesothelioma, pericardial effusion, lymphangitis carcinomatosis, mediastinal involvement, RT/systemic anticancer therapy (SACT) -induced toxicity, and pulmonary embolism/micro embolism (Gleeson, 2022). Coughing is a possible indication of advanced lung cancer, and radiation might temporarily exacerbate this symptom. In certain instances, however, radiation can lessen coughing by shrinking the tumour. Palliative radiation for advanced lung cancer can produce a variety of symptoms such as fatigue, skin responses, nausea and vomiting, pain, breathlessness, and coughing (King et al., 2022, Martin et al., 2022). Nevertheless, these symptoms are frequently treatable with medications and supportive care. The response rate for cough after palliative RT was 54.1% (Reinfuss et al., 2011), and consistent, significant improvement was seen in cough (Fraser et al., 2019, Stevens et al., 2015).

6.1.1.4 Weight loss

Weight loss was one of the top five symptoms in this study and, just like in the study by Martin et al. (2022), one of the most severe symptoms. This symptom severity was found to be a statistically significant predictor of a decline in QOL.

However, a Colombian study written in Spanish found that weight loss was the least distressing symptom (Llamas-Ramos et al., 2022). One of the negative clinical prognosis factors of chemoradiotherapy in patients with locally advanced stage III NSCLC was weight loss >10% over the last 6 months (Strøm et al., 2013). The severity of weight loss was the one of the core elements for the development of cachexia, which involves an impaired food intake and systemic inflammation; these symptoms are associated with physiological impairment and a reduced survival time (Gleeson, 2022).

The Scored Patient-Generated Subjective Global Assessment (PG-SGA) is a validated screening tool designed specifically for use with cancer patients. This instrument includes questions regarding past weight loss, food consumption, 'nutrition impact' symptoms, and performance status. Monitoring and prevention advice should be sufficient for individuals with cancer to manage these aspects. Then, consideration should be given to the performance status, the prognosis, and individuals' expectations. Further management is contingent on the possibility of reversibility: corticosteroids or megestrol acetate should be considered for patients with poor performance who are nearing the end of life. This may also be the best option when anorexia is the predominant issue. A better prognosis (performance status of 0–3, patients undergoing palliative chemo-/RT) can allow concentration on oral consumption, exercise, anti-inflammatory treatment, and pharmacological management (Gleeson, 2022).

6.1.1.5 I don't look like myself

The feeling "I don't look like myself" can be due to various factors such as cachexia, treatment-related side effects, and psychological impact (Turner et al., 2007). These factors can cause changes in physical appearance, including muscle wasting, weight loss, hair loss, skin changes, and changes in body image. The loss of muscle mass can result in a change in appearance, making patients appear emaciated and weaker than usual (Zhou et al., 2017). Lung cancer treatments such as radiation therapy can also cause skin changes, such as redness, flaking, and dryness, which can alter the appearance of patients. The psychological effects of a cancer diagnosis and treatment may also contribute to a patient's perception that they no longer resemble themselves (Gosselin et al., 2020).

The diagnosis and treatment of cancer can result in anxiety, melancholy, and changes in body image, all of which can have a negative impact on a patient's self-esteem and body image (Lindell and Danoff, 2021). Healthcare providers should be aware of these factors so that they can provide better supportive care for lung cancer patients.

For both patients and caregivers, the psychological subscale shows the highest score at visit 3 (last week of RT), which is similar to a study of patients with breast cancer which shows that emotional function was the most affected element even at the beginning of RT, and it was the worst affected at the end of RT (Sharma and Purkayastha, 2017). However, a study conducted in a palliative care setting found that 38.2% of patients experienced mood disorder but that this was not the effect of the duration of the illness (Mitchell et al., 2011). Because the majority of published research has relied on psychological symptom screening methods rather than diagnostic instruments, the picture is especially unclear (Mitchell et al., 2010).

The psychological subscale shows the highest scores at the last week of RT treatment for lung cancer patients. This finding is supported by other studies that have reported high levels of psychological distress during RT, with the highest scores occurring towards the end of treatment. Healthcare providers should prioritise providing psychological support to lung cancer patients during RT, especially towards the end of treatment. The symptom score was reduced from baseline at all visits, as in the study by Sundstrøm et al. (2005). Other studies have shown that palliative RT can substantially reduce the symptoms of patients with advanced lung cancers. At all visits, the symptom score decreased from baseline, indicating an improvement in symptom burden over the course of treatment.

6.1.1.6 Lack of appetite/appetite loss/anorexia

It is important to discuss these symptoms because they affect up to 80% of patients with cancer, and this study found that lack of appetite was a frequent symptom by the end of RT. This symptom can be associated with oesophagitis and can cause treatment interruption and hospitalisation (Nieder et al., 2020). Numerous factors contribute to appetite loss associated with cancer, such as other diseases and cancer treatment. Oral nutritional interventions encompass the provision of dietary advice or education, with or without modifications to the diet, and nutritional supplements. These supplements typically include general protein-calorie supplements and various combinations of vitamins, minerals, and other compounds. However, specific herbal supplements and highly targeted supplements, such as carnitine and individual vitamins, are regarded as distinct interventions (Christine Baldwin et al., 2012).

6.1.1.7 Difficulty sleeping/insomnia/sleep-wake disturbances

These symptoms involve actual or perceived changes in night sleep, leading to daytime impairments. Several factors can elevate the risk of sleep problems in cancer patients, including demographic data, lifestyle, and environmental-related, disease-related, and treatment-related factors. Pain, nausea, anxiety, depression, and hot flushes can also contribute to these symptoms. Some reports have indicated that 30-75% of cancer patients experience these symptoms (Garland et al., 2014, Johnson et al., 2015). This study found difficulty sleeping in the top five most frequent and severe symptoms at the third and fourth visits, and in the top five most distress symptoms at every visit. The healthcare provider should pay attention to symptom management. Cognitive behavioural intervention focuses on the connections between thoughts, feelings, and behaviours to help patients recognise and modify negative and unhelpful behaviours, to set goals, and to develop problem-solving skills to implement new, effective coping strategies. Structured programmes based on cognitive behavioural approaches may include activities like education or relaxation training and may be provided individually or in groups and be delivered in person, by phone, or through another method. This intervention is recommended as a useful part of practice.

6.1.1.8 Difficulty concentrating

This symptom is a sub-symptom of cognitive impairment, which is defined as a decline in one or more cognitive domains, such as attention, concentration, executive function, information processing speed, language, visuospatial skills, psychomotor ability, learning, and memory. Cognitive impairment has been observed in up to 80% of adult patients with a brain tumour, lung cancer patients 70-80%, and 40% of those with acute myeloid leukaemia. It has also been reported in up to 75% of breast cancer patients and in patients who have undergone bone marrow transplantation following high-dose systemic anticancer therapy. This impairment can persist long after treatment ends. Additionally, individuals treated for childhood cancers may experience long-term cognitive changes, prompting early research that has led to adjustments in treatments to mitigate this effect (Chan et al., 2015, Oh and Kim, 2016).

This study revealed a noteworthy trend: difficulty concentrating emerged as a significant symptom by the end of RT and persisted afterward, despite not being present initially. This highlights the potential impact of cancer treatment on cognitive function. Cognitive training has emerged as a promising intervention for improving cognitive function in cancer survivors. This evolving field offers various approaches, including computerised exercises, strategy training, and compensatory strategies, which can be tailored to individual needs and cognitive challenges *(*Chan et al., 2015*)*. Recent research indicates that cognitive training can enhance attention, memory and executive function. However, further investigation is crucial to optimise its effectiveness, timing, and long-term benefits (Cherrier et al., 2022).

6.1.1.9 Worrying

The definition of worrying is future-oriented anxiety or apprehension about potentially negative events, and it sometimes includes the individual's reaction to the situation. According to the American Psychiatric Association [APA] (1987), unrealistic or excessive anxiety and worry (apprehensive expectation) about two or more life circumstances was highlighted as criterion A regarding generalised anxiety disorder (Gerlach and Gloster, 2020). Anxiety is an emotional and physiological response commonly experienced by patients coping with a cancer diagnosis. This type of response can vary from a normal reaction to severe dysfunction, impacting decision-making, treatment adherence, and various aspects of quality of life and functioning.

Anxiety can arise at different times throughout the various phases of cancer care, typically peaking shortly after diagnosis and decreasing over time. However, 20–30% of patients continue to experience anxiety even after completing treatment. The interventions that are recommended are cognitive behavioural interventions, mindfulness-based stress reduction, music therapy, psychoeducation, and yoga (Bro et al., 2018, Cobeanu and David, 2018, Danhauer et al., 2017, Howell et al., 2017, Zhang et al., 2015). While worrying can be a symptom of anxiety, its presence at visit 4 might also reflect a normal response to the transition to survivorship and the uncertainties that come with it.

6.1.1.10 The MSAS score

The analysis of the psychological subscale, total physical subscale, Global Distress Index, and total MSAS score throughout the different visits provides valuable insights into the experiences of the patients undergoing RT. These findings reveal distinctive patterns in how patients perceive and experience symptoms across the treatment period. Firstly, the psychological subscale results indicate a notable peak in mean scores during the third visit, coinciding with the last week of RT. This peak suggests that patients may experience heightened psychological distress and challenges towards the end of their treatment. Interestingly, the subsequent drop in mean scores during the fourth visit, a month after RT, signifies a significant decrease in reported psychological symptoms. This fluctuation highlights the dynamic nature of psychological well-being throughout the treatment trajectory (He et al., 2022, Mosher et al., 2015, Sharma and Purkayastha, 2017).

Conversely, the total physical subscale demonstrates a consistent downward trend from the baseline to the fourth visit. This decline illustrates a reduction in the overall physical symptom burden experienced by patients following RT. The gradual improvement in physical symptoms suggests a positive response to treatment and potentially enhanced quality of life in terms of physical well-being (McFarland et al., 2020, Pongthavornkamol et al., 2019). Moreover, the Global Distress Index and total MSAS score mirror this trend, indicating a decrease from the first visit to the last visit. The decline in the Global Distress Index reflects an overall reduction in distress levels experienced by patients across the treatment period. Similarly, the decrease in the total MSAS score from baseline to the fourth visit suggests an alleviation of symptom burden encompassing both physical and psychological aspects, albeit to a varying degree (Chen et al., 2022, He et al., 2022, McFarland et al., 2020).

Notably, the divergence between the trajectories of the physical and psychological symptom burdens is intriguing. While physical symptoms show a consistent decrease over time, psychological symptoms do not follow the same pattern of significant reduction. This observation underscores the complexity of the patient experience during and after RT, indicating that psychological well-being may require additional attention and support post-treatment. These results emphasise the importance of comprehensive care that addresses both the physical and psychological aspects of symptom management in patients undergoing RT. Further research and tailored interventions focusing on psychological support and symptom management could enhance the overall well-being and recovery outcomes for individuals receiving RT.

To enhance psychological support and symptom management for individuals receiving RT, several interventions have shown promise. Cognitive-behavioural interventions, such as CBT and ACT, can help patients manage anxiety, distress, and improve psychological flexibility (Nakao et al., 2021). Mindfulness-based interventions, including mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT), can reduce stress, anxiety, and depression, and may even help prevent relapse (Hofmann and Gómez, 2017). Other beneficial interventions include supportive-expressive group therapy to reduce isolation and improve coping, yoga and exercise to enhance physical and mental well-being, and music therapy to provide emotional support and reduce anxiety (Bradt et al., 2021, Leckey, 2011, Mayden, 2012, Vajpeyee et al., 2022). Further research is needed to determine the most effective approaches and tailor interventions to individual needs, ultimately improving overall well-being and recovery outcomes.

The future of prognosis and symptom experience in healthcare is indeed changing rapidly and is driven by several key factors. With advancements in diagnostics and treatment, for example in precision medicine and genomics, treatments are becoming increasingly tailored to individual patients. This allows for more accurate prognoses and better management of symptoms (Punnett et al., 2023). Targeted therapies and immunotherapy: These newer treatments often have fewer side effects than traditional chemotherapy, leading to improved quality of life and symptom experience for patients. Artificial intelligence (AI) is being used to analyse vast amounts of data, leading to earlier and more accurate diagnoses, personalised treatment plans, and better prediction of treatment response and side effects (Mamta et al., 2019).

Focusing on patient-centred care for shared decision-making, patients are becoming more involved in their own care, working with healthcare providers to make informed decisions about treatment options based on their individual needs and preferences (Pardon et al., 2009). With regards to symptom management, there is a growing emphasis on managing symptoms and improving quality of life, not just prolonging life. This includes a holistic approach that addresses physical, emotional, and social well-being. Remote monitoring and telehealth allow for continuous monitoring of symptoms and provide convenient access to care, empowering patients to manage their health proactively.

6.1.2 Caregiver burden

Throughout the study period, most caregivers reported experiencing little to no burden, ranging from 64.3% to 80.4%, which is consistent with findings from Thai research by Chindaprasirt et al. (2014) about patients with advanced cancer. A study conducted in a palliative care unit in Malaysia showed a mild to moderate burden (Zubaidi et al., 2020). It has been found that the level of caregiver burden is higher in Europe than in Asia. A Spanish study showed that the highest level, an intense burden, was reported by 41.6% of the participants (Perpiñá-

Galvañ et al., 2019). Caregiver burden was especially high for caregivers of patients with non-small cell lung cancer (NSCLC) receiving second or later lines of therapy in France, Germany, and Italy (Wood et al., 2019).

One possible explanation in this thesis for the level of no burden or little burden of caregivers' burden is that 25% of the patients were admitted to hospital and the universal coverage system was available for most patients in this longitudinal observational study, which covered the cost of treatment. However, this system often lacks coverage for their post-discharge care and provides minimal support for caregivers. This study revealed that the level of burden was lower than that found in a comparative study on caregivers of patients with advanced cancer, dementia, and brain injury (Harding et al., 2015) and another on caregivers of critically ill patients, who faced a moderate to severe burden (Fu et al., 2021). The ZBI scores of spouse caregivers were significantly lower than those of other caregivers, and formal medical aid systems also played a positive role in reducing subjective caregiving burdens (Fu et al., 2021).

No statistical significance was found in multivariate analysis between the caregiver's characteristics and the change in the caregiver's burden. In other studies of caregivers providing palliative care to cancer patients, there was a significant correlation between anxiety, depression, fatigue, and post-traumatic growth, and caregivers of patients with depression and anxiety experienced a higher burden (Yuen and Wilson, 2021, Perpiñá-Galvañ et al., 2019). This study's findings on caregiver burden differ from those in other regions, notably showing a lower overall burden compared to European studies, potentially due to cultural factors and social support networks in Thailand. While universal healthcare coverage may lessen financial strain, limited post-discharge and caregiver support remain challenges. Interestingly, spouse caregivers experienced higher burden than other relatives, possibly reflecting Thai cultural norms.

Furthermore, this study observed a decreasing burden trend over time, contrasting with some longitudinal research, likely due to the specific population (advanced lung cancer with palliative RT) and interventions provided. The review highlighted the association between perceived caregiver burden and negative effects on work productivity and finances, changes in social and family dynamics, and increased needs for direct intervention and support (Junkins et al., 2020). Predictors of burden included being younger, female, more educated, having pessimistic expectations, psychological symptoms, a longer duration of care, family debt, and their patient self-rating their health (Fu et al., 2021, Yuen and Wilson, 2021, Weber-Raley and Smith., 2015).

Employment status was correlated with caregiver burden. As a consequence of their caregiving responsibilities, 8.8% of caregivers reduced their working hours or switched jobs, while three (0.8%) caregivers quit their jobs entirely (Wood et al., 2019). Financial pressures exacerbate psychological stresses. According to earlier research, bigger burdens are produced by higher expenses and lower income levels. Surprisingly, nevertheless, caregivers in debt-ridden households had fewer subjective difficulties. This may be explained by the fact that families that are in debt tend to have greater social connections than other families, maybe as a result of receiving financial assistance from family and friends. Additionally, low earnings and poverty may lead to pessimism, dissatisfaction, interpersonal anxiety, and rejection – attitudes that may make it difficult to effectively connect with possible social support systems (Fu et al., 2021).

We also found that spouse caregivers experienced a significantly higher subjective burden than other relatives who provided care, which is consistent with studies conducted in rural China (Fu et al., 2021). This finding was unsurprising in the Thai context since spouses who live with their patients encounter less role-related conflict (Chaiyarit, 2012). In addition, caregivers whose patients are receiving active treatment may devote all their attention and time to giving care, neglecting social and personal pursuits. When active treatment is over, caregivers may find it challenging to return to the formal social world and rebuild their social networks because the opportunities and social support networks may no longer exist (Liu et al., 2021). After their care recipient's therapy had ended, caregivers in the present research could have experienced a greater loss of social connection (Mora-Lopez et al., 2022).

This study also shows that the trend for the scores for caregiver burden was to decrease from baseline at all visits. Most studies of caregiver burden have been cross-sectional, and the longitudinal study of caregiver burden across home-based palliative care in Canada shows that the burden on caregivers increased in a non-linear fashion from the start of the study to when patients died. A higher caregiver burden was associated with increased monthly caregiving time costs that remained uncompensated, monthly personal support worker costs, emergency department visits, and a low functional status of the patient (Guerriere et al., 2016).This study indicates that current caregiver support programs may be effective in reducing caregiver burden. However, several factors could contribute to this outcome, including the support intervention itself, the natural progression of the care recipient's condition, or other external factors affecting caregiver well-being. Further research is needed to pinpoint the specific reasons behind this positive trend.

A systematic review of interventions aimed at reducing caregiver burden found that interventions such as psychoeducation, respite care, support groups, caregiver skills training, couples therapy, support with decision-making, mindfulness-based stress reduction, multicomponent interventions, and palliative care were effective in reducing caregiver burden (Adelman et al., 2014, Jadalla et al., 2020). A review of the literature on caregivers' burden in clinical trials found that the burden scores are a useful measure of the impact of a disease on a patient's quality of life and can help identify the effectiveness of interventions in improving patient outcomes (Zhu et al., 2022).

While seemingly paradoxical, the observation of shorter survival times in some patients receiving palliative care can be attributed to several factors. Patients with aggressive cancers or late-stage diagnoses may require more intensive interventions yet still face a poorer prognosis (Golob et al., 2024). Additionally, despite efforts to minimise complications, some treatments carry inherent risks and side effects that can impact survival. Patient factors such as comorbidities and individual responses to treatment also play a significant role (Pickett and Tipton, 2024). Nevertheless, palliative care, even in the context of shorter survival, remains vital for improving quality of life, managing symptoms, and providing comprehensive support to patients and their families.

Although high-quality care should be a fundamental right, access disparities persist due to socioeconomic inequalities, geographical barriers, and healthcare system limitations (Kaikeaw et al., 2023). Thailand's universal health care system strives to provide care for all citizens, but challenges remain in ensuring equitable resource distribution and addressing the needs of vulnerable populations (Paek et al., 2016, Barker et al., 2019). To achieve true health equity, ongoing advocacy is crucial to promote policies and initiatives that guarantee access to high-quality care for everyone, regardless of their background or circumstances.

The absence of caregivers places a significant burden on patients, who face challenges managing daily tasks, medications, transportation, and emotional well-being. This lack of support can lead to poorer treatment adherence, increased hospitalisations, and a diminished quality of life (Chua et al., 2020). Therefore, it is essential to identify alternative support systems for patients without family caregivers, such as community organisations, home healthcare services, and support groups, to ensure they receive the necessary assistance and maintain their well-being throughout their cancer journey.

Recognising the patient-caregiver dyad as the unit of care is crucial for providing truly holistic support. This approach acknowledges the interconnectedness of their experiences and emphasises the importance of addressing the needs of both individuals (Joung and Jones, 2025). Including caregivers in shared decision-making not only respects cultural values of family involvement but also promotes more informed and patient-centred care (Légaré and Witteman, 2013). Furthermore, recognising the mutual influence of patient and caregiver well-being highlights the importance of supporting both the patient and caregiver. Improving the well-being of one can positively impact the other, ultimately leading to better overall outcomes (McCauley et al., 2021).

While research suggests higher caregiver burden in Europe compared to Asia, critiquing this finding requires considering cultural nuances like collectivism versus individualism, filial piety, and social support networks (Tran et al., 2023). Methodological limitations, including variations in measurement tools, sampling biases, and publication bias, must also be acknowledged (Dhumal et al., 2023). Additionally, healthcare systems, access to formal support, financial burdens, cancer type and stage, and caregiver characteristics can all influence perceived burden. Further research is needed to explore these factors comprehensively and develop culturally sensitive support interventions. This requires careful evaluation of existing studies, considering their strengths and limitations, proposing alternative explanations for observed differences, and identifying areas that require further investigation to gain a more nuanced cross-cultural understanding of caregiver burden.

While Thailand is classified as an upper-middle-income country with a universal healthcare system, it's crucial to recognise the significant socioeconomic disparities that exist within its borders. Income inequality, rural-urban disparities, and the vulnerability of specific populations like ethnic minorities and migrant workers can impact access to lung cancer care and support services (Wongsuwanphon et al., 2024). These disparities may influence caregiver burden, information needs, and health literacy, potentially creating barriers to informed decision-making and optimal care. Addressing these challenges requires policies and interventions that promote equity, provide culturally sensitive support, and tailor interventions to meet the diverse needs of patients and caregivers across different socioeconomic groups (Kosiyaporn et al., 2020).

Low socioeconomic status significantly amplifies the challenges faced by lung cancer patients and their caregivers in Thailand. Financial toxicity due to out-of-pocket costs for treatment and supportive care can be devastating, while limited access to resources like nutritious food, adequate housing, and transportation further compromises well-being (Geater and Thongsuksai, 2023). Caregivers from low-SES backgrounds often struggle to balance work and caregiving, facing potential job loss and reduced income. These challenges can lead to increased stress, anxiety, social isolation, and even stigma. Addressing these disparities requires comprehensive solutions, including expanded financial assistance programs, transportation subsidies, increased respite care availability, and strengthened community-based support services to ensure equitable access to care and improve the overall well-being of those affected by lung cancer (Saranrittichai et al., 2020).

6.1.3 Information needs

Patients' needs for information regarding symptom self-management can vary significantly depending on the specific condition or symptoms that patients are experiencing. Patients need to clearly understand their symptoms, including what they should tell their clinician about and when to seek medical attention. Providing educational materials or resources can help patients recognise symptoms and understand their significance. Self-care strategies benefit from practical advice on managing symptoms at home. This may include lifestyle modifications, rest, hydration, and over-the-counter medications. Clear instructions about when to rest versus when to engage in light activity can be helpful. Patients need guidance regarding monitoring and tracking their symptoms. This could involve keeping a symptom diary, tracking pain levels, or noting any changes. Apps or tools that allow patients to record symptoms and share them with healthcare providers can enhance self-management. Patients should know when their symptoms require professional evaluation and seek professional help.

Clear guidelines about red flags (e.g. severe pain, sudden changes) are essential. Patients with advanced lung cancer require clear information on symptom self-management, including when to seek immediate medical attention. Red flag symptoms, such as sudden onset or worsening shortness of breath, haemoptysis, severe pain, limb weakness or numbness, high fever, and mental status changes, could indicate serious complications and warrant prompt evaluation (UKONS, 2024). Educational resources should provide practical advice on self-care strategies, symptom monitoring, and recognising these red flags, empowering patients to effectively manage their condition and seek timely medical support. Additionally, patients should be provided with resources from reputable cancer organisations and information on online symptom trackers to further enhance their understanding and self-management capabilities. Patients should be encouraged to seek medical attention promptly if symptoms worsen or become unmanageable. The emotional impact of symptoms should be acknowledged. Patients may experience anxiety, frustration, or fear. Providing resources for coping with emotional aspects can improve overall self-management.

A spouse or partner has a bigger information need than those with a different relationship to the patient. The top information needs for caregivers in this study concerned complementary and alternative therapies. Caregivers play an important role in supporting patients with lung cancer and often have a strong desire to obtain information about complementary and alternative therapies that may help manage symptoms and improve outcomes. They expressed a desire to know about complementary and alternative therapies that could help alleviate symptoms, such as pain and fatigue, and improve the overall well-being of patients. Caregivers in this study wanted to know about potential side effects, safety concerns, and the availability of these therapies, which was the same finding as in one systematic review study conducted with patients with advanced cancer (Dongen et al., 2020). Another study found that needs related to symptom management were those most frequently assessed (Kim et al., 2023).

Another study also found that caregivers of lung cancer patients were interested in learning about complementary and alternative therapies, particularly herbal remedies, vitamins, and dietary supplements, and also Thai traditional medicine (Chotipanich et al., 2019, Juckmeta et al., 2019, Kanjanahattakij et al., 2019). The study reported that caregivers wanted information about the safety and efficacy of these therapies, as well as about their potential interactions with conventional treatments. In addition to wanting to know about their disease and treatment, caregivers of patients undergoing RT also required information about the logistical aspects of RT, as demonstrated by the longitudinal results presented in this study.

The information source which patients and caregivers needed the most was healthcare providers, and this finding agrees with that of Wiljer et al. (2012), who found that most patients felt their needs had been met and identified by healthcare providers and their healthcare providers were identified as both the best and the most useful sources of information. They also indicated that lung cancer patients experienced high levels of anxiety during the pre-diagnosis phase and that their informational and emotional needs were the most pressing during this time. Today, patients and their families utilise the internet as a source of cancer-related information in our technologically advanced world. Comparable to a telephone hotline in terms of its advantages, online support has been characterised as a convenient and simple method of obtaining information (Durnin et al., 2021).

The information type which patients and caregivers needed the most was talk. Because verbal information allowed patients to address their individual information needs as they emerged, it was the most popular source of information among patients. In Thai culture, patients usually want to talk to the healthcare provider to obtain information. Similar findings in patients with breast cancer receiving RT have been documented by Halkett et al. (2010). Patients desired various amounts of information, which was consistent with previous research. Because some specific RT-related information was initially unavailable and patients were anxious about preparing for each procedure, many patients in the current study actively sought verbal information from staff as opposed to from external sources.

The patient sample in this longitudinal study needed information about the symptoms that they had. Patients with advanced lung cancer and their caregivers often face significant challenges related to symptom management and maintaining well-being. The results showed that information about self-management strategies regarding a lack of energy was the most needed information by both patients and caregivers at all visits. This related to symptom changes throughout treatment but particularly after RT was over. Clinicians and nurses provide follow-up care and support if patients need to know what to do about their symptoms.

In line with the results from this longitudinal study, healthcare providers should recognise this information need and provide patients and caregivers with evidence-based information about self-management strategies to help them cope with fatigue (Bade et al., 2015, Chayadi et al., 2022, Twomey et al., 2018), other frequently found symptoms, the most severe symptom, and the most distressing symptom (Gleeson, 2022).

We also found that the most pressing information needs for patients and caregivers concerned things that patients can do to help themselves get better. That ties in well with their need to know more about what to do about specific symptoms that they had. Empowering patients to actively participate in their own care can be an important component of managing advanced lung cancer. Patients and their caregivers may feel more in control of their situation and better able to cope with the physical and emotional challenges of their illness if they learn strategies to improve their own health and well-being (He et al., 2022). This may include lifestyle changes such as taking exercise and healthy eating, as well as other self-care practices like relaxation techniques and stress reduction techniques (Lindell and Danoff, 2021).

The information needs reduced from baseline through to the fourth visit for every item, as in a study on breast cancer patients during RT (Halkett et al., 2010). Patients' information needs were highest at the time of the first appointment and the time of planning. Durnin et al. (2021) also found that lung cancer patients seek information more actively in the pre-treatment phase than at any other time. Even if patients have been given information in the past, they will continue to have information needs throughout their treatment, and health personnel must be aware of this.

This longitudinal study found that the patients required the most information when they met the radiation oncologist for the first time and during the planning appointment. Because the planning appointment is difficult, it may be useful to provide patients with additional information beforehand. Patients and caregivers still have a substantial information need at this time point, but the fact that no support is provided by the Thai healthcare system needs to be highlighted. It provides follow-up care and support at this point, but no follow-up referral information is sent from the hospital to primary care regarding monitoring patients’ information needs. Survivorship care could be established in Thailand. There are gaps in the clinical support after RT, as mentioned before, indicating that healthcare teams should be aware of those patients and caregivers once RT is over.

In summary, when our study examined the information needs of patients and caregivers regarding managing advanced lung cancer, it focused on the most pressing information needs, the preferred sources of information, and the type of information required. This examination highlights that caregivers are interested in complementary and alternative therapies and that both patients and caregivers need information from healthcare providers the most. Patients and caregivers require information about self-management strategies and the things that patients can do to help themselves get well. This thesis also suggests that patients' information needs are highest at the beginning of treatment and that healthcare providers should be aware of this and provide patients with additional information before their planning appointment.

Communication approaches used verbal and non-verbal communication in the centres, but they all vary one way from healthcare professionals to patient and caregiver (Brock et al., 2024, Guetterman et al., 2024). Effective communication in lung cancer care necessitates a multi-faceted approach that moves beyond a one-way flow of information. Healthcare professionals should utilise active listening, empathy, and clear language, alongside non-verbal cues like open posture and visual aids, to foster a two-way exchange with patients and caregivers (Brock et al., 2024). Furthermore, diverse communication channels, such as written materials, support groups, and technology, can enhance understanding and provide ongoing support(Kwame and Petrucka, 2021). It is essential to consider communication within the patient-caregiver dyad, recognising its cultural nuances and potential barriers like language differences or emotional distress (Jacops et al., 2022). By promoting open and supportive communication, healthcare professionals can empower patients and caregivers to actively participate in shared decision-making and navigate the challenges of their cancer journey together.

6.2 Predictors

6.2.1 The predictors associated with patients having an increased symptom experience

Smokers, men, single people, and patients on 3D RT reported a greater symptom experience overall. Psychological symptom scores were higher in patients with a smoking history and those who were single or divorced. Physical symptom scores showed a positive correlation with smoking history. Moreover, smoking history was indicative of heightened Global Distress Index scores.

1) Smoking history

Multivariable analysis identified smoking history as a significant predictor of increased symptom burden in patients with advanced lung cancer undergoing palliative radiotherapy (RT). These findings align with existing literature indicating that smoking is associated with worse cancer-related symptom burden (Oswald et al., 2022). Heavy smoking may be related to increased symptom frequency due to a more severe clinical manifestation of lung cancer (Khalil et al., 2016). This study indicates that a smoking history was a predictor associated with an increase in the total MSAS score, the physical subscale score, and the Global Distress Index, particularly in patients with a heavy smoking history, who experienced a larger increase compared to non-smokers. This finding suggests that patients who were heavy smokers tended to report more symptoms. However, other studies focusing on symptom burden and alternative predictors in this area have not been identified.

Most studies give information about smoking history but did not determine a correlation with symptom burden (Dean et al., 2019, He et al., 2022). Nonetheless, Harle et al. (2020) noted that despite commonly held beliefs about clinical factors associated with cough, such as a smoking history, comorbidities such as COPD or cancer characteristics such as tumour location or histology type, were not found to be associated with cough prevalence. The experience of receiving a diagnosis of lung cancer was characterised by feelings of shock, disbelief, and fear, with individuals reacting in their own unique ways. For those who had never smoked, the unexpectedness of the diagnosis amplified their emotional response, and they often felt a sense of desperation when trying to understand how they could have developed lung cancer (Fitch, 2020). This may lead to some of the symptoms found in this study, such as worrying, difficult concentrating, and difficulty sleeping.

Healthcare providers and patients may hold differing values, potentially leading to unequal and biased care delivery. This can result in prejudice and discrimination, particularly towards vulnerable and underserved populations. Therefore, providers must be mindful of their own biases to ensure equitable palliative care for all patients, including those with smoking-related lung cancer. It is crucial to respect patient autonomy and avoid imposing personal values, even when patients continue to smoke (Lindell and Danoff, 2021). Finally, Lindell and Danoff (2021) urge healthcare providers to acknowledge that patients with a smoking history may be affected by discrimination or bias, even if it is unintentional. Lindell and Danoff (2021) emphasises the importance of avoiding discrimination in healthcare systems and ensuring that all patients receive equal and fair treatment, regardless of their background or health status.

Koch et al. (2020) determined gender differences in relation to smoking. Men are more likely to have a smoking history, and a lower percentage of men are non-smokers compared to women. The number of pack-years was higher among men than among women, and this corresponds with men's higher level of self-reported wheezing. The risk factors for insomnia include medical conditions, unhealthy lifestyles, smoking, alcoholism, and caffeine dependence (Sateia et al., 2017). A meta-analysis has revealed that there is a significant negative correlation between cancer-related fatigue and continued smoking after surgical treatment. Therefore, it is highly recommended that more smoking cessation programmes are implemented for such patients because smoking can worsen existing respiratory problems, comorbidities, and fatigue.

To translate research findings into action, active engagement with hospitals is crucial. This involves formally communicating findings and recommendations to Chulabhorn Hospital, Thailand National Cancer Institute, and Rajavithi Hospital, emphasising the need for smoking cessation programs (Chaisai et al., 2024). Collaboration with healthcare providers, researchers, and administrators within these hospitals can facilitate the implementation of such programs (Chaisai et al., 2022a). Offering presentations and workshops on smoking cessation in cancer care can further educate healthcare professionals (Duangchan and Matthews, 2020). Expanding efforts to other hospitals through dissemination, networking, and advocacy can promote wider adoption of smoking cessation initiatives (Chaisai et al., 2024). Specific recommendations include integrating smoking cessation into routine care, developing specialised programs for cancer patients, providing training for healthcare providers, and raising public awareness about the risks of smoking and benefits of quitting (Chaisai et al., 2022b).

2) Gender

Our research shows that males have a bigger reduction in the total MSAS score (a measure of symptom) than females. Gender was a predictor associated with an increased total MSAS score in patients, which is a similar result to that found in a multicentre study in China concerning hospitalised patients with advanced cancer (He et al., 2022). A study of the effect on middle-aged and older urban residents showed that women who live in a city with a less developed economy have a higher incidence of depressive symptoms than men (Zhou et al., 2022). Female patients were more likely to have symptoms despite receiving treatment for those symptoms; in other words, female patients were more likely to receive inadequate treatment for their symptoms. Even when they had symptoms, female patients were less likely to be treated. These findings suggest that gender influences symptom burden and management and that specific assessment and intervention should be considered (Koch et al., 2020). Therefore, determining differences in the way different genders are treated is essential for identifying patient needs and ensuring the best possible clinical outcome.

Koch et al. (2020) found that men are more likely to have a smoking history as either current smokers or ex-smokers and that a lower proportion of men than women are non-smokers. Men also had a higher number of pack-years and reported more coughing than women, indicating a greater impact of smoking on their respiratory health. This higher number of pack-years and men’s higher prevalence of smoking could be likely causes of coughing. Furthermore, Koch et al. (2020) found that only two scales revealed statistically significant differences: cough severity was greater in men than in women, p=0.022, and diarrhoea severity was greater in women than in men, p=0.03. However, despite this association, coughing is still not well researched or understood concerning its relationship with lung cancer. Therefore, more research is needed to fully understand this issue.

Individual backgrounds encompass a variety of factors that can influence symptom experiences and coping strategies. Socioeconomic background, including income, education and occupation, can impact access to healthcare and resources (Caballo et al., 2021). Cultural background, encompassing beliefs, norms and practices related to health and illness, can shape how individuals perceive and respond to symptoms (Kahissay et al., 2017). Personal history, such as past experiences with illness, family history, and personal health beliefs, can also influence coping mechanisms and help-seeking behaviours. These diverse individual backgrounds contribute to the complex interplay of factors that shape health and well-being (Hacker and Houry, 2022, Hacker et al., 2022).

The differences in individual backgrounds based on gender may lead to various coping strategies and responses to symptoms and different levels of seeking medical help. These differences in coping mechanisms and help-seeking behaviour may arise due to variations in gender-related socialisation and cultural factors that can influence one's health-related beliefs and attitudes. (Sangruangake et al., 2022). Linden et al. (2012) showed that certain types of cancer can lead to higher levels of anxiety in female patients. The study found that female patients with gynaecological, haematological, head and neck, and lung cancers reported the highest levels of anxiety. These gender differences in anxiety levels suggest that gender-related factors may contribute to the psychological impact of cancer on patients.

3) Marital status

Marital status, specifically being single versus being married or in a committed relationship, was a predictor of symptom experiences in patients with advanced lung cancer who are receiving palliative RT. Marital status was associated with increased psychological symptoms in patients, with a borderline being a statistically significant result (p = 0.048). Those with a marital status of single had a significant reduction in psychological symptoms at visit 4 compared with those who were not single. Studies have shown that patients who are married or in a committed relationship may experience fewer symptoms, such as fatigue and pain, compared to patients who are single. This may be due to the emotional and social support provided by a partner, which can help to alleviate stress and improve coping strategies.

Nevertheless, Martin et al. (2022) found that the pooled sample characteristic factors (age, gender, race , and marital status) were not predictive of lung cancer symptoms, and a study examining the effect of urban green space on depressive symptoms in China revealed that marital status did not have a significant effect on depressive symptoms (Zhou et al., 2022). While this study found an association between marital status and psychological symptoms in advanced lung cancer patients, this contrasts with other studies that found no such relationship. This discrepancy could be due to variations in study populations, methodologies, or cultural contexts, highlighting the need for further research to explore this complex relationship. Limitations of the current study, such as sample size and specific measures used, should also be considered when interpreting the findings. Further investigation is needed to understand how marital status, social support, and other factors interact to influence symptom experiences in cancer patients, ultimately informing supportive care interventions.

4) RT type

RT type was a predictor associated with an increased total MSAS score for patients receiving 3-dimensional conformal radiotherapy (3D-CRT), who had a bigger increase in this respect than those receiving 2-dimensional radiotherapy (2D-RT). There is no study concerning lung cancer patients that compares RT type. Most studies focus on the optimal dose and fractionation schedule for palliative care (King et al., 2022). However, a Korean study on patients with nasopharyngeal carcinoma compared intensity modulated radiation therapy (IMRT) with 2D-RT and 3-CRT and indicated that the 3D-CRT and IMRT were associated with a longer local progression-free survival and overall survival than 2D-RT. In terms of overall survival, IMRT was significantly preferable for advanced primary tumours (Moon et al., 2016). Palliative RT for lung cancer improves symptoms in about two-thirds of patients, with consistent and significant improvement seen in cough, chest pain, and haemoptysis. Haemoptysis was found to be the most responsive symptom, with improvement seen as early as 24-48 hours after radiation delivery. Palliative thoracic RT has also been reported to improve general well-being, symptoms of nausea and anorexia, and performance status, with one trial reporting an improvement in 40–60% of patients with a performance status of 3 or greater (Stevens et al., 2015).

Kumar et al. (2019) made a comparison between two groups of patients; one treated with cobalt and the other with Linear accelerator (LINAC). It was found that 76% of patients in the cobalt group and 86% of patients in the LINAC group had improved symptoms. Additionally, 62% of patients in the cobalt group and 79% in the LINAC group experienced improved QOL. It is important to note that while the study found an association between RT type and total MSAS score, the reasons for this association are not fully understood. It is possible that the more precise targeting of the tumour with 3D conformal RT results in greater symptom experiences, or that the higher doses of radiation used with 3D conformal RT may contribute to increased symptoms.

It is also important to note that the decision to use 2D or 3D conformal RT should be based on individual patient factors and treatment goals, and that the effectiveness of RT in treating symptoms and improving quality of life depends on many factors. In addition, the MSAS is just one tool for assessing symptom experiences, and other factors such as patient-reported outcomes and physician assessments should also be taken into consideration. In conclusion, the reasons for this association are not fully understood, and the decision to use RT type should be based on individual patient factors and treatment goals.

The prognosis and symptom experience for patients with advanced lung cancer receiving palliative radiotherapy are undergoing rapid transformation due to a confluence of technological and philosophical shifts in care. Advances in precision radiotherapy, such as stereotactic ablative radiotherapy (SABR) and intensity-modulated radiotherapy (IMRT), coupled with improved imaging, allow for highly targeted radiation delivery, minimising side effects and improving symptom control, as supported by studies demonstrating enhanced symptom relief in palliative thoracic radiotherapy (e.g., references detailing symptom control in palliative thoracic radiotherapy) (King et al., 2022). This is significant as the integration of these radiotherapy techniques with SACT like targeted therapy and immunotherapy is extending survival, shifting the focus of palliative radiotherapy from solely end-of-life symptom relief to active management alongside ongoing cancer treatment (Lehto, 2016, Chiou et al., 2024).

Furthermore, the symptom burden is being addressed more effectively through advanced imaging and treatment planning, which minimise side effects like fatigue and nausea, and through hypo fractionated radiotherapy schedules that reduce treatment burden (Khandelwal et al., 2024). This proactive approach to symptom management, supported by the earlier integration of palliative care and supportive therapies, reflects a growing emphasis on patient-centred care and quality of life. This holistic approach, combining technological advancements with a patient-centred focus, is transforming the experience of advanced lung cancer patients receiving palliative radiotherapy, leading to improved symptom control, enhanced quality of life, and, in some cases, extended survival (King et al., 2022). It is important to look at studies that specifically address the quality-of-life improvements in advanced lung cancer patients undergoing palliative radiation.

6.2.2 The predictors associated with an increased caregivers’ burden

In this study, univariable analysis revealed a statistically significant correlation between caregivers' age and their Zarit Burden Interview (ZBI) scores, indicating that age may influence perceived caregiver burden. However, when conducting multivariable analysis, accounting for various caregiver characteristics no statistically significant associations were found between these characteristics and changes in ZBI scores. This suggests that while certain individual factors like age may appear influential in isolation, their impact may diminish when considering the broader context of multiple variables. These findings align with previous research indicating that caregiver burden is multifaceted and may not be solely predicted by demographic factors (Springate and Tremont, 2014).

Junkins et al. (2020) suggest that the significant predictors of distress in cancer caregivers include being younger, having a female gender, having pessimistic expectations, and having an extended duration of care. Various challenges are faced by older adult caregivers who take care of older adults with cancer. These caregivers often have limited resources in terms of social, financial, and palliative care. They also tend to have more serious health conditions themselves and experience poor bereavement outcomes in the long term (Adashek and Subbiah, 2020).

Interestingly, a study examining the correlation between caregiver demographics (age, gender, health status) and caregiving characteristics (relative to the patient, living arrangements, treatment status, caregiving duration) found no significant association between the caregiver's age and any of the caregiving factors. This suggests that factors like close relative to the patient and the duration of caregiving may be more influential than the caregiver's age. (Yuen and Wilson, 2021).

Moreover Hu et al. (2018) found that the age of the patient also correlates with caregiver burden. Caregiver burden is influenced by a complex interplay of factors. While some research suggests older caregivers may experience a higher burden due to potential health issues, longer caregiving hours, and limited resources, other studies find no direct link between caregiver age and burden level. Additionally, the age and needs of the patient, as highlighted by Hu et al. (2018), can significantly impact caregiver burden. Furthermore, factors like caregiver gender, expectations, and the duration of care can also contribute to distress, as noted by Junkins et al. (2020). These findings emphasise the need to consider multiple factors and individual circumstances when assessing and addressing caregiver burden.

Older adult caregivers may experience higher levels of burden compared to younger caregivers. This is because older caregivers often have their own age-related health issues that can make caregiving more challenging. Additionally, older caregivers are more likely to provide care for longer hours and with fewer resources compared to younger caregivers. Older caregivers may also have limited access to support services due to age-related factors such as mobility issues or social isolation (Adashek and Subbiah, 2020). The age of the caregiver is an important factor in predicting caregiver burden. It is important for healthcare providers to recognise the unique challenges faced by older adult caregivers and to provide them with appropriate support services to help alleviate caregiver burden. This may include respite care, counselling services, and education about managing caregiver stress.

To effectively support caregivers, healthcare providers should incorporate routine screenings for caregiver burden into patient visits, utilising tools like the Zarit Burden Interview. Fostering open communication allows caregivers to express their challenges, enabling providers to offer individualised support such as respite care, counselling services, support groups, education, and financial guidance. Caregiver-focused interventions should also be implemented, considering factors like age and potential isolation (Velloze et al., 2022). It is crucial to remember that each caregiver's experience is unique, requiring a tailored approach and early intervention to prevent burnout and promote the well-being of both the caregiver and the patient (Blampye, 2025).

1) Gender

Having a female or male gender made a significant difference to the Zarit burden interview score in this study. The gender of the caregiver was found to be a significant predictor of caregiver burden. Research studies consistently report that female caregivers experience a higher level of burden than male caregivers (Johansen et al., 2018, Lütscher et al., 2022, Stenberg et al., 2014).

They also report that female caregivers were significantly more likely to report higher levels of anxiety (Yuen and Wilson, 2021). This is because female caregivers often take on more caregiving responsibilities than male caregivers, such as providing more hands-on care, managing medications, and coordinating healthcare appointments.

Research consistently shows female caregivers experience a higher burden than male caregivers. This is likely due to a combination of factors, including societal expectations, the types of tasks they undertake, and emotional factors. Studies like the one conducted by Yuen and Wilson (2021) show that female caregivers report higher anxiety levels. This could be linked to feeling inadequately informed, as Lütscher et al. (2022) suggest, or to the overall weight of responsibilities and expectations. The fact that caregiving is predominantly done by women, even though patients are equally male and female, highlights the influence of traditional gender roles.

Lütscher et al. (2022) stated that female caregivers often feel more inadequately informed by healthcare providers than male caregivers, which is significant as caregiving is typically performed by women. In its analysis, the study confirms that caregivers are mostly female, while the patients they care for are equally male and female. This gender disparity in caregiving could be due to traditional gender roles and the higher level of participation of women in surveys. Spatuzzi et al. (2022) found that the caregiver’s burden was higher in older female caregivers than older male caregivers and is a predictor of caregiver burden.

Gender was a predictor associated with an increased symptom burden in caregivers. Researchers were unable to identify any statistically significant gender-related differences in any other study. Johansen et al. (2018) showed that both caregivers and cancer patients reported significant sleep disturbances and fatigue, with higher levels in female caregivers and cancer patients compared to males (Johansen et al., 2018). The study by Stenberg et al. (2014) found that female caregivers reported higher levels of effects of caregiving on health and finances, a greater lack of family support, and lower caregiver self-esteem than male caregivers. These differences suggest that female patients and caregivers may require more professional support.

Several factors contribute to the gender-based differences in caregiver burden. For example, traditional gender roles may lead to the assumption that caregiving is a primarily female role, which can result in male caregivers receiving less support and recognition (Swinkels et al., 2017). Several factors contribute to the unequal support and recognition often experienced by male caregivers. Traditional gender roles often portray caregiving as a primarily female responsibility, leading to lower expectations and acceptance of men in these roles. Furthermore, men may face stigma associated with seeking help or expressing vulnerability, hindering their ability to access support. Additionally, healthcare providers and support services may be less aware of the unique needs of male caregivers, potentially overlooking their struggles and assuming they require less assistance (Schwartz and McInnis-Dittrich, 2015).

Additionally, women caregivers may have more emotional attachments to the care recipient and may experience more guilt and emotional distress if they are unable to provide the level of care they would like to (Pillemer et al., 2018). Furthermore, research suggests that female caregivers are more likely to experience negative health outcomes such as depression, anxiety, and physical strain compared to male caregivers. This could be due to the increased physical demands of caregiving, as well as to the fact that female caregivers may have other caregiving and household responsibilities in addition to providing care for the patient.

It is important to note that while female caregivers may experience a higher level of burden, this does not mean that male caregivers do not experience any burden. All caregivers, regardless of gender, can experience stress, fatigue, and other negative outcomes as a result of their caregiving duties. Therefore, it is important to provide support and resources to all caregivers, regardless of gender, to help alleviate their burden and improve their overall well-being (Reinhard et al., 2008b). Nurses should recognise that female caregivers are at a greater risk of encountering issues and symptoms and may require tailored support. Several factors, including demographic, medical, and personal characteristics impact how cancer patients and caregivers adjust to the illness, and early assessment of and intervention for symptoms and problems may enhance their long-term adaptation to the disease.

2) Employment status

This univariate analysis showed that employment status was a statistically significant difference between caregivers who still worked and those who did not work and was statistically significant in the Zarit Burden Interview score at fourth visit (p = 0.035) but was not significant in the multiple regression analysis. This aspect was the same as in a study of caregivers of patients with stroke and bedridden patients; the caregivers' employment status had a small to moderate effect size regarding the predictor variable (Zhu and Jiang, 2018). In another study, caregivers' employment status was found to be a significant predictor of caregiver burden (Bekdemir and İlhan, 2019). Ryuno et al. (2021) found a significant association between total sleep time and care burden and a negative effect among employed caregivers but no positive effect. Unemployed caregivers had less of a care burden and negative effects. However, an increase in total sleep time among unemployed caregivers was associated with a decrease in negative effect the following day. The study suggests that reducing total sleep time can increase the care burden and negative effects, and that total sleep time may be influenced by employment status.

Xu et al. (2023) illustrated that the correlation between caregiver burden and overall health, happiness, and well-being was affected by whether or not the caregiver was employed. Among caregivers with a high burden, those who were working had better well-being compared to those who were not working. Employment status can affect both physical and mental health, which in turn may impact caregiver burden. A low socioeconomic status Galindo-Vazquez et al. (2015) and its correlates, such as poverty and poor health, can lead to inequities in health distribution and quality of life, ultimately affecting society (Association, 2010). Additionally, being in poor health is associated with an increased risk of job loss, while access to affordable health insurance has a positive effect on people's ability to work. Furthermore, the employment status of caregivers may affect their ability to provide care to patients with advanced lung cancer who are receiving palliative RT. For example, caregivers who are employed full time may have less time and energy to devote to caregiving responsibilities, leading to increased caregiver burden. So, there is a need for early improvement in patients' daily self-care activities. Training in caregiving skills for caregivers could also be helpful to reduce the workload (Xu et al., 2023)

The correlation between the caregiving workload and caregiver burden was positive, implying that the more caregiving tasks a caregiver performed, the greater the burden borne by the caregiver. However, the predictors concerning the characteristics of caregivers primarily consisting of caregiving burden and emotional distress were always present when providing care. This result suggests that different clinical professionals should implement specific interventions at various times. In conclusion, employment status may directly affect caregiver burden in caregivers of patients with advanced lung cancer who are receiving palliative RT by impacting their physical and mental health as well as their caregiving responsibilities. The support provided by home healthcare units to caregivers is essential for preserving their physical, mental, and social health and preventing an increased caregiver burden. The support provided by home healthcare units to caregivers is essential for preserving their physical, mental, and social health and preventing the aggravation of caregiver burden.

3) Income

The current study shows that income was found to be a statistically significant difference among the three categories of participants (0-10,000, 10,001-30,000, >30,001) and in the ZBI at all visits ($p = 0.002$, $p = 0.006$, 0.039, 0.050 respectively). We did find some studies that explored the association between caregiver burden and the income level of the caregiver. One study found that the income level of the caregiver was significantly associated with caregiver burden (Tuttle et al., 2022). Another study reported that caregivers who left their jobs to care for cancer patients experienced increased caregiver burden (Morgan et al., 2022).

Tuttle et al. (2022) describe how caregivers play an essential role in providing care for a person with a disability who is unable to perform daily activities independently. They are not compensated for providing care and are likely to have less time for sleeping, recreation, and earning an income. This experience may result in emotional tension, poor health, and diminished life quality. Most of the participants in our study live in rural areas and have an income that is lower than average. The lack of financial resources is a factor that contributes to caregiver burden. Many caregivers quit their jobs to care for a cancer patient, which is a predictor for an increased burden. Caregivers with higher household incomes have lower levels of burden (Thana et al., 2021b).

It is important to note that caregiver burden is a complex issue that can be influenced by a wide range of factors, including the patient's condition, the caregiver's personality and coping strategies, and the availability of social support and resources. Therefore, further research is needed to fully understand the association between income and caregiver burden regarding caregivers of patients with advanced lung cancer. A lower functional status of the patient was associated with increased caregiver burden. It was also found that a higher burden of care was associated with a decline in physical health compared to before caregiving began, a decrease in life satisfaction, and increased levels of depression and anxiety.

Significant predictors of caregiving burden regarding bedridden patients were caregivers' health problems, their employment status, their capacity to care for their own health, their type of residence, and the degree to which patients depended on them for daily living activities. Work, parenthood, marriage, and social roles compete with the responsibilities of caregiving. And for early, middle, or late adulthood, post-cancer care is frequently lengthy (Junkins et al., 2020). The reasons for the markedly increased burden for caregivers in France of patients receiving later lines of therapy are not immediately apparent. More patients in France were receiving only formal caregiver support, and French caregivers provided markedly fewer hours of care each week than did those in Italy (19.8 vs. 35.0 h) (Wood et al., 2019). Verbakel (2018) suggested that the organisational characteristics of healthcare systems that provide home care support services may influence the burden of caregivers. Caregivers who had a high level of education and provided care for more than 14 hours per day were at least twice as likely to experience caregiver burden. Those with depression and anxiety symptoms were three times more likely to experience caregiver burden (Zubaidi et al., 2020).

Caregivers from lower socioeconomic backgrounds often experience increased burden due to the challenges of deprivation and poverty. Limited access to resources, financial strain, and inadequate housing can significantly impact their quality of life and ability to provide care (Liu et al., 2020a). Furthermore, financial hardship can hinder access to healthcare, nutritious food, and transportation, potentially affecting both the caregiver's and the patient's health (Bouldin et al., 2018). Therefore, it is crucial to recognise these unique challenges and provide targeted support, including financial assistance, access to community resources, and respite care, to ensure equitable caregiving support for all.

Further research should delve into the complex interplay of employment status, income, and caregiver burden, examining how these factors influence each other, moderated by variables such as caregiving tasks, patient condition, and access to support (Kajiwara et al., 2024). This research should also explore the specific challenges faced by caregivers from lower socioeconomic backgrounds, identifying effective interventions to address their needs and mitigate the impact of financial strain on their well-being. Additionally, it is crucial to evaluate the effectiveness of various support services, including home healthcare units, in alleviating caregiver burden across different employment and income levels. Finally, investigating the long-term effects of caregiving on caregivers' financial stability and career trajectories is essential to understand the full impact of these responsibilities and develop strategies for sustainable support.

Further research is required to identify the factors that influence caregiver burden across healthcare systems. This research may disclose best practice insights that can inform future service enhancements. Caregivers of loved ones with advanced cancer felt a huge sense of responsibility for taking care of them as they neared the end of their life. They worked hard to make their loved ones feel better but didn't have much help from healthcare professionals. The beliefs and values of their culture influenced how they saw their role as a caregiver. In the end, caregiving helped them find personal meaning in their unique experience and helped them to grow.

6.2.3 Information needs

6.2.3.1 The predictors associated with patients having increased information needs

1) Smoking history

This thesis identified smoking history as a predictor of increased information needs in patients with advanced lung cancer with heavy smokers having a larger increase in information needs than non-smoking patients. While previous research has explored the link between smoking history and various aspects of lung cancer, such as treatment efficacy and survival outcomes, none have directly examined its association with information needs. This highlights a gap in the literature that our study addresses. Interestingly, a separate study found that patients with a smoking history experience a higher rate of pulmonary complications after thoracoscopic surgery for lung cancer. This finding underscores the potential impact of smoking history on various aspects of the disease and recovery process, further emphasising the need for tailored information and support for these patients (Yamamichi et al., 2022).

While research has explored various factors affecting outcomes in advanced lung cancer, a gap exists in understanding the association between smoking history and information needs. For instance, one study found that smoking status influenced survival outcomes in patients with advanced NSCLC undergoing SACT, with non-smokers demonstrating better outcomes (Kogure et al., 2013). This, along with other research indicating differences in treatment outcomes and risk profiles between smokers and non-smokers, suggests that these groups may have distinct information needs related to their disease and treatment options. Our study addresses this gap by identifying smoking history as a predictor of increased information needs in patients with advanced lung cancer.

Patients with lung cancer who are smokers or ex-smokers may feel guilty or embarrassed, which may influence their information-seeking behaviours. These patients might believe that they do not deserve to know more about their condition, leading to a low level of information needs (Durnin et al., 2021). Further research is needed to clarify why this patient group shows a low desire for information. Overall, while there may be a correlation between information needs and smoking history, the nature of this association is likely to be complex and influenced by a variety of factors. It is important for health professionals and researchers to continue to explore this relationship in order to better understand how to effectively communicate with individuals who smoke and help them make informed decisions about their health.

2) Area of treatment

Our study found that the association between the specific area of the body receiving RT, and the information needs of lung cancer. Patients who had radiation on their bones had a bigger reduction in their information needs than those who had radiation on their brain. There seems to be no discussion of any direct correlation between RT fields and the information needs of patients with lung cancer. However, some studies have discussed the effectiveness of managing the personal information needs of patients receiving RT and the information needs of the families who support them (Durnin et al., 2021). Other studies have explored the factors that were also found to be associated with the information needs of patients undergoing radiation treatment, such as age, gender, type of cancer, how difficult patients found it to understand information, and anxiety level (Zeguers et al., 2012).

The observed disparity in information needs reduction between advanced lung cancer patients receiving bone versus brain radiation likely stems from a combination of factors. Firstly, bone radiation's effective pain palliation may diminish the perceived need for information (Velden et al., 2018), while brain metastases associated neurological symptoms and potential cognitive impairment can increase anxiety and ongoing information seeking (Ariello et al., 2021). Furthermore, the perceived severity and disease trajectory associated with brain metastases may drive a greater need for information regarding prognosis and end-of-life care compared to localised bone pain management, compounded by the potentially more severe side effects from brain radiation (Harrison et al., 2024). Further research comparing patient-reported outcomes and information-seeking behaviours between these groups is necessary to fully elucidate these differences.

Furthermore, RT is an important modality that is used for the treatment of lung cancer, and it can be used as curative or palliative treatment across all stages of the disease. When cure is not a possibility, doctors recommend palliative treatment, which may include the use of medications, systemic anticancer therapy (SACT), radiation therapy (RT), or other measures to relieve symptoms of lung cancer without eliminating the tumour. The doctor will use smaller doses of radiation therapy to avoid side effects (RadiologyInfo, 2021).

In summary, while there seems to be no discussion of any direct correlation between RT fields and the information needs of patients with lung cancer, understanding the information needs of patients and their families is crucial for managing the disease and providing appropriate support during the treatment process.

3) Education level

In our study, education level is a predictor associated with patients having increased information needs. With those who had completed a primary-level education having a bigger increase in their need for information than those who attended university. The search results suggest that there is a correlation between educational level and the information needs of patients with lung cancer. Several studies have specifically examined how educational level is related to lung cancer patients' perceptions of the importance of having their information needs met and how well those needs were met (Chua et al., 2018, Hsieh et al., 2018, Jacobs-Lawson et al., 2009, Matsuyama et al., 2011). One study found that a higher educational level was associated with higher levels of satisfaction with how information needs regarding treatment and decision-making were dealt with (Hsieh et al., 2018). Tan et al. (2015) found that significant covariates of information-seeking included being younger at diagnosis, having a higher education level, and being at an earlier cancer stage at diagnosis.

However, Palmer et al. (2020) indicated that patients with a bachelor's degree reported fewer information needs and needs in significantly fewer domain categories compared to patients without a college degree. Patients without a college degree were more likely to report at least one need regarding tests and treatment, health promotion, and emotional domains than individuals with a degree. They were also more likely to report needs related to fatigue after cancer, nutrition, managing fears about recurrence, and getting or keeping insurance after cancer. The study also highlighted that nearly two-thirds of the sample had less than a bachelor's degree level of education, which is associated with limited health literacy. The study suggested that there is a need to examine factors related to education and literacy, such as information-finding skills, self-efficacy, environmental resources, and understanding, and to use appropriate language in educational materials aimed at rural cancer survivors who may have a lower level of education and health literacy (Palmer et al., 2020).

Overall, understanding the information needs of lung cancer patients is critical for developing interventions to assist them with treatment-related decisions (Chua et al., 2018). Additionally, documentation of education level on intake assessment forms may be useful for understanding the attributes that higher education confers and the relevance of those attributes to cancer care information needs (Matsuyama et al., 2011).

4) *RT dose*

This study reveals that the RT dose was a predictor associated with patients having increased information needs. With patients who had a bigger dose than 30Gy/10F having a larger increase in their information needs. After conducting a search, there were a few relevant results, but none that specifically addressed the correlation between RT dose and the information needs of patients with advanced lung cancer. In terms of RT dose, the Cochrane collaboration found that there was no clear evidence that any regimen provides better palliation than others, and higher dose regimens can lead to acute toxicity and an increased risk of radiation myelitis (Stevens et al., 2015). The study suggested that care should be taken with the dose applied to the spinal cord to prevent radiation myelopathy and that higher-dose, more fractionated palliative RT regimens do not provide better or more durable palliation; in addition, there is no strong evidence to support their use for prolonging survival.

The recommendations for RT treatment dosages and fractionation regimens based on performance status for patients with poorer performance status (performance status 2 to 4) recommend that there is no survival advantage to using more fractionated regimens. Current American Society for Radiation Oncology (ASTRO) (https://www.astro.org/provider-resources/guidelines/clinical-practice-guidelines) and Royal College of Radiologists (RCR) (https://www.rcr.ac.uk/) guidelines recommend using systemic anticancer therapy combined with palliative thoracic external beam RT for the treatment of non-small cell lung cancer (NSCLC). The task force recommends administering a platinum-containing systemic anticancer therapy doublet concurrently with moderately hypo fractionated palliative thoracic radiation therapy for patients with stage III NSCLC who are not suitable for curative therapy but meet certain criteria: 1) they are candidates for systemic anticancer therapy , 2) they have an Eastern Cooperative Oncology Group PS of 0 to 2, and 3) they have a life expectancy of at least 3 months. For patients with stage IV NSCLC, the routine use of concurrent thoracic chemoradiation is not recommended (Moeller et al., 2018, Radiologists, 2019).

Another study evaluated the information needs of RT patients and their families and found that emotional and information needs were the most important ones during the pre-diagnosis stage, although this study did not specifically focus on advanced lung cancer (Durnin et al., 2021). One study found that patients with lung cancer, particularly older males, were less likely to require as much information as patients with other malignancies. Another study found that most new RT patients desire a lot of information about their disease, treatment, and prognosis, but less information about psychosocial issues. Palmer et al. (2020) study looked at the health information needs of breast, prostate, and colorectal cancer survivors who lived in rural areas two to five years post-diagnosis. The study found that survivors reported an average of four information needs, with the most common needs being related to side effects and symptoms, health promotion, and tests and treatment. There were some differences in information needs depending on the type of cancer people had, with prostate cancer survivors more concerned with sexual problems and colorectal cancer survivors more concerned with the risk of cancer in their families.

Kim et al. (2021) found that male cancer patients had higher demands for sexual information compared to female cancer patients. Men expressed a greater need for sexual information and professional intervention in this regard. Among men, income was a significant factor influencing their sexual information needs. For women, age, alcohol consumption, and systemic anticancer therapy were significant factors. The study revealed significant differences in overall sexual information needs and related factors between male and female cancer patients. This suggests that it is important to develop a strategy that considers gender differences to enhance the sexual health of cancer patients. However, research in this area is limited, and more comprehensive studies are needed to explore the range of problems and needs affected by gender.

This study identified smoking history, age, and area of RT as predictors of increased information needs in patients with advanced lung cancer. While previous research has explored the impact of smoking history and age on various aspects of lung cancer, this study is the first to directly link these factors to information needs in this patient population. Notably, the area of treatment also emerged as a significant predictor, suggesting that patients receiving treatment in certain areas may have greater information needs. These findings highlight the importance of considering individual patient characteristics, including smoking history, age, and treatment location, when assessing and addressing information needs in advanced lung cancer care.

It is important to note that the decision to provide patients with information should be based on individual preferences and needs rather than on generalisations based on demographic factors or a diagnosis. Healthcare providers should work with patients to understand their information needs and provide them with the appropriate resources for making informed decisions about their care. While there is some evidence to suggest that these predictors may play a role in the information needs of patients with advanced lung cancer, more research is needed in this area. It is important for healthcare providers to tailor information to individual patients' needs, regardless of age or disease stage, to ensure that they are fully informed and involved in their own care.

6.2.3.2 The predictors associated with caregivers having increased information needs

1) ***Gender***

Gender was a predictor associated with information needs, with male caregivers having a bigger reduction in supportive care needs on the information need subscale than female caregivers. Few studies determine the information needs of caregivers. However, an investigation into Thai caregivers of patients with cholangiocarcinoma found that the total scores for supportive care needs were found to be correlated with gender. This correlation may be explained by patients reporting more unmet needs when their caregivers were male, which may result in different ways of coping with and responding to symptoms and different help-seeking behaviour (Sangruangake et al., 2022).

Carmel, Singer, Yosef-Sela, and Bachner (2020)'s study highlights the significant role of gender in determining the level of open communication between spousal caregivers and terminally ill cancer patients regarding the latter's illness and approaching death. It suggests that factors such as self-efficacy, ethnic origin, and duration of care also contribute to the level of open communication among both male and female caregivers. The study emphasises the importance of considering these factors when healthcare professionals, including nurses, develop intervention programmes aimed at increasing open communication between caregivers and their terminally ill loved ones.

Xiong et al. (2020) conducted a survey about technology-related needs and preferences with caregivers of persons with dementia. Most respondents had limited knowledge and experience of caregiving-related technologies. Important factors for purchasing and setting up technology were ease of installation, learning, and cost. Reliability was crucial for using technology. Female respondents were more knowledgeable about technology, while male respondents were willing to pay higher amounts for it. The study suggests considering sex- and gender-related factors, such as cost and reliability, in technology design and promotion for caregivers. Further research is needed to understand the interaction between sex, gender, and other factors.

Gender has a significant impact on caregivers' distress levels. Women are more likely to act as primary caregivers than men. In the sample analysed, there were significantly more female caregivers accessing the information and support line compared to male caregivers. This suggests that male caregivers may be less likely to seek dedicated support services. One possible explanation for this is that male caregivers may experience lower levels of distress than female caregivers, leading to a reduced likelihood of seeking support. Another explanation could be that male caregivers adhere to societal expectations of appearing strong in the face of adversity, leading them to underreport their distress or avoid seeking support. A lack of support or a failure to seek support can contribute to increased caregiver burden and distress. Therefore, healthcare professionals should screen for distress and provide appropriate interventions to address the unique needs of male caregivers (Kirk et al., 2021 2021).

A systematic review of the needs of caregivers of dementia patients outlines that the needs of caregivers are influenced by various factors beyond the diagnosis of the individuals they care for. Caregiving needs are shaped by the personal attributes of caregivers and the resources at their disposal. Social attributes such as age, gender, socioeconomic status, and support networks also impact the needs of caregivers. Additionally, the psychological resilience and agency of caregivers play significant roles in determining their needs and prioritising their needs. Caregivers' needs result from the complex interactions of multiple caregiving activities. The more tasks that caregivers juggle simultaneously, the higher their stress levels, which affects the needs they identify at any given moment. The coping methods developed by caregivers during their lives can influence their sense of burden when managing caregiving.

Furthermore, external factors such as healthcare, accessible housing, and available funding for caregivers and those they care for can moderate the burden experienced and influence the type of assistance required (Atoyebi et al., 2022).

Ketcher et al. (2020) state that most caregivers are women. Female caregivers reported significantly higher levels of perceived stress, depression, anxiety, and social strain compared to male caregivers. Additionally, female patients with male caregivers were more inclined to use social support as a coping mechanism compared to male patients with female caregivers. Overall, these studies suggest that there is a correlation between gender and caregivers' information needs. Thus, it was difficult to draw a conclusion about the role of gender. However, further research is needed to gain a more comprehensive understanding of this correlation and its implications for providing appropriate support to caregivers.

2) The relationship between the patient and the caregiver

The relationship between the patient and the caregiver was a predictor associated with the spouse/partner having a bigger increase in supportive care needs on the information needs subscale than other relationships in our study. The spouse often takes on the role of caregiver for the partner diagnosed with advanced lung cancer, leading to stressors related to prognosis, symptom management, role changes, and the possibility of losing their partner. Spousal caregivers experience higher psychological pressure than non-spousal caregivers. The caregiving responsibilities disrupt family organisation, roles, and activities, requiring the spouse to accompany the patient during treatments and to manage household tasks. They may feel incapable of fulfilling the caregiving role and may receive limited support. The needs and health problems of spouse caregivers may be overlooked by healthcare professionals, despite their significant impact on both caregiver well-being and patient adjustment. Researchers aim to gain a deeper understanding of the experiences of caring for a spouse with advanced lung cancer during hospital treatment (Ketcher et al., 2020).

The systematic review of the literature on the information needs of partners and family members of cancer patients by Adams et al. (2009) revealed that the participants often had an unmet need for information related to supportive care rather than to medical information and were significantly more likely to identify information needs around intimacy and sexuality. However, the concept of "information need" in this context is not well-developed or theorised in the existing papers. The conclusion emphasises the importance of conducting research to establish the information needs of the partners and family members of cancer patients. It suggests that more empirical research with strong conceptual and theoretical foundations is needed to enhance our understanding in this neglected area of study (Adams et al., 2009).

The study by Ullrich et al. (2019) found that in the context of caregiving, spouses or partners of male patients are more frequently expected to provide home-based care. On the other hand, female patients tend to be attributed with higher concerns about burdening others. In terms of information, formal healthcare systems are a key source of information for patients and caregivers. However, there is a lack of clarity among service providers regarding the type, amount, timing, and purpose of information specifically tailored for caregivers. The correlation between informal caregivers and information needs is an important but under-studied area, and more research is needed to understand the specific information needs of informal caregivers and how to effectively address them. In summary, while there is limited research on the correlation between informal caregivers and information needs, caregivers play a crucial role in caregiving, and their information needs should be acknowledged and addressed to improve their caregiving experience. Further empirical research and a better understanding of the needs of informal caregivers are essential to develop effective strategies and support systems for this vital caregiving population.

Other predictors found in the literature were that younger caregivers (aged 18–45 years) were significantly associated with moderate to high unmet needs regarding health-related information and support for the care recipient, health service management, and accessibility to support services. There were no significant differences in unmet needs between countries or the conditions of the care recipient, suggesting that general interventions could benefit caregivers across countries. Increased awareness of the unmet needs of caregivers, especially younger caregivers, among healthcare providers may lead to improved support for them (Denham et al., 2020). A systematic review identified similar patient characteristics associated with a greater need for information, including having a female gender, being younger, having a low income, having an advanced disease, and living in a rural/remote location (Harrison et al., 2009).

Another study, about Thai cholangiocarcinoma caregivers, illustrated that supportive care needs for caregivers were significantly correlated with physical symptoms, anxiety, depression, and education level (Sangruangake et al., 2022). Chen et al. (2016) showed that caregivers with a multitude of physical issues likely had a number of unmet needs and that these definitely increased when patients suffered from anxiety, depression, or low performance status. García-Torres et al. (2020) found that some domains of social support, specifically levels of support-seeking and a lack of informational support, predicted anxiety in caregivers within the first 6 months of diagnosis. Lütscher et al. (2022) found that when caregivers discussed their concerns with doctors, they expressed a need for support with building confidence in their ability to care for the patient. They also expressed a need for information about supportive programmes for caregivers and about how to coordinate medical services sufficiently. Few caregivers, however, felt the need for support regarding participating in treatment decisions or the medical care of the patient.

Significant associations were found between demographic information (age, gender, disease stage, current treatment, education, employment status, and having children) and information needs over time. Regardless of disease stage, the need for disease-related information remained significant. To cover knowledge disparities between patients and healthcare providers, oncology nurses can use the findings of this study to better meet the informational needs of patients.

Johansen et al. (2018) showed that self-efficacy regarding coping with cancer-related stress was high in cancer patients, with the highest scores for seeking and understanding medical information. Caregivers' depression, fatigue, and symptoms were significant predictors of caregiver burden, but sleep disturbance, energy, self-efficacy, and social support were not. The study used reliable instruments, and multivariate analyses were adjusted for age and gender to investigate the associations between variables and caregiver burden (Morgan et al., 2022).

Zhu et al. (2022) revealed five synthesised findings. Caregivers take on the primary responsibility for care while balancing multiple roles and face enormous pressure during the care process, and social support is the primary way to facilitate them to respond positively to challenges. Shifting to a patient-centred life takes up most caregivers' energy and time, leaving them physically and mentally exhausted. Many caregivers express shock, are unprepared for the inevitable death, and are unsure of the meaning of death. Caregiving provides an opportunity for self-growth as caregivers change their perspective, discover their inner strength, and find the meaning of life.

Caregivers show a strong sense of responsibility for care and try hard to alleviate their loved one's suffering but often lack professional support. Cultural beliefs play a significant role in caregivers' responsibilities and recognition of their role. Ultimately, caregiving can help caregivers achieve personal transcendence, but it is a challenging and culture-specific experience. Effective professional support, such as early palliative care, should be provided to improve caregivers' experience, and cultural beliefs should be taken into account to understand what support is needed and to develop appropriate support (Zhu et al., 2022). Therefore, we recommend that the specific needs of caregivers are addressed openly at the beginning of any palliative treatment.

6.3 Study strengths and limitations

The strengths of this study are the repeated measurement of burden and information needs that allows the researcher to see patterns of change. This longitudinal study has relied on validated measures to increase the accuracy of the measurements. No one refused to participate and there was a low attrition rate and a low rate of missing data. This was an observational, correlational, repeated measures design, so sample size was calculated on the basis of the change in symptom burden.

The three centres from which data were collected were typical healthcare facilities in Thailand that might accurately reflect how advanced lung cancer is managed with RT. They might also offer a representative perspective on symptom burden in patients with advanced lung cancer during palliative RT at the same stages of disease and with the same performance status and tumour progression, as well as patients on medication and radiation schedules who completed the same questionnaires. The longitudinal studies cover a wide range of topics related to symptom management, caregiver burden, and information needs in relation to advanced lung cancer, providing a comprehensive exploration and understanding of these aspects.

This study is the first study of its kind in Thailand, which makes the information presented even more interesting. The studies consider various predictors and factors that contribute to symptom burden, caregiver burden, and information needs, providing a more nuanced understanding of these phenomena. In addition, the studies highlight interventions such as psychoeducation, respite care, support groups, and palliative care that have been shown to reduce caregiver burden and meet information needs, offering practical recommendations for healthcare providers.

This study is the first to examine the association between information needs and smoking history in Thai lung cancer patients. While previous research has explored caregiver burden in Western contexts, this study provides a unique perspective on the experiences of Thai caregivers. Although several studies have investigated information needs in cancer patients, none have specifically focused on the role of smoking history in shaping these needs (Lee et al., 2025, Lekdamrongkul et al., 2022). Existing research on caregiver burden has primarily focused on individual factors. This study expands on this by considering the influence of Thai cultural values on caregiving experiences.

Thai culture emphasises collectivism and interdependence, which may explain why family members play a central role in caregiving and decision-making (Manasatchakun et al., 2018). The cultural value of respecting elders may influence how patients communicate their information needs to healthcare providers. Buddhist beliefs about karma and acceptance of suffering could contribute to the lower levels of burden reported by Thai caregivers (Sethabouppha and Kane, 2005). The low levels of caregiver burden observed in this study may be related to the Thai cultural emphasis on filial piety and the expectation that children will care for their aging parents (Manasatchakun et al., 2018). The finding that spouses have greater information needs than other family members could be linked to the cultural importance of the marital relationship in Thai society (Badr et al., 2008, Manasatchakun et al., 2018, Netchang, 2012). The reduction in psychological symptoms among single patients may be because they receive more social support from their extended family and community, reflecting the collectivist nature of Thai culture (Suwankhong and Liamputtong, 2016).

This study has several limitations. Firstly, it did not collect data on family income or ethnicity, which are known to influence health outcomes and potentially information needs (Morgan et al., 2022). Secondly, while the study identified caregiving duration as a significant predictor of caregiver burden, it did not collect detailed data on the time aspects of caregiving. Thirdly, the study's specific settings and regions may limit the generalisability of findings. Fourthly, reliance on self-reported measures introduces potential biases like recall bias and social desirability bias.

Future research could benefit from a dyadic approach, examining patient-caregiver pairs to better understand their interconnected needs (Badr and Krebs, 2013). Additionally, employing more specific questions during data collection could provide richer insights. For example, instead of simply asking about ‘pain’, researchers could inquire about the specific aspects of pain that patients want to understand better. Follow-up assessments could also determine if previously identified needs have been met.

While questionnaires offer valuable insights into information needs, it is crucial to acknowledge that patients and caregivers may not be fully aware of all their needs, especially amidst the initial shock and unfamiliarity of a lung cancer diagnosis. Their needs evolve throughout the cancer journey, influenced by disease progression, treatment changes, and individual factors (Webb et al., 2021). Healthcare professionals play a vital role in proactively assessing and addressing these evolving needs through ongoing communication, tailored education, and anticipation of future challenges.

Support groups and patient education materials can further empower patients and caregivers to identify unmet needs and access relevant information. While striving for comprehensiveness, questionnaires may not capture all potential needs, highlighting the importance of continuous assessment and support in facilitating informed decision-making and enhancing the overall care experience (Papadakos et al., 2022).

6.4 Summary

The key findings and implications shift the landscape of palliative radiotherapy. Palliative radiotherapy is not just about end-of-life care. It is increasingly integrated with systemic therapies, extending survival and necessitating a more active approach to symptom management throughout the cancer journey. Technological advancements like SABR and IMRT, coupled with a patient-centred focus on quality of life, are transforming the patient experience, leading to improved symptom control, reduced treatment burden and enhanced well-being.

Symptom experiences and its predictors, fatigue, pain, cough, weight loss, and changes in self-perception are prevalent symptoms among patients receiving palliative radiotherapy. Smoking history, gender, marital status, and type of radiotherapy are significant predictors of symptom burden, highlighting the need for tailored interventions and support based on individual patient characteristics.

Caregiver burden is generally lower in Thailand compared to Western countries, likely due to cultural factors and social support networks. However, challenges remain, including limited post-discharge support and the vulnerability of specific caregiver groups, such as spouses and those from lower socioeconomic backgrounds (Phetsitong et al., 2019).

Patients and caregivers have significant information needs related to symptom self-management, complementary and alternative therapy, and coping strategies. These needs evolve throughout the cancer journey, influenced by factors like smoking history, age, treatment location, and education level. Healthcare providers must proactively assess and address these needs, providing tailored information and support to facilitate informed decision-making and empower patients and caregivers.

Healthcare providers should adopt a holistic approach to care, integrating palliative radiotherapy with systemic therapies and supportive care to optimise symptom management and quality of life. Culturally sensitive interventions are crucial, particularly for addressing caregiver burden and information needs within the Thai context. Future research should focus on developing and evaluating tailored interventions, exploring the complex interplay of patient and caregiver factors, and addressing disparities in access to care and support services.

This chapter has explored the principal findings and key messages from the study in the context of the previous literature. The predictors of each variable have also been identified. The result is a picture of the current state of healthcare providers’ provision of help for this population in the form of symptom management and supportive care. The following chapter summarises the contributions made by this research The strengths and weaknesses of the study have also been explored, enabling conclusions and recommendations for practice, education, and research to be drawn

Chapter 7 Conclusions and Recommendations

7.1 Conclusions

The study focused on three main aspects: the prevalence of symptoms in patients with advanced lung cancers who are undergoing radiotherapy (RT), the burden experienced by caregivers, and the dyad of information needs. Fatigue emerged as the most frequently reported symptom, and it significantly impacted patients' physical functioning and daily activities. Pain, affecting various body areas, and coughing, indicative of advanced lung cancer, were prevalent symptoms. Weight loss, changes in physical appearance, psychological distress, and mood disorders also featured prominently. Palliative RT was found to alleviate symptom burden, emphasising the importance of ongoing symptom management and supportive care. Meanwhile, caregiver burden, predominantly found among female and married caregivers, correlated with factors such as age, employment status, and income. While burden levels decreased over time, certain interventions like psychoeducation and palliative care were effective in reducing caregiver burden.

The information needs of caregivers, particularly regarding complementary and alternative therapies, were explored. Healthcare providers, preferred and trusted sources of information, should be aware of caregivers' preference for verbal communication and their evolving information needs throughout the treatment process. Predictors of symptom burden in patients included a smoking history, gender, marital status, and RT type. Age, gender, employment status, and income were identified as factors contributing to caregiver burden. For patients and caregivers, predictors of increased information needs included a smoking history, age, area of treatment, education level, and RT dose. It is crucial for healthcare providers to recognise individual preferences and needs when addressing information gaps, necessitating tailored resources and support. Further research is needed to deepen our understanding of these predictors and to inform the development of effective interventions and strategies.

7.2Recommendations for practice, research, and education

The findings of the study have many implications for the practice of palliative nursing. Nurses play a pivotal role in prioritising the assessment and management of the symptoms of patients with lung cancer. Responsibilities include conducting a comprehensive assessment to identify the full spectrum of symptoms experienced and to note their prevalence, frequency and severity and the distress they cause patients. This includes evaluating fatigue, pain, coughing, weight loss, and changes in physical appearance and psychological symptoms. Symptom management, which means nurses implementing and monitoring interventions, ensures that patients receive timely and effective relief.

This may involve medication administration, breathing exercises, and other therapeutic techniques. Nurses educate patients and caregivers about symptom management strategies, treatment plans, and what to expect during the course of the disease and treatment. This empowers patients to take an active role in their own care. Nurses coordinate with other healthcare professionals, such as oncologists, palliative care specialists, and social workers, to provide comprehensive and cohesive care that is tailored to each patient's needs.

Nurses provide crucial emotional support, helping patients and caregivers cope with the stress and anxiety associated with a diagnosis and treatment. Nurses advocate for patients, ensuring they have access to necessary resources and support systems and that their concerns and preferences are heard and addressed by the healthcare team.

7.2.1 Recommendations for nursing practice

Nurses' efforts should include the provision of appropriate interventions and therapies aimed at alleviating symptoms and enhancing patients' quality of life. Studies have demonstrated the effectiveness of palliative RT in reducing symptom burden and improving overall well-being in patients with lung cancer. Therefore, nurses should incorporate palliative RT into their care plans as a valuable intervention for symptom management. By actively addressing and managing these symptoms, nurses can significantly contribute to improving the well-being and overall quality of life for patients with lung cancer.

These findings demonstrate the importance of implementing patient-centred symptom assessment and the development of associated interventions for screening-positive patients, as indicated in the guideline Palliative Care and in international guidelines and programmes (Yang-Huang et al., 2022). It is important to consider the preferences of caregivers regarding the types of support they receive and the optimal time to provide such support to improve its efficiency. Caregivers often prioritise the patient's needs over their own and tend to remain silent about their own needs. Therefore, healthcare providers should encourage caregivers to express their needs and take care of themselves (Zhu et al., 2022). Early interventions that take into consideration caregivers' preferences for hospice care, such as the timing, content, location, and manner of care, can help improve their preparedness and decision-making regarding such care.

Regarding support for caregivers, nurses should recognise the significant role that caregivers play in the care of patients with advanced lung cancer and address their specific needs. This includes providing psychoeducation, respite care, support groups, and palliative care interventions to reduce caregiver burden. Nurses should also assess factors such as age, gender, employment status, income, and marital status to identify caregivers at higher risk of burden and provide targeted support accordingly. They should be part of the wider multidisciplinary team, where symptoms are triaged and assessed, and then collaborative work is done, or specialist referrals are made to address and monitor the situation.

Normally after patients with advanced lung cancer finish RT in Thailand, they will start another treatment, and some might be on concurrent treatments. A follow-up 1 month after this treatment is standard care for almost all patients. One communication that they receive is a recommendation to go back to the hospital. The healthcare team has no choice but to leave patients and caregivers to deal with the residual side effects of RT or other symptoms. Nurse-led clinics where patients are followed up are urgently needed to monitor and manage this issue.

In light of these results, the Thai healthcare system should aim to provide seamless patient care regarding symptom management after cancer treatment. Home-based care is offered in Thailand, but the system is poor at forwarding information regarding continuing care to enhance support for these patients and caregivers at home. The Thai healthcare system should also seek to improve the psychological treatment available and make skills training accessible to caregivers. Such a strategy might reduce caregiver stress and perceived obligations while also improving patient and family outcomes. Our findings suggest that spousal and caregivers may need additional support to effectively manage the responsibilities of their caregiving role. The findings indicate that caregivers, especially spouses, may need assistance with transitioning once their care recipient's treatment has ended.

Healthcare providers, including nurses, should be the preferred and trusted source of information for patients and caregivers. They should be knowledgeable about complementary and alternative therapies and provide evidence-based information about their safety, efficacy, and availability. Verbal communication should be prioritised to address individual needs, and information should cover self-management strategies and actions that patients and caregivers can take to improve well-being. Information needs may decrease over time, but healthcare providers should remain attentive to patients' and caregivers' information needs, particularly during the initial stages of treatment.

In view of the predictors of symptom burden and information needs, nurses should consider certain predictors associated with lung cancer patients' increased symptom burden and increased information needs. Factors such as a smoking history, gender, marital status, and RT type can influence symptom burden, while a smoking history, age, education level, and a caregiver's gender can affect information needs. By recognising these predictors, nurses can tailor their assessments, interventions, and communication strategies to address the specific needs of patients and caregivers.

The nurse provides individualised care by conducting a thorough assessment of the patient's physical and psychological symptoms, taking into account their smoking history and potential RT side effects (Atia Elasrag et al., 2025). The nurse tailors' education to the patient's specific needs, focusing on managing respiratory issues and offering smoking cessation resources (Rice et al., 2017). Recognising the importance of their marital status, the nurse involves the spouse in care discussions, assesses well-being, and provides support resources (Reinhard et al., 2008a). The nurse fosters open communication, creating a safe space for the patient and their spouse to express concerns and ask questions (Lowey, 2008). The nurse collaborates with other healthcare professionals to ensure comprehensive care and refers them to additional support services if needed.

It is essential for nurses to provide individualised care based on the preferences and needs of patients and caregivers. While certain predictors may indicate higher levels of burden or information needs, it is crucial to avoid generalisations and instead to work closely with individuals to understand their unique situations and provide tailored resources, support, and interventions. It is crucial for healthcare providers to recognise and address these factors when assessing and supporting caregivers. Providing appropriate support services, such as respite care, counselling, and education, can help alleviate caregiver burden and improve overall well-being. Additionally, understanding the cultural beliefs and values of caregivers can aid in tailoring support to their unique experiences and promoting personal meaning and growth. Further research is needed to explore the complex dynamics of caregiver burden and to identify strategies to enhance support for caregivers in the context of advanced lung cancer (Fumaneeshoat and Ingviya, 2020, Morgan et al., 2022, Wood et al., 2019).

For my perspective, Nurses play a crucial role in supporting lung cancer patients receiving palliative RT, but it's important to accurately represent their involvement. Instead of directly incorporating RT into care plans, which is the responsibility of the radiation oncology team, nurses should advocate for its consideration when appropriate. They should educate patients and caregivers about the potential benefits, risks, and side effects of palliative RT, offering support throughout the process. This includes coordinating care with the radiation oncology team to ensure seamless transitions and addressing any concerns (Tan and Ramchandran, 2020). By accurately reflecting this collaborative approach, we emphasise the nurse's vital role in comprehensive patient care and interprofessional teamwork.

7.2.2 Recommendations for nursing research

The symptom management intervention research regarding the top five most prevalent symptoms and their frequency, severity, and the distress they cause has been cited, but there is little implementation of them in the real world (Kochamat et al., 2024). The gap between research findings and real-world implementation of symptom management interventions in Thailand may be attributed to various factors. Limited resources in some healthcare settings can hinder the implementation of complex interventions, while a lack of awareness among healthcare professionals regarding the latest research and effective interventions can also contribute to this gap (Dokmai et al., 2021). Furthermore, cultural beliefs and practices may influence symptom management preferences and healthcare-seeking behaviours (Wangnamthip et al., 2021). Systemic barriers, such as referral pathways and access to specialised services within the healthcare system, can further pose challenges to implementing research-based interventions.

There are guidelines and recommendations for practice regarding symptoms, but more non-pharmacological symptom management strategies are needed, such as in relation to cough, numbness/tingling in hands/feet, and dizziness, which have fewer mentions in the Oncology Nursing Society (ONS)(Ginex et al., 2020, Gosselin et al., 2020, Ding et al., 2020, Oh and Kim, 2016), NCCN (NCCN, 2024) and ESMO guideline (Adashek and Subbiah, 2020, He et al., 2022, Roila et al., 2016). Future research must include longer-term follow-up to ensure the sustainability and effectiveness of these interventions. Primarily, long-term research is needed to allow nurses to understand how symptoms change after RT and what issues are persistent. This will help gain a better understanding of the required duration and intensity of interventions to manage those symptoms. If an intervention is given and stops too early, symptoms may relapse and the patient may not benefit much, which can have an impact on quality of life.

Long-term studies can provide valuable insights into the chronicity of symptoms, the long-term impact of early symptom management, and the overall survivorship experience (Firkins et al., 2020). Factors like median survival time should guide the establishment of a realistic follow-up period (Das et al., 2023). Additionally, researchers should consider the trajectory of symptoms, including the potential for late effects, and prioritise capturing the long-term impacts on patients' quality of life across physical, psychological, and social domains (Firkins et al., 2020). Despite the challenges posed by disease progression, long-term studies in this population are essential for understanding evolving symptom management needs and the sustained effectiveness of interventions (Stein et al., 2008).

This research can inform best practices and guidelines for ongoing care, helping to improve long-term outcomes and the quality of life of patients undergoing RT. Nurses can actively advocate for research by drawing on their clinical experience to identify key research priorities that can improve patient care. They can collaborate with researchers to design and conduct studies, ensuring that research addresses relevant clinical questions. Nurses also play a crucial role in disseminating research findings to colleagues, patients, and policymakers, promoting evidence-based practice. Furthermore, they can actively participate in research studies by recruiting patients, collecting data, and providing valuable feedback on study protocols, contributing to the advancement of knowledge and improvement of patient outcomes (Ballintine and Potter, 2023).

Nurses have a pivotal role to play in advocating for further research in the domains of symptom management, caregiver support, and information provision for patients with advanced lung cancer. Research on what exactly patients and caregivers need for self-symptom management at home needs to be done.

Continued research endeavours are crucial to identify additional effective interventions, understand the underlying reasons for observed trends, and develop targeted strategies to alleviate burden and improve outcomes. There is a need for additional research into appropriate cut-off points in performance status to distinguish patients able to respond to a survey independently from those requiring assistance. Symptom clusters, that is, many symptoms that are related to each other, could be considered in relation to this patient population.

There is a need to know more about what information patients or caregivers need to help deal with symptoms at home and further qualitative research is needed in this respect. Additional research is also required to determine how these information needs can be met more effectively. It has been noted that information needs were highest at the first appointment, and there is a need for additional research into methods that could be used to meet patients' informational needs prior to their planning appointment. A patient education session provided by health personnel who are involved in planning appointments may facilitate the opportunity to meet patients' informational and emotional needs, thereby reducing their anxiety.

Cultural beliefs and values influence the perception and experience of caregivers who are caring for patients with advanced lung cancer (Chan et al., 2012, Xiao et al., 2024). Specifically, Asian culture places a strong emphasis on family cohesiveness, filial piety, and Confucian values, which influence caregivers' sense of having an obligation and a responsibility to care for their loved ones. This cultural influence may act as a protective factor against caregiver burden and improve psychological outcomes (Xiao et al., 2024, Chan et al., 2012). Future research should explore the impact of cultural background on caregivers' perception of their role and on patients' well-being. Lastly, it will be essential to determine the extent to which personnel who administer treatment accept the implementation and utilisation of screening.

A key implication of this study for future research in the area of caregiving is the need to address the gap in knowledge regarding the experiences, attitudes, and needs of male caregivers. Research focused on male caregivers is crucial because they are often underrepresented in studies, leading to a limited understanding of their unique experiences and needs (Mazanec et al., 2018). Caregiving experiences can differ significantly based on gender due to societal expectations, coping styles, and access to support (Sharma et al., 2016). By understanding the specific challenges and needs of male caregivers, healthcare providers can develop tailored interventions to better address their needs and improve their overall well-being.

This research would contribute to a better understanding of caregivers as a whole and would provide insights into the unique experiences of male caregivers caring for someone with advanced lung cancer. To enhance the validity of the findings, future research should consider employing longitudinal designs, conducting studies with diverse populations, utilising objective measures, and addressing potential biases. Further investigation is needed to establish direct correlations between predictors and outcomes that may currently lack direct evidence. The effectiveness of non-pharmacological treatments and psychological interventions for symptoms like fatigue and cough requires further investigation (Gleeson, 2022).

For my perspective, specific future research utilising a longitudinal design with multiple follow-up assessments is needed to understand how symptoms change after RT and which issues persist. A qualitative study employing in-depth interviews with patients and caregivers could provide valuable insights into their experiences with self-managing symptoms at home. To determine the effectiveness of non-pharmacological treatments for fatigue and coughing, a randomised controlled trial comparing different interventions would be beneficial.

Future research should utilise validated measures such as the Functional Assessment of Cancer Therapy - Lung (FACT-L) to assess quality of life and the Edmonton Symptom Assessment System (ESAS) to track symptom burden over time. Given the advanced stage of disease, future studies should consider utilising shorter follow-up intervals and flexible data collection methods to minimise participant burden.

7.2.3 Recommendations for nursing education

Nursing education should focus on providing knowledge and skills related to effective symptom management for lung cancer patients. This should include understanding the impact of symptoms such as fatigue, pain, coughing, weight loss, and changes in physical appearance. Nurses should be trained in assessing and addressing these symptoms through appropriate interventions, including the use of palliative RT when appropriate.

Regarding caregiver support and education, nursing education should emphasise the importance of supporting caregivers of lung cancer patients. This should involve providing education regarding caregiver burden and its associated factors such as age, gender, employment status, and income. Nurses should be equipped with strategies for assessing and addressing caregiver burden, including via the implementation of interventions like psychoeducation, respite care, support groups, and palliative care. Education should also focus on communication skills so that nurses can effectively provide information and support to caregivers.

Nursing education concerning patient and caregiver information provision should train nurses in effective communication and information provision so that they can meet the information needs of patients and caregivers. Nurses should be knowledgeable about complementary and alternative therapy, self-management strategies, and actions that can improve the well-being of patients. They should also be aware of the preferred sources of information, such as healthcare providers and the internet, and understand the importance of verbal communication for addressing individual needs. Additionally, nurses should be able to adapt their information provision strategies as patients progress through the treatment process, recognising that information needs may decrease over time.

In view of predictors and individual needs, nurses should be educated about the predictors of increased symptom burden, caregiver burden, and the information needs of lung cancer patients. This includes factors such as a smoking history, gender, marital status, age, education level, area of treatment, and RT dose. By considering these predictors, nurses can tailor their care and interventions to individual patients, ensuring a patient-centred approach that addresses their specific needs and preferences.

Influencing nursing education in Thailand requires a multifaceted approach encompassing curriculum development, advocating for the integration of research findings into nursing programs at universities and training institutions with an emphasis on symptom management, caregiver support, and effective communication (Buachu et al., 2023). Faculty development through workshops and training sessions is crucial to disseminate knowledge and equip educators with the skills to effectively teach these concepts. Collaboration with professional organisations, including nursing associations and regulatory bodies, is essential to promote the integration of research-based recommendations into professional development programs and continuing education initiatives (Bandansin et al., 2022).

For my perspective, policy advocacy targeting policymakers and healthcare leaders is necessary to raise awareness and advocate for policies that support the implementation of these educational priorities. Finally, mentorship and role modelling by nurse researchers can inspire and guide nursing students and novice nurses, demonstrating the importance of evidence-based practice and patient-centred care in improving outcomes for lung cancer patients and their families.

Nursing educators should emphasise the importance of ongoing professional development to keep nurses updated on the latest research and evidence-based practices in lung cancer care. This thesis found that factors such as smoking history, gender, and marital status were associated with increased symptom burden in lung cancer patients. Nursing education should therefore equip nurses with the knowledge and skills to assess and address these factors when providing care. This will enable nurses to provide the highest quality of care, incorporating new interventions and strategies as they emerge. Continuing education programmes and opportunities for nurses to engage in research and evidence-based practice should be promoted.

By incorporating these recommendations into nursing education, nurses will be better prepared to provide holistic care, support symptom management, address caregiver burden, and meet the information needs of patients and their families in the context of advanced lung cancer patients who are undergoing palliative RT. Incorporating these recommendations into nursing education necessitates a systematic approach involving curriculum revision in collaboration with nursing schools to include content on symptom management, caregiver support, and communication strategies tailored to the needs of lung cancer patients. Interactive learning modules, case studies, and simulations should be developed to enhance student engagement and knowledge retention (Kavakli and Konukbay, 2024, Skedsmo et al., 2023). Clinical placements in palliative care settings are essential to provide students with hands-on experiences working with lung cancer patients and their families (Skedsmo et al., 2023).

Furthermore, integrating assessment methods that evaluate students' competency in symptom management, caregiver support, and communication skills is crucial. Finally, faculty training should be prioritised to equip educators with the necessary knowledge and resources to effectively teach these concepts and mentor students in these areas. This comprehensive approach will better prepare future nurses to deliver high-quality, patient-centred care to individuals with advanced lung cancer.
More specific discussion of education in Symptom Management Education, Interactive Case Studies, Nursing education should incorporate interactive case studies that present realistic scenarios of lung cancer patients experiencing common symptoms like fatigue, pain, and dyspnoea (Skedsmo et al., 2023). These case studies can challenge students to apply their knowledge, critically analyse assessment findings, and develop appropriate nursing interventions. Simulation training can provide students with opportunities to practice essential

skills such as assessing symptom severity, administering medications, and providing patient education in a safe and controlled environment.

High-fidelity simulations can mimic real-life clinical situations, allowing students to develop confidence and competence in managing complex symptom presentations. Skill Development workshops focused on specific symptom management techniques can be valuable. For example, a workshop on respiratory care could teach students techniques for managing dyspnoea, such as pursed-lip breathing and positioning, while a pain management workshop could cover pharmacological and non-pharmacological pain relief strategies.

Caregiver Support Education including Role-Playing Exercises can help students develop effective communication skills for interacting with caregivers (Rojas-Ocaña et al., 2021). These exercises can simulate challenging situations, such as delivering difficult news, addressing caregiver burden, and navigating family dynamics. Nursing education should familiarise students with available caregiver support resources, such as respite care programs, support groups, and online resources (Rojas-Ocaña et al., 2021). Students can be assigned projects to research and present on these resources, developing their knowledge and ability to connect caregivers with appropriate support. Cultural Competency Training is essential for nurses working with diverse populations. Education should emphasise the cultural nuances of caregiving in Thailand, including the influence of family dynamics, religious beliefs, and traditional healing practices. This can help students provide culturally sensitive care and support to caregivers (Songwathana and Siriphan, 2015).

Information Provision Education contains the Teach-Back Method, where students practice explaining complex medical information to patients and caregivers and then assess their understanding by asking them to "teach back" the information in their own words. This technique promotes clear communication and ensures that information is effectively conveyed (Talevski et al., 2020). Developing Patient Education Materials such as brochures or online resources, on topics relevant to lung cancer care. This allows them to apply their knowledge and gain experience in creating accessible and informative resources for patients and caregivers. Effective Communication Strategies including active listening, empathy, and nonverbal communication (Kourkouta and Papathanasiou, 2014). Students can practice these skills through role-playing and simulations, learning to tailor their communication style to individual needs and preferences.

To maximise the impact of this research on lung cancer care in Thailand, a multifaceted dissemination strategy is essential, targeting key stakeholders including healthcare professionals, policymakers, researchers, patients and caregivers, and nursing educators. Tailoring the dissemination approach to each group's needs and roles ensures that the findings are effectively communicated and utilised.

For healthcare professionals, particularly those involved in lung cancer care, the focus should be on enhancing clinical practice through targeted educational initiatives. Workshops and continuing education sessions can be organised to address symptom management, caregiver support, and communication skills (Liu et al., 2025). Incorporating case studies and role-playing exercises can facilitate practical learning and application. Additionally, developing digital platforms, such as online modules accessible via smartphones or computers, can provide flexible learning opportunities, accommodating the busy schedules of healthcare workers in Thailand. Establishing communities of practice where professionals can share experiences and solutions further promotes collaborative learning and improvement in patient care (Vallée et al., 2020).
Policymakers play a crucial role in translating research findings into actionable health policies. Dissemination to this group should emphasise the practical implications of the research, highlighting how the findings can inform policy decisions and improve lung cancer care (Arnautu and Dagenais, 2021). Preparing policy briefs that summarise key findings and recommendations can facilitate informed decision-making. Engaging policymakers in discussions and forums where research findings are presented and deliberated upon can also promote the integration of evidence into policy development (Kilbourne et al., 2022).
Researchers, both within Thailand and internationally, can benefit from detailed presentations of the study's methodology, findings, and limitations.

Disseminating the research through academic journals, conferences, and collaborative networks fosters knowledge exchange and encourages further investigation in the field (Wilson et al., 2010). Providing platforms for researchers to discuss and critique the findings can lead to refinements in research methodologies and the development of new research questions.

For patients and caregivers, the dissemination strategy should prioritise clear and accessible communication. Developing patient education materials, such as brochures, videos, and online resources, can help individuals understand the implications of the research and how it relates to their care. Organising support groups and community outreach programs can provide platforms for patients and caregivers to engage with the research findings, ask questions, and share experiences. These initiatives empower patients and caregivers, enabling them to make informed decisions about their care and support (Viseskul et al., 2025).

Nursing educators are instrumental in integrating research findings into nursing curricula and training programs (Herbener, 1994). Dissemination to this group should focus on the implications of the research for nursing education (Shon et al., 2024). Incorporating the findings into curriculum development ensures that nursing students are equipped with the knowledge and skills necessary to provide high-quality care to lung cancer patients. Faculty development programs can be organised to train educators on the latest research and best practices, fostering a culture of continuous learning and improvement in nursing education (Yasin et al., 2025).

For my perspective, utilising diverse dissemination channels enhance the reach and impact of the research. Publishing findings in peer-reviewed journals and presenting them at conferences ensures that the research is accessible to the academic community. Leveraging digital platforms, such as social media, institutional websites, and online repositories, can disseminate the research to a broader audience, including the general public. Engaging with the community through public lectures, workshops, and patient support groups fosters a deeper understanding of the research and its implications for lung cancer care.

Finally, ensuring that the dissemination materials are accessible to all individuals is paramount. Translating materials into Thai and other relevant languages ensures that language barriers do not impede understanding. Providing information in accessible formats, such as large print or audio recordings, caters to individuals with visual or auditory impairments. Using clear, jargon-free language ensures that the information is comprehensible to individuals with varying levels of health literacy.

By implementing these tailored dissemination strategies, the research findings can effectively reach and influence key stakeholders, leading to improved lung cancer care and support in Thailand. This comprehensive approach ensures that the research contributes to evidence-based practice, policy development, and education, ultimately enhancing the quality of care for lung cancer patients and their families.

Appendices

Appendix 1 *Full text screening*

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
36	10683087	Short-course palliative radiotherapy in non-small-cell lung cancer: results of a prospective study.	https://dx.doi.org/10.1097/00000421-200002000-00024	American Journal of Clinical Oncology. 23(1):89-93, 2000 Feb.	Clinician assessment
63	10704708	Radiotherapy for non-small cell lung cancer in patients aged 75 and over: safety, effectiveness and possible impact on survival.	appppapappaapphttps://dx.doi.org/ 10appenappendixappendixopp.1016/s0169-5002(99)00117-8	Lung Cancer. 28(1):43-50, 2000 Apr.	Not related
23	10758317	Quality of life after palliative radiotherapy in non-small cell lung cancer: a prospective study.	https://dx.doi.org/10.1016/s0360-3016(99)00540-4	International Journal of Radiation Oncology, Biology, Physics. 47(1):149-55, 2000 Apr 01.	Included
35	10776977	Thoracic reirradiation for symptomatic relief after prior radiotherapeutic management for lung cancer.	https://dx.doi.org/10.1097/00000421-200004000-00011	American Journal of Clinical Oncology. 23(2):160-3, 2000 Apr.	Clinician assessment
11	10837953	Response of global quality of life to high-dose palliative radiotherapy for non-small-cell lung cancer.	https://dx.doi.org/10.1016/s0360-3016(00)00439-9	International Journal of Radiation Oncology, Biology, Physics. 47:691-701, 2000 Jun 01.	Not related
62	10924977	A palliative accelerated irradiation regimen for advanced non-small-cell lung cancer vs. conventionally fractionated 60 GY: results of a randomized equivalence study.	https://dx.doi.org/10.1016/s0360-3016(00)00607-6	International Journal of Radiation Oncology, Biology, Physics. 48(1):95-103, 2000 Aug 01.	Not related

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
22	10927134	The impact of three-dimensional radiation on the treatment of non-small cell lung cancer. [Review] [43 refs]	https://dx.doi.org/10.1016/s0167-8140(00)00207-3	Radiotherapy & Oncology. 56(2):157-67, 2000 Aug.	Not related
74	11224985	Radiation therapy for non-small cell lung cancer (NSCLC). [Review] [83 refs]	https://dx.doi.org/10.1007/978-1-4615-1589-0_5	Cancer Treatment & Research. 105:121-48, 2001.	Not related
10	11230886	External irradiation versus external irradiation plus endobronchial brachytherapy in inoperable non-small cell lung cancer: a prospective randomized study.	https://dx.doi.org/10.1016/s0167-8140(00)00345-5	Radiotherapy & Oncology. 58:257-68, 2001 Mar.	Included
61	11304764	Prospective study on quality of life before and after radical radiotherapy in non-small-cell lung cancer.	https://dx.doi.org/10.1200/JCO.2001.19.8.2123	Journal of Clinical Oncology. 19(8):2123-33, 2001 Apr 15.	Included
9	11373887	Long-term survival in patients with non-small cell lung cancer treated with palliative radiotherapy.	https://dx.doi.org/10.1053/clon.2001.9227	Clinical Oncology (Radiologists). 13(2):95-8, 2001.	Not related
50	11441624	Symptom frequency and severity in patients with metastatic or locally recurrent lung cancer: a prospective study using the Lung Cancer Symptom Scale in a community hospital.	https://dx.doi.org/10.1089/109662101750290191	Journal of Palliative Medicine. 4(2):157-65, 2001 Summer.	Not related
20	11474269	Palliative radiotherapy for synchronous bilateral lung cancers.	https://dx.doi.org/10.1097/00000421-200108000-00016	American Journal of Clinical Oncology. 24(4):385-7, 2001 Aug.	Not related
8	11687016	Palliative radiotherapy regimens for non-small cell lung cancer. [Review] [43 refs]	https://dx.doi.org/10.1002/14651858.CD002143	Cochrane Database of Systematic Reviews. :CD002143, 2001	Not related
55	11720762	Radiotherapy for non-small cell lung cancer. [Review] [28 refs]	https://dx.doi.org/10.1016/s0169-5002(01)00365-8	Lung Cancer. 34 Suppl 2:S177-80, 2001 Dec.	Not related

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
6	11804694	A short radiotherapy course for locally advanced non-small cell lung cancer (NSCLC): effective palliation and patients' convenience.	https://dx.doi.org/10.1016/s0169-5002(01)00327-0	Lung Cancer. 35(2):203-7, 2002 Feb.	Clinician assessment
7	11949846	The role of palliative radiotherapy in locally advanced non-small cell lung cancer.		Neoplasma. 48(6):506-10, 2001.	Clinician assessment
21	12018566	Palliative treatment of advanced non small cell lung cancer with weekly fraction radiotherapy.		Indian Journal of Cancer. 37(4):148-52, 2000 Dec.	Clinician assessment
73	12202326	Immediate versus delayed palliative thoracic radiotherapy in patients with unresectable locally advanced non-small cell lung cancer and minimal thoracic symptoms: randomised controlled trial.	https://dx.doi.org/10.1136/bmj.325.7362.465	BMJ. 325(7362):465, 2002 Aug 31.	Clinician assessment
34	12377323	Randomized phase III trial of single versus fractionated thoracic radiation in the palliation of patients with lung cancer (NCIC CTG SC.15).	https://dx.doi.org/10.1016/s0360-3016(02)02989-9	International Journal of Radiation Oncology, Biology, Physics. 54:719-28, 2002 Nov 01.	Included
19	12402061	Short-course palliative radiotherapy for airway stenosis in non-small cell lung cancer.	https://dx.doi.org/10.1007/s1014 70200041	International Journal of Clinical Oncology. 7(5):284-8, 2002 Oct.	Not related
44	12714878	Palliative thoracic radiotherapy for non-small-cell lung cancer: a systematic review. [Review] [39 refs]	https://dx.doi.org/10.1097/00000421-200304000-00002	American Journal of Clinical Oncology. 26(2):112-20, 2003 Apr.	Not related
33	12911288	The role of radiotherapy and chemotherapy for curative management of medically inoperable and stage III nonsmall cell lung cancer, and radiotherapy	https://dx.doi.org/10.1016/s1078-5337(02)00087-4	Respiratory Care Clinics of North America. 9(2):163-90, 2003 Jun.	Mixed sample

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
		for palliation of symptomatic disease. [Review] [95 refs]			
5	12972363	No consensus on the optimal palliative radiotherapy regimen for people with inoperable non-small-cell lung cancer. [Review] [8 refs]	https://dx.doi.org/10.1016/s0305-7372(03)00166-x	Cancer Treatment Reviews. 29(5):445-7, 2003 Oct.	Not related
60	14637126	Assessing fatigue and self-care strategies in patients receiving radiotherapy for non-small cell lung cancer.	https://dx.doi.org/10.1016/s1462-3889(03)00046-2	European Journal of Oncology Nursing. 7(4):231-41, 2003 Dec.	Clinician assessment
49	14990635	Hypofractionated palliative radiotherapy (17 Gy per two fractions) in advanced non-small-cell lung carcinoma is comparable to standard fractionation for symptom control and survival: a national phase III trial.	https://dx.doi.org/10.1200/JCO.2004.06.123	Journal of Clinical Oncology. 22(5):801-10, 2004 Mar 01.	Mixed sample
59	15001250	Prospective study of palliative hypofractionated radiotherapy (8.5 Gy x 2) for patients with symptomatic non-small-cell lung cancer. [Review] [27 refs]	https://dx.doi.org/10.1016/j.ijrobp.2003.08.005	International Journal of Radiation Oncology, Biology, Physics. 58(4):1098-105, 2004 Mar 15.	Clinician assessment
32	15050314	Hypofractionated external beam radiotherapy as retreatment for symptomatic non-small-cell lung carcinoma: an effective treatment?.	https://dx.doi.org/10.1016/j.ijrobp.2003.09.087	International Journal of Radiation Oncology, Biology, Physics. 58(5):1388-93, 2004 Apr 01.	Clinician assessment
48	15552805	Palliative percutaneous radiotherapy in non-small-cell lung cancer. [Review] [26 refs]	https://dx.doi.org/10.1016/j.lungcan.2004.07.969	Lung Cancer. 45 Suppl 2:S239-45, 2004 Aug.	Not related
31	15714933	Symptom control and quality of life in people with lung cancer: a randomised trial of two palliative	https://dx.doi.org/10.1016/j.clon.2004.09.008	Clinical Oncology (Radiologists). 17(1):61-7, 2005 Feb.	Clinician assessment

OR N	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
		radiotherapy fractionation schedules.			
58	15770205	A prospective, randomised study to compare two palliative radiotherapy schedules for non-small-cell lung cancer (NSCLC).	https://dx.doi.org/10.1038/sj.bjc.6602477	British Journal of Cancer. 92(6):1038-45, 2005 Mar 28.	Included
54	15845045	Outcome following radiotherapy for loco-regionally recurrent non-small cell lung cancer.	https://dx.doi.org/10.1111/j.1440-1673.2005.01353.x	Australasian Radiology. 49(2):108-12, 2005 Apr.	Not related
72	15860852	Results of the Dutch National study of the palliative effect of irradiation using two different treatment schemes for non-small-cell lung cancer.	https://dx.doi.org/10.1200/JCO.2005.01.685	Journal of Clinical Oncology. 23(13):2962-70, 2005 May 01.	Clinician assessment
47	15958462	The role of radiotherapy in non-small-cell lung cancer. [Review] [49 refs]	https://dx.doi.org/10.1093/annonc/mdi726	Annals of Oncology. 16 Suppl 2:ii223-8, 2005.	Not related
18	16022913	Do elderly people with lung cancer benefit from palliative radiotherapy?.	https://dx.doi.org/10.1016/j.lungcan.2005.01.010	Lung Cancer. 49(2):193-202, 2005 Aug.	Clinician assessment
30	16094739	Immediate or delayed radiotherapy in advanced non-small cell lung cancer (NSCLC)? Data from a prospective randomised study.	https://dx.doi.org/10.1016/j.radonc.2005.03.028	Radiotherapy & Oncology. 75(2):141-8, 2005 May.	Included
71	16298550	A study to assess the existence of the symptom cluster of breathlessness, fatigue and anxiety in patients with advanced lung cancer.	https://dx.doi.org/10.1016/j.ejon.2005.02.003	European Journal of Oncology Nursing. 9(4):325-33, 2005 Dec.	Clinician assessment
57	17054152	Palliative radiotherapy regimens for non-small cell lung cancer. [Review] [43 refs]	https://dx.doi.org/10.1002/14651858.CD002143.pub2	Cochrane Database of Systematic Reviews. (4):CD002143, 2006 Oct 18	Not related

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
43	17348437	Palliative re-irradiation for in-field recurrence after definitive radiotherapy in patients with primary lung cancer.		Anticancer Research. 27(1B):531-4, 2007 Jan-Feb.	Clinician assessment
17	17409965	Palliative thoracic radiotherapy in locally advanced non-small cell lung cancer: can quality-of-life assessments help in selection of patients for short- or long-course radiotherapy?.		Journal of Thoracic Oncology: Official Publication of the International Association for the Study of Lung Cancer. 1(8):816-24, 2006 Oct.	Mixed sample
46	17482301	The role of radiotherapy in lung cancer: where is the evidence?. [Review] [86 refs]	https://dx.doi.org/10.1016/j.radonc.2007.04.004	Radiotherapy & Oncology. 83(2):203-13, 2007 May.	Not related
4	17689029	Use of palliative radiotherapy among patients with metastatic non-small-cell lung cancer.	https://dx.doi.org/10.1016/j.ijrobp.2007.04.059	International Journal of Radiation Oncology, Biology, Physics. 69(4):1001-7, 2007 Nov 15.	Not related
42	18262087	Has the pattern of practice in the prescription of radiotherapy for the palliation of thoracic symptoms changed between 1999 and 2006 at the rapid response radiotherapy program?.	https://dx.doi.org/10.1016/j.ijrobp.2007.10.046	International Journal of Radiation Oncology, Biology, Physics. 70:693-700, 2008 Mar 01.	Not related
70	18711191	Palliative thoracic radiotherapy for lung cancer: a systematic review. [Review] [34 refs]	https://dx.doi.org/10.1200/JCO.2007.15.3312	Journal of Clinical Oncology. 26(24):4001-11, 2008 Aug 20.	Not related
41	19032397	Patients' preference for radiotherapy fractionation schedule in the palliation of symptomatic unresectable lung cancer.	https://dx.doi.org/10.1111/j.1440-1673.2008.02002.x	Journal of Medical Imaging & Radiation Oncology. 52(5):497-502, 2008 Oct.	Clinician assessment
29	19373944	Is re-irradiation effective in symptomatic local recurrence of non small cell lung cancer patients? A		Journal of B.U.On.. 14(1):33-40, 2009 Jan-Mar.	Not related

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
		single institution experience and review of the literature. [Review] [32 refs]*			
3	20009771	Split-course palliative radiotherapy for advanced non-small cell lung cancer.	https://dx.doi.org/10.1097/JTO.0b013e3181c6eb20	Journal of Thoracic Oncology: Official Publication of the International Association for the Study of Lung Cancer. 5(2):185-90, 2010 Feb.	Clinician assessment
16	20079949	Radiotherapy for lung cancer in the elderly. [Review] [122 refs]	https://dx.doi.org/10.1016/j.lungcan.2009.12.004	Lung Cancer. 68(2):129-36, 2010 May.	Not related
40	20397921	Palliative thoracic radiotherapy for lung cancer. [Review] [69 refs]	https://dx.doi.org/10.1586/era.10.22	Expert Review of Anticancer Therapy. 10(4):559-69, 2010 Apr.	Not related
28	20423316	Hypofractionated radiotherapy in non small cell lung cancer: a review of the current literature. [Review] [62 refs]	https://dx.doi.org/10.2174/157488710791233608	Reviews on Recent Clinical Trials. 5(2):103-11, 2010 May.	Not related
69	20674068	Palliative thoracic radiotherapy in non-small cell lung cancer. An analysis of 1250 patients. Palliation of symptoms, tolerance and toxicity.	https://dx.doi.org/10.1016/j.lungcan.2010.06.019	Lung Cancer. 71:344-9, 2011 Mar.	Clinician assessment
68	21131165	Managing symptoms in patients with advanced lung cancer during radiotherapy: results of a psychoeducational randomized controlled trial.	https://dx.doi.org/10.1016/j.jpainsymman.2010.04.024	Journal of Pain & Symptom Management. 41(2):347-57, 2011 Feb.	Clinician assessment
67	21474620	The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer.	https://dx.doi.org/10.1177/0269216311399489	Palliative Medicine. 25(7):675-81, 2011 Oct.	Not related

OR N	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
15	22252390	Radiation therapy at the end of life in patients with incurable nonsmall cell lung cancer.	https://dx.doi.org/10.1002/cncr.27401	Cancer. 118(17):4339-45, 2012 Sep 01.	Not related
2	22554216	Evaluating a complex intervention: a process evaluation of a psycho-education program for lung cancer patients receiving palliative radiotherapy.	https://dx.doi.org/10.5172/conu.2012.40.2.234	Contemporary Nurse. 40(2):234-44, 2012 Feb.	Not related
27	23295799	Palliative radiation therapy practice in patients with metastatic non-small-cell lung cancer: a Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) Study.	https://dx.doi.org/10.1200/jco.2012.43.7954	Journal of Clinical Oncology. 31(5):558-64, 2013 Feb 10.	Not related
53	23891240	Radiotherapy for stage III non-small-cell lung carcinoma in the elderly (age >= 70 years).	https://dx.doi.org/10.1016/j.cllc.2013.05.001	Clinical Lung Cancer. 14(6):674-9, 2013 Nov.	Not related
26	24974909	Meta-analysis comparing higher and lower dose radiotherapy for palliation in locally advanced lung cancer.	https://dx.doi.org/10.1111/cas.12466	Cancer Science. 105(8):1015-22, 2014 Aug.	Clinician assessment
25	25001608	The Vancouver rapid access clinic for palliative lung radiation, providing more than just rapid access.	https://dx.doi.org/10.1007/s00520-014-2345-6	Supportive Care in Cancer. 23(1):125-32, 2015 Jan.	Not related
56	25484031	Palliative thoracic radiotherapy for patients with advanced non-small cell lung cancer and poor performance status.	https://dx.doi.org/10.1016/j.lungcan.2014.11.015	Lung Cancer. 87(2):130-5, 2015 Feb.	Clinician assessment
14	25586198	Palliative radiotherapy regimens for patients with thoracic symptoms from non-small cell lung cancer. [Review]	https://dx.doi.org/10.1002/14651858.CD002143.pub4	Cochrane Database of Systematic Reviews. 1:CD002143, 2015 Jan 14.	Clinician assessment

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
66	28595431	Palliative efficacy and local control of conventional radiotherapy for lung metastases.	https://dx.doi.org/10.21037/apm.2017.03.08	Annals of Palliative Medicine. 6(Suppl 1):S21-S27, 2017 Aug.	Clinician assessment
1	28727277	High-dose palliative radiotherapy for malignant pleural mesothelioma.	https://dx.doi.org/10.1111/1754-9485.12636	Journal of Medical Imaging & Radiation Oncology. 61(6):797-803, 2017 Dec.	Not related
13	29191598	Prospective analysis of patient reported symptoms and quality of life in patients with incurable lung cancer treated in a rapid access clinic.	https://dx.doi.org/10.1016/j.lungcan.2017.07.033	Lung Cancer. 112:35-40, 2017 10.	Included
65	29199702	Palliative thoracic radiotherapy in advanced lung cancer: A single institution experience.	https://dx.doi.org/10.4103/0019-509X.219587	Indian Journal of Cancer. 54(1):262-266, 2017 Jan-Mar.	Not related
64	29475917	How Should Palliative Thoracic Radiotherapy Be Fractionated for Octogenarians with Lung Cancer?.	https://dx.doi.org/10.21873/invivo.11242	In Vivo. 32(2):331-336, 2018 Mar-Apr.	Not related
45	29548561	Cancer Trials Ireland (ICORG) 06-34: A multi-centre clinical trial using three-dimensional conformal radiation therapy to reduce the toxicity of palliative radiation for lung cancer.	https://dx.doi.org/10.1016/j.radonc.2018.02.028	Radiotherapy & Oncology. 127(2):253-258, 2018 May.	Included
39	30298381	Radiotherapy in palliation of thoracic tumors: a phase I-II study (SHARON project).	https://dx.doi.org/10.1007/s10585-018-9942-6	Clinical & Experimental Metastasis. 35(8):739-746, 2018 12.	Clinician assessment
78	30448075	Early response assessment of re-ossification after palliative conventional radiotherapy for vertebral bone metastases.	https://dx.doi.org/10.1016/j.jos.2018.08.018	Journal of Orthopaedic Science. 24(2):332-336, 2019 Mar.	Not related
76	30876833	Population-based patterns of treatment and survival for patients with stage I and II non-small cell	https://dx.doi.org/10.1016/j.jgo.2019.03.001	Journal of Geriatric Oncology. 10(4):547-554, 2019 07.	Not related

ORN	UI	TI	DO	SO	Not related/Clinician assessment /Mixed sample/Included
		lung cancer aged 65-74years and 75years or older.			
77	32592442	30-day mortality following palliative radiotherapy.	https://dx.doi.org/10.1111/1754-9485.13073	Journal of Medical Imaging & Radiation Oncology. 64(4):570-579, 2020 Aug.	Not related
	32600918	Palliative Lung Radiotherapy: Higher Dose Leads to Improved Survival?.	https://dx.doi.org/10.1016/j.clon.2020.05.003	Clinical Oncology (Radiologists). 32(10):674-684, 2020 10.	Not related
75	32921077	The role of palliative radiation therapy in treating pleural or peritoneal disseminated tumors: 22 cases and a review of the literature. [Review]	https://dx.doi.org/10.21037/apm-19-495	Annals of Palliative Medicine. 9(5):2586-2591, 2020 Sep.	Not related
12	33259933	Radical Hemithoracic Radiotherapy Versus Palliative Radiotherapy in Non-metastatic Malignant Pleural Mesothelioma: Results from a Phase 3 Randomized Clinical Trial.	https://dx.doi.org/10.1016/j.ijrobp.2020.11.057	International Journal of Radiation Oncology, Biology, Physics. 109(5):1368-1376, 2021 04 01.	Clinician assessment
52	33723301	A systematic review and meta-analysis of treatment-related toxicities of curative and palliative radiation therapy in non-small cell lung cancer.	https://dx.doi.org/10.1038/s41598-021-85131-7	Scientific Reports. 11(1):5939, 2021 03 15.	Not related
51	34389004	Use of palliative radiotherapy among patients with metastatic non-small-cell lung cancer in Puerto Rico.	https://dx.doi.org/10.1186/s12904-021-00819-x	BMC Palliative Care. 20(1):127, 2021 Aug 13.	Not related
37	34775767	Split course palliative radiotherapy for advanced lung cancer with 3D planning based analysis of outcome: a retrospective review.	https://dx.doi.org/10.21037/apm-21-1589	Annals of Palliative Medicine. 11(2):423-430, 2022 Feb.	Not related
24	36115746	The Use of Palliative Radiotherapy in the Treatment of Lung Cancer.	https://dx.doi.org/10.1016/j.clon.2022.08.032	Clinical Oncology (Radiologists). 34(11)p:761-770, 2022 11.	Clinician assessment

Appendix 2 Summary quality scores indicating methodological quality of the included studies

Author (year)	**Question number**														**%**
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	
Bezjak et al. (2002)	2	2	2	1	2	2	2	2	2	2	2	2	1	2	93
Eldeeb et al. (2014)	2	2	2	2	2	1	1	2	1	2	2	2	2	2	89
Langendijk et al. (2000)	2	2	1	1	na	na	na	2	2	2	2	2	2	2	91
Langendijk et al. (2001).	2	2	2	1	na	na	na	2	2	2	2	2	1	2	91
Lefresne et al. (2017)	2	2	2	2	na	na	na	2	1	2	1	2	1	2	86
McDermott et al. (2018)	2	2	2	2	na	na	na	2	1	2	2	2	1	2	91
Senkus-Konefka et al. (2005)	2	2	1	2	2	2	2	2	2	1	2	2	1	2	89
Sundstrøm et al. (2005)	2	2	2	2	na	na	na	2	2	2	2	2	2	1	96

(% = Actual score/Highest possible score).

Abbreviations:

na = not applicable, 0 = No, 1 = Partial, 2 = Yes

1. Question / objective sufficiently described? 2. Study design evident and appropriate? 3. Method of subject/comparison group selection or source of information/input variables described and appropriate? 4. Subject (and comparison group, if applicable) characteristics sufficiently described? 5. If interventional and random allocation was possible, was it described? 6. If interventional and blinding of investigators was possible, was it reported? 7. If interventional and blinding of subjects was possible, was it reported? 8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported? 9. Sample size appropriate? 10. Analytic methods described/justified and appropriate? 11. Some estimate of variance is reported for the main results? 12. Controlled for confounding? 13. Results reported in sufficient detail? 14. Conclusions supported by the results?

Appendix 3 Detail of the performance status

SCORE	WHO PERFOMANCE STATUS
0	Asymptomatic (fully active, able to carry on all pre-disease activities without restriction)
1	Symptomatic but completely ambulatory (restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature; for example, light housework, office work)
2	Symptomatic, < 50% in bed during the day (ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours)
3	Symptomatic, > 50% in bed, but not bedbound (capable of only limited self-care, confined to bed or chair 50% or more of waking hours)
4	Bedbound (completely disabled, cannot carry on any self-care, totally confined to bed or chair)
5	Death

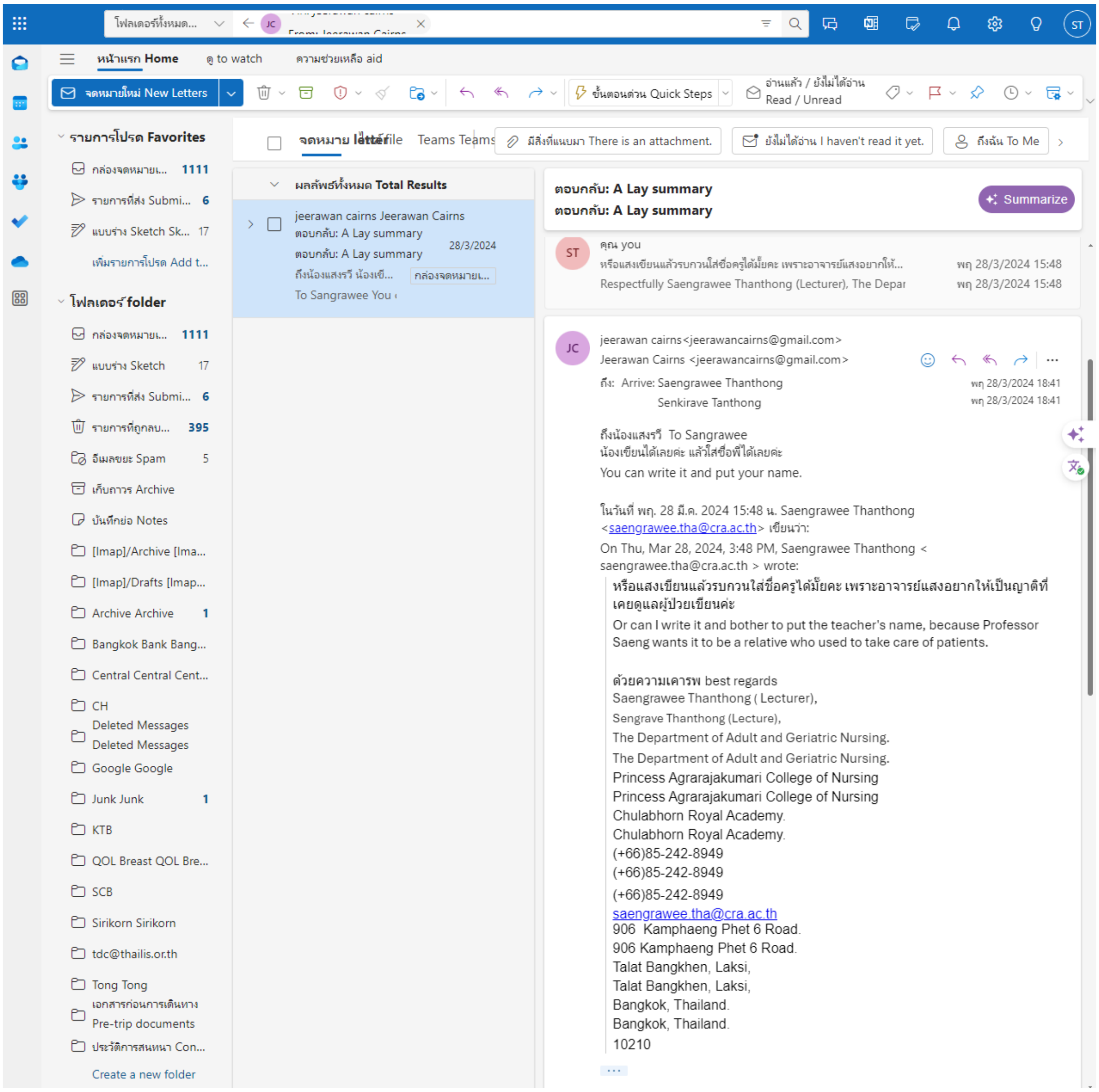
GRADE	ECOG PERFOMANCE STATUS
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

SCORE	KARNOFSKY PERFORMANCE STATUS
100	Normal, no complaints; no evidence of disease
90	Able to carry on normal activity; minor signs or symptoms of disease
80	Normal activity with effort, some signs or symptoms of disease
70	Cares for self but unable to carry on normal activity or to do active work
60	Requires occasional assistance but is able to care for most of personal needs
50	Requires considerable assistance and frequent medical care
40	Disabled; requires special care and assistance
30	Severely disabled; hospitalization is indicated although death not imminent
20	Very ill; hospitalization and active supportive care necessary
10	Moribund
0	Dead

PALLIATIVE PERFORMANCE STATUS					
LEVEL	AMBULATION	ACTIVITY AND EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONCIOUS LEVEL
STABLE					
100%	Full	Normal activity and work / No evidence of disease	Full	Normal	Full
90%	Full	Normal activity and work / Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort / Some evidence of disease	Full	Normal or reduce	Full
HOSPICE APPROPRIATE					

70%	Reduced	Unable to do normal job or work / Significant disease	Full	Normal or reduce	Full
60%	Reduced	Unable to do hobby or housework / Significant disease	Occasional assistance necessary	Normal or reduce	Full confusion
50%	Mainly sit/lie	Unable to do any work / Extensive disease	Considerable assistance required	Normal or reduce	Full confusion
40%	Mainly in bed	Unable to do most activity / Extensive disease	Mainly assistance	Normal or reduce	Full or drowsy +/- confusion
30%	Totally bedbound	Unable to do any activity / Extensive disease	Total care	Normal or reduce	Full or drowsy +/- confusion
20%	Totally bedbound	Unable to do any activity / Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
10%	Totally bedbound	Unable to do any activity / Extensive disease	Total care	Mouth care only	Full or drowsy +/- confusion
0%	Death	-	-	-	-

Appendix 4 Patient and Public Involvement consent



jeerawan cairns Jeerawan Cairns
ตอบกลับ: A Lay summary
ตอบกลับ: A Lay summary
28/3/2024
ถึงน้องแสงรวี น้องเขี...
กล่องจดหมายเ...
To Sangrawee You

ตอบกลับ: A Lay summary
ตอบกลับ: A Lay summary

คุณ you
หรือแสงเขียนแล้วรบกวนใส่ชื่อครูได้มั๊ยคะ เพราะอาจารย์แสงอยากให้... พฤ 28/3/2024 15:48
Respectfully Saengrawee Thanthong (Lecturer), The Depar พฤ 28/3/2024 15:48

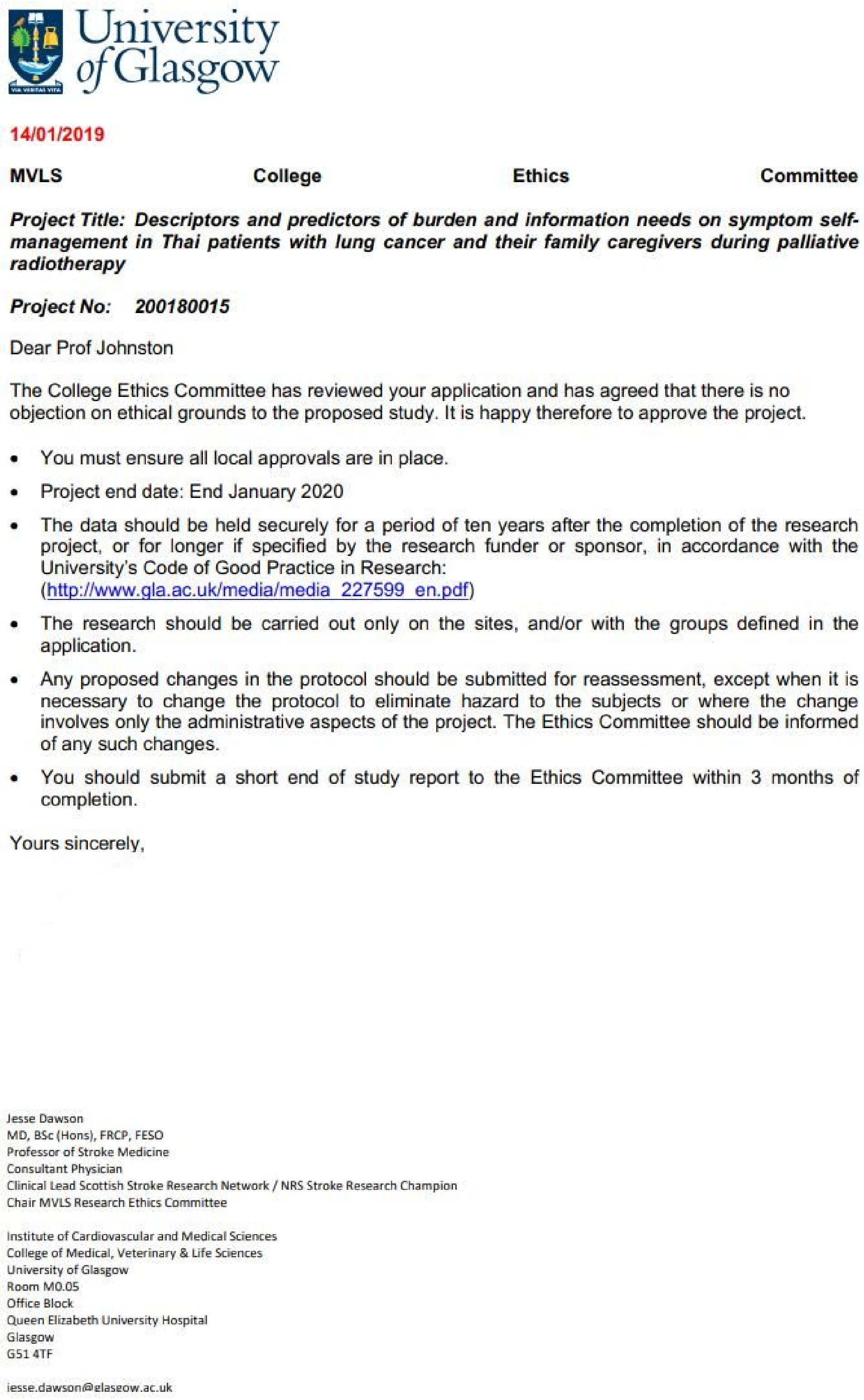
jeerawan cairns<jeerawancairns@gmail.com>
Jeerawan Cairns <jeerawancairns@gmail.com>
ถึง: Arrive: Saengrawee Thanthong
Senkirave Tanthong
พฤ 28/3/2024 18:41
พฤ 28/3/2024 18:41

ถึงน้องแสงรวี To Sangrawee
น้องเขียนได้เลยค่ะ แล้วใส่ชื่อพี่ได้เลยค่ะ
You can write it and put your name.

ในวันที่ พฤ. 28 มี.ค. 2024 15:48 น. Saengrawee Thanthong <saengrawee.tha@cra.ac.th> เขียนว่า:
On Thu, Mar 28, 2024, 3:48 PM, Saengrawee Thanthong < saengrawee.tha@cra.ac.th > wrote:

> หรือแสงเขียนแล้วรบกวนใส่ชื่อครูได้มั๊ยคะ เพราะอาจารย์แสงอยากให้เป็นญาติที่เคยดูแลผู้ป่วยเขียนค่ะ
>
> Or can I write it and bother to put the teacher's name, because Professor Saeng wants it to be a relative who used to take care of patients.
>
> ด้วยความเคารพ best regards
> Saengrawee Thanthong (Lecturer),
> Sengrave Thanthong (Lecture),
> The Department of Adult and Geriatric Nursing.
> The Department of Adult and Geriatric Nursing.
> Princess Agrarajakumari College of Nursing
> Princess Agrarajakumari College of Nursing
> Chulabhorn Royal Academy.
> Chulabhorn Royal Academy.
> (+66)85-242-8949
> (+66)85-242-8949
> (+66)85-242-8949
> saengrawee.tha@cra.ac.th
> 906 Kamphaeng Phet 6 Road.
> 906 Kamphaeng Phet 6 Road.
> Talat Bangkhen, Laksi,
> Talat Bangkhen, Laksi,
> Bangkok, Thailand.
> Bangkok, Thailand.
> 10210

Appendix 5 *Ethics and research and development approval documentations*



14/01/2019

MVLS College Ethics Committee

Project Title: Descriptors and predictors of burden and information needs on symptom self-management in Thai patients with lung cancer and their family caregivers during palliative radiotherapy

Project No: 200180015

Dear Prof Johnston

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- You must ensure all local approvals are in place.
- Project end date: End January 2020
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

Institute of Cardiovascular and Medical Sciences
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Room M0.05
Office Block
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Glasgow
G51 4TF

jesse.dawson@glasgow.ac.uk

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:

Project Number:

Subject Identification Number for this trial:

CONSENT FORM – PATIENT VERSION

Title of Project: Descriptors and predictors of burden and information needs on symptom self-management in Thai patients with lung cancer and their family caregivers during palliative radiotherapy.

Name of Researcher(s): Saengrawee Thanthong, Prof. Bridget Johnston and Dr. Grigorios Kotronoulas

Please initial box

I confirm that I have read and understand the information sheet dated ___________ (Version 2 date 13/12/18) for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

I understand that relevant sections of my medical notes and data collected during the study may be looked at by the researcher. I give permission for these individual to access my records. ☐

I understand that agreeing to take part will involve completing a set of questionnaires four times during the study, each time taking up approximately 15 minutes. ☐

I understand that any data I provide for this study will be kept confidential throughout study. Anonymous data may be used in reports and publications. ☐

I understand that I will not be able to be identified in these reports.

I agree to take part in the above study. ☐

_________________________ __________ ____________________

Name of participantDateSignature

_________________________ __________ ____________________

Name of Person taking consentDateSignature

(if different from researcher)

_________________________ __________ ____________________

ResearcherDateSignature

(1 copy for participant; 1 copy for researcher)

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:

Project Number:

Subject Identification Number for this trial:

CONSENT FORM – CAREGIVER VERSION

Title of Project: Descriptors and predictors of burden and information needs on symptom self-management in Thai patients with lung cancer and their family caregivers during palliative radiotherapy.

Name of Researcher(s): Saengrawee Thanthong, Prof. Bridget Johnston and Dr. Grigorios Kotronoulas

Please initial box

I confirm that I have read and understand the information sheet dated ___________ (Version 2 date 13/12/18) for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. ☐

I understand that agreeing to take part will involve completing a set of questionnaires four times during the study, each time taking up approximately 15 minutes. ☐

I understand that any data I provide for this study will be kept confidential throughout the study. Anonymous data may be used in reports and publications. I understand that I will not be able to be identified in these reports. ☐

I agree to take part in the above study. ☐

________________________________ ______________ _________________________

Name of participantDateSignature

________________________________ _____________ _________________________

Name of Person taking consentDateSignature

(if different from researcher)

________________________________ _____________ _________________________

ResearcherDateSignature

University of Glasgow | College of Medical, Veterinary & Life Sciences

PARTICIPANT INFORMATION SHEET- Patient Version

1. Study title

Descriptors and predictors of burden and information needs on symptom self-management in Thai patients with lung cancer and their family caregivers during palliative radiotherapy

2. Invitation paragraph

My name is Saengrawee Thanthong, and I am a PhD student at the University of Glasgow. I am required to undertake a project as part of my course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the information below. Please read it carefully and be sure to ask any questions you might have and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

3. What is the purpose of the study?

You have been scheduled to receive radiotherapy for lung cancer. You may have some symptoms before, during and after your treatment. Also, you and your family may need more information about how best to manage your symptoms at home.

This project will help us better understand how patients' symptoms change during radiotherapy for lung cancer. We will also be able to understand what factors put some patients at greater risk for greater symptom burden compared to others. Finally, we will be able to understand what sort of information patients and family members may want in order for them to be able to deal with symptoms at home.

Our findings will help healthcare professionals be better informed about those patients and family members who may need greater support during radiotherapy for lung cancer. Our findings will also help health care professionals to understand what sort of information patients and families need when dealing with symptoms at home, and when this information should be offered.

4. Why have I been invited to participate?

You have been invited to take part in this study because you were diagnosed with lung cancer, and you will be treated with radiotherapy. The study will be carried out in Bangkok, Thailand. A total of 112 participants from three hospitals in will participate in this study. Each participant is expected to be involved in the study for approximately six weeks.

5. Do I have to take part?

No. Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your future medical care or your relationship with medical staff looking after you.

6. What will happen to me if I take part?

We will give you information and ask you to take part in the study. If you decide to take part, we will ask you to sign a consent form to let us know that you do want to take part.

We will then ask you to nominate your primary caregiver (i.e. a family member, friend or neighbour, who you feel provides most care and support to you). We will invite him/her to take part in the study, too.

During the study, we will ask you to complete a set of questionnaires at four time points. These time points will be the following: before the start of radiotherapy, first week of radiotherapy, second week of radiotherapy, and one month after the end of radiotherapy.

At each time point, the questionnaires will ask you questions about your symptoms and information needs. The questionnaires will be the same at all time points. You can complete the questionnaires either in the clinic or at home, and they will require approximately 15 minutes of your time.

7. What do I have to do?

Throughout your participation you will only be asked to give information about your symptoms and information needs during radiotherapy by completing the questionnaires we will provide you.

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

As this study does not affect the treatment and care you receive, there are no real side effects of taking part. Participation will not affect your ability to receive treatment or incur any additional expenses to you (or your involved family member).

However, we understand that giving information about your personal experience might become upsetting. As you will be asked to reflect on your symptoms and information needs, you may be thinking about them more than you might if you were not asked to complete the questionnaires. Although some people may find it upsetting to focus on their symptoms or needs so much, others find this helpful or don’t notice any difference. If you feel too uncomfortable when completing the questionnaires, you do not need to continue. If you feel that taking part in the study may make you think too much about your experience, then you can withdraw without having any effect on your future treatment and care. You should discuss these feelings or concerns with your doctor or nurse.

9. What are the possible benefits of taking part?

Although you may not directly benefit from taking part, you may benefit in an indirect manner. This study aims to inform and educate the health professionals involved in your care (i.e. doctors, nurses etc.) about your experience of symptoms and information needs during radiotherapy, to provide better care to you. Therefore, your health care team will be able to treat you in the best way possible in case you complain of symptoms, or you have unmet information needs. In addition, by completing the set of questionnaires you will have the opportunity to reflect on your experience, which may urge you to discuss this with a member of health care team to get help, should you need it.

10. Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the study will be kept strictly confidential. Any information about you, which leaves the hospital, will have your name and address removed from it so that you cannot be recognised from it. Your personal data will be identified only by a participant study ID number.

Your medical records may be inspected by the research team organising the research for purposes of checking information and collecting data. If you decide to take part, your radiologist will be informing the research team about your treatment schedule, so that they can invite you to the study.

If you decide to take part, your signed Informed Consent Form will be kept separately from any other information you provide and will be stored in a locked drawer for the Researcher's use only and will not be shared with anyone else.

11. What will happen to my data?

- In order to undertake this study, we will be collecting and storing your identifiable information, for example name, telephone number and address. This means that the University of Glasgow is responsible for looking after your information and using it properly. We will keep identifiable information about you for 6 months after the study has finished and will not pass this information to a third party without your express permission.
- If you withdraw from the study, we will keep the research data that we have already obtained. To safeguard your rights, we will use the minimum identifiable information possible. You can find out more about how we use

your information from the principal researcher, i.e. Saengrawee Thanthong (please see below for contact details).

- The research team (including the principal researcher and her academic supervisors; please see below for details) from the University of Glasgow will collect, store, and process all personal information in accordance with the General Data Protection Regulation (2018).
- All study data will be held in accordance with The General Data Protection Regulation (2018).
- Anonymised research data will be stored in archiving facilities in line with the University of Glasgow's retention policy for up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.
- Your data will form part of the study results that will be published in expert journals, presentations, student dissertations/theses (if applicable) and on the internet for other researchers to use. Your name will not appear in any publications.

12. What will happen to the results of the research study?

The information you provide will be used to draw general conclusions on symptom experience and information needs during radiotherapy for lung cancer. The results of the study will then be used for research and education purposes (including reports, publications, and presentations) with strict preservation of your anonymity.

13. Who is organising and funding the research?

The study is being organised by the University of Glasgow. It is being funded by a PhD Student Grant.

14. Who has reviewed the study?

The University of Glasgow Research Ethics Committee, which has responsibility for scrutinising all proposals for research conducted by the University of Glasgow, has examined the proposal, and has raised no objections from the point of view of human ethics. It is a requirement that your records in this research, together with any relevant medical record, be made available for scrutiny by the Institutional Review Board from Chulabhorn Hospital, Thailand National Cancer Institute and Ramathibodi Hospital in Thailand, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

15. Contact for Further Information

Should you wish any further information about the study, please contact one of the researchers below:

Researcher – PhD Student

Saengrawee Thanthong

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2nd Supervisor

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If you would like to speak about a problem or a complaint you have to someone who knows about this study who is an independent advisor, please contact:xxx

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Thank you for taking the time to read this Information Sheet and for considering taking part in this study.

University of Glasgow | College of Medical, Veterinary & Life Sciences

PARTICIPANT INFORMATION SHEET- Caregiver Version

1. Study title

Descriptors and predictors of burden and information needs on symptom self-management in Thai patients with lung cancer and their family caregivers during palliative radiotherapy

2. Invitation paragraph

My name is Saengrawee Thanthong, and I am a PhD student at the University of Glasgow. I am required to undertake a project as part of my course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the information below. Please read it carefully and be sure to ask any questions you might have and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

3. What is the purpose of the study?

You have been nominated as the informal caregiver of a patient scheduled to receive radiotherapy for lung cancer. Your patient may have some symptoms before, during and after, and you may need support and information about how best to manage his/her symptoms at home.

This project will help us better understand how patients' symptoms change during radiotherapy for lung cancer. We will also be able to understand what factors put some patients at greater risk for greater symptom burden compared to others. Finally, we will be able to understand what sort of information patients and family members may want in order for them to be able to deal with symptoms at home.

Our findings will help healthcare professionals be better informed about those patients and family members who may need greater support during radiotherapy for lung cancer. Our findings will also help health care professionals to understand what sort of information patients and families need when dealing with symptoms at home, and when this information should be offered.

4. Why have I been invited to participate?

You have been invited to take part in this study because you were nominated as the informal caregiver of a patient with lung cancer, who will be treated with radiotherapy. The study will be carried out in Bangkok, Thailand. A total of 112 participants from three hospitals in will participate in this study. Each participant is expected to be involved in the study for approximately six weeks.

5. Do I have to take part?

No. Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your legal rights or your patient’s medical care.

6. What will happen to me if I take part?

We will give you information and ask you to take part in the study. If you decide to take part, we will ask you to sign a consent form to let us know that you do want to take part.

During the study, we will then ask you to complete a set of questionnaires at four-time points. These time points will be the following: before the start of radiotherapy, first week of radiotherapy, second week of radiotherapy, and one month after the end of radiotherapy.

At each time point, when questionnaires will ask you questions about your needs for information and support in your caring role. The questionnaires will be the same at all-time points and for you both. You can complete the questionnaires either in the clinic or at home and they will require approximately 15 minutes of your time.

7. What do I have to do?

Throughout your participation you will only be asked to give information about your needs for information and support in your caring role during the patient's radiotherapy by completing the questionnaires we will provide you.

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

As this study does not affect you or the treatment and care that your patient receives, there are no real side effects of taking part. Participation will not affect your ability to provide care to the patient or incur any additional expenses to you (or the patient).

However, we understand that giving information about your personal experience might become upsetting. As you will be asked to reflect on your needs for information and support, you may be thinking about them more than you might if you were not asked to complete the questionnaires. Although some people may find it upsetting to focus on their needs so much, others find this helpful or don't notice any difference. If you feel too uncomfortable completing the questionnaires, you do not need to continue. If you feel that taking part in the study may make you think too much about your experience, then you can withdraw without having any effect on your legal rights. You should discuss these feelings or concerns with a member of the health care team.

9. What are the possible benefits of taking part?

Although you may not directly benefit from taking part, you may benefit in an indirect manner. This study aims to inform and educate health professionals about your experiences of providing care for a person who receives radiotherapy for lung cancer, to provide better care to you both. Therefore, the health care team will be able to support you both in the best way possible in case you have unmet information needs or need more support. In addition, by completing the set of questionnaires you will have the opportunity to reflect on your experience, which may urge you to discuss this with a member of your own health care team to get help, should you need it.

10. Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the study will be kept strictly confidential. Any information about you, which leaves the hospital, will have your name and address removed from it so that you cannot be recognised from it. Your personal data will be identified only by a participant number.

Your medical records may be inspected by the research team organising the research for purposes of checking data. If you provide your consent, your General Practitioner will be sent a letter, telling him/her that you are taking part in this study.

If you decide to take part, your signed Informed Consent Form will be kept separately from any other information you provide and will be stored in a locked drawer for the Researcher's use only and will not be shared with anyone else.

11. What will happen to my data?

- In order to undertake this study, we will be collecting and storing identifiable information, for example name, telephone number and address. This means that the University of Glasgow is responsible for looking after your information and using it properly. We will keep identifiable information about you for 6 months after the study has finished and will not pass this information to a third party without your express permission.
- If you withdraw from the study, we will keep the research data that we have already obtained. To safeguard your rights, we will use the minimum identifiable information possible. You can find out more about how we use your information from the principal researcher, i.e. Saengrawee Thanthong (please see below for contact details).
- The research team (including the principal researcher and her academic supervisors; please see below for details) from the University of Glasgow will collect, store and process all personal information in accordance with the General Data Protection Regulation (2018).

- All study data will be held in accordance with The General Data Protection Regulation (2018).
- Anonymised research data will be stored in archiving facilities in line with the University of Glasgow’s retention policy for up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.
- Your data will form part of the study results that will be published in expert journals, presentations, student dissertations/theses (if applicable) and on the internet for other researchers to use. Your name will not appear in any publications.

12. What will happen to the results of the research study?

The information you provide will be used to draw general conclusion on family caregivers’ needs for information and support when caring for a patient receiving radiotherapy for lung cancer. The results of the study will then be used for research and education purposes (including reports, publications, and presentations) with strict preservation of your anonymity.

13. Who is organising and funding the research?

The study is being organized by the University of Glasgow. It is being funded by a PhD Student Grant.

14. Who has reviewed the study?

The University of Glasgow Research Ethics Committee, which has responsibility for scrutinising all proposals for research that is conducted by the University of Glasgow, has examined the proposal, and has raised no objections from the point of view of human ethics. It is a requirement that your records in this research, together with any relevant medical record, be made available for scrutiny by the Institutional Review Board from Chulabhorn Hospital, Thailand National Cancer Institute and Ramathibodi Hospital in Thailand, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

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Thank you for taking the time to read this Information Sheet and for considering taking part in this study

Appendix 6 *Questionnaires*

The Memorial Symptom Assessment Scale

MEMORIAL SYMPTOM ASSESSMENT SCALE

Name Date

Section 1

Instructions: We have listed 24 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how OFTEN you had it, how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK Did you have any of the following symptoms?	DID NOT HAVE	IF YES How OFTEN did you have it?				IF YES How SEVERE was it usually				IF YES How much did it DISTRESS or BOTHER you?					Do you need information at home on this symptom?
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much	Yes/No
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4	
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4	
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4	
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4	
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4	
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4	

Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4	
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4	
Numbness/tingling in hands/feet		1	2	3	4	1	2	3	4	0	1	2	3	4	
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4	
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4	
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4	
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4	
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4	
Diarrhoea		1	2	3	4	1	2	3	4	0	1	2	3	4	
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4	
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4	
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4	
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4	
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4	
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4	
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4	
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4	
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4	
Section 2															

"INSTRUCTIONS: We have listed 8 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an ""X"" in the box marked ""DID NOT HAVE."" "

DURING THE PAST WEEK Did you have any of the following symptoms?	DIDNOTHAVE	IF YES How SEVERE was it usually				IF YES How much did it DISTRESS or BOTHER you?					Do you need information at home on this symptom?
		Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much	Yes/No
Mouth sores		1	2	3	4	0	1	2	3	4	
Change in the way food tastes		1	2	3	4	0	1	2	3	4	
Weight loss		1	2	3	4	0	1	2	3	4	
Hair loss		1	2	3	4	0	1	2	3	4	
Constipation		1	2	3	4	0	1	2	3	4	
Swellin of arms or legs		1	2	3	4	0	1	2	3	4	
"I don't look like myself"		1	2	3	4	0	1	2	3	4	
Changes in skin		1	2	3	4	0	1	2	3	4	
IF YOU HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED YOU.											
Other:						0	1	2	3	4	
Other:						0	1	2	3	4	

Other:	0	1	2	3	4	

The Supportive Care Needs Survey - Patient version (SCNS).

Information need subscale

The Supportive Care Needs Survey - Patient version (SCNS-P), Information need subscale.

In the last month, what was your level of need for help with:		**No need**		**Some need**		
		Not applicable	**Satisfied**	**Low need**	**Moderate need**	**High need**
1	To be given written information about the important aspects of your care	1	2	3	4	5
2	To be given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
3	To be informed about your test results as soon as feasible	1	2	3	4	5
4	To be informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
5	To be informed about things you can do to help yourself get well	1	2	3	4	5
6	To be informed about support groups in your area	1	2	3	4	5

The Supportive Care Needs Survey - Partners and Caregivers version (SCNS-P&C),

In the last month, what was your level of need for help with:		No need		Some need		
		Not applicable	**Satisfied**	**Low need**	**Moderate need**	**High need**
1	Accessing information relevant to your needs as a carers/partner	1	2	3	4	5
2	Accessing information about the person with cancer's prognosis, or likely outcome	1	2	3	4	5
3	Accessing information about support services for carers/partners of people with cancer	1	2	3	4	5
4	Accessing information about alternative therapies	1	2	3	4	5
5	Accessing information on what the person with cancer's physical needs are likely to be	1	2	3	4	5
6	Accessing information about the benefits and side-effects of treatments	1	2	3	4	5

Information need subscale.

The Zarit Burden Interview

0: NEVER, 1: RARELY, 2: SOMETIMES, 3: QUITE FREQUENTLY, 4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

1	Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4	Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5	Do you feel angry when you are around your relative?	0 1 2 3 4
6	Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7	Are you afraid what the future holds for your relative?	0 1 2 3 4
8	Do you feel your relative is dependent on you?	0 1 2 3 4
9	Do you feel strained when you are around your relative?	0 1 2 3 4
10	Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11	Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12	Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4
13	Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14	Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	0 1 2 3 4
15	Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16	Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4

17	Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
18	Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19	Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20	Do you feel you should be doing more for your relative?	0 1 2 3 4
21	Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22	Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of Score:

0 - 21 little or no burden

21 - 40 mild to moderate burden

41 - 60 moderate to severe burden

61 - 88 severe burden

Appendix 7 *supplementary material to findings*

Reliability Statistics

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.965	.971	239

Data management and statistical methods

Patients potential predictors (predictors of information need, or symptoms, etc.)

Variable	Variable Type
Patient characteristics	
Age	Continuous (Normally distributed)
Gender	Binary
Marital status	Categorical
Education level	Categorical
Working status	Binary
Career	Categorical
Income	Categorical
Smoking history	Categorical
Smoking type	Categorical
Treatment information	
Pathology	Categorical
Radiotherapy type	Binary
Radiotherapy dose	Categorical
Area of radiotherapy	Categorical

Outcomes (information need, MSAS total score, MSAS sub-domain scores, etc.)

Outcome	Variable Type	RQ	Potential predictors
MSAS subdomains			
Total MSAS	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
The PHYS	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
The PSYCH	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
The GDI	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
MSAS Information Needs	Continuous (nonnormal distribution)	3 (Information)	Age, gender, etc.
SCNS Information Needs	Continuous (nonnormal distribution)	3 (Information)	Age, gender, etc.
Change MSAS subdomains			
Change total MSAS	Continuous (normal distribution)	1 (Symptoms)	Age, gender, etc.
Change The PHYS	Continuous (normal distribution)	1 (Symptoms)	Age, gender, etc.
Change The PSYCH	Continuous (normal distribution)	1 (Symptoms)	Age, gender, etc.
Change The GDI	Continuous (normal distribution)	1 (Symptoms)	Age, gender, etc.
Change MSAS Information Needs	Continuous (normal distribution)	3 (Information)	Age, gender, etc.
Change SCNS Information Needs	Continuous (normal distribution)	3 (Information)	Age, gender, etc.

Different associations

Variable	Outcome	Test
Change total MSAS and MSAS subdomains	Total MSAS (continuous) nonnormal distributed	Wilcoxon Signed Ranks Test
	MSAS subdomains (continuous) nonnormal distributed	Wilcoxon Signed Ranks Test
Patient characteristics		
Age (continuous) normal distributed	Total MSAS (continuous) nonnormal distributed	Correlation (Spearman)
	MSAS subdomains (continuous) nonnormal distributed	Correlation (Spearman)
	MSAS Information Needs (continuous) nonnormal distributed	Correlation (Spearman)
	SCNS Information Needs (continuous) nonnormal distributed	Correlation (Spearman)
	Change total MSAS (continuous) normal distributed	Correlation (Pearson)
	Change The PHYS (continuous) normal distributed	Correlation (Pearson)
	Change The PSYCH (continuous) normal distributed	Correlation (Pearson)
	Change The GDI (continuous) normal distributed	Correlation (Pearson)
	Change MSAS Information Needs (continuous) normal distributed	Correlation (Pearson)
	Change SCNS Information Needs (continuous) normal distributed	Correlation (Pearson)
Gender (Binary)	Total MSAS (continuous)nonnormal distributed	Mann Whitney test
	MSAS subdomains (continuous) nonnormal distributed	Mann Whitney test
	MSAS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	SCNS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	Change total MSAS (continuous) normal distributed	Independent T-test
	Change The PHYS (continuous) normal distributed	Independent T-test
	Change The PSYCH (continuous) normal distributed	Independent T-test
	Change The GDI (continuous) normal distributed	Independent T-test
	Change MSAS Information Needs (continuous) normal distributed	Independent T-test
	Change SCNS Information Needs (continuous) normal distributed	Independent T-test
Marital status (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
Education level (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA

	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
Working status (Binary)	Total MSAS (continuous)nonnormal distributed	Mann Whitney test
	MSAS subdomains (continuous) nonnormal distributed	Mann Whitney test
	MSAS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	SCNS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	Change total MSAS (continuous) normal distributed	Independent T-test
	Change The PHYS (continuous) normal distributed	Independent T-test
	Change The PSYCH (continuous) normal distributed	Independent T-test
	Change The GDI (continuous) normal distributed	Independent T-test
	Change MSAS Information Needs (continuous) normal distributed	Independent T-test
Career (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
Income (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
Smoking history (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous)	Kruskal Wallis
	Change The PHYS (continuous)	ANOVA
	Change The PSYCH (continuous)	ANOVA
	Change The GDI (continuous)	ANOVA
	Change MSAS Information Needs (continuous)	ANOVA
	Change SCNS Information Needs (continuous)	ANOVA
Smoking type (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis

	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
Treatment information		
Pathology (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
Radiotherapy type (Binary)	Total MSAS (continuous)nonnormal distributed	Mann Whitney test
	MSAS subdomains (continuous) nonnormal distributed	Mann Whitney test
	MSAS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	SCNS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
Radiotherapy dose (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Change total MSAS (continuous) normal distributed	ANOVA
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
Area of radiotherapy (Categorical)	Total MSAS (continuous)nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous)	Kruskal Wallis
	SCNS Information Needs (continuous)	Kruskal Wallis
	Change The PHYS (continuous)	ANOVA
	Change The PSYCH (continuous)	ANOVA
	Change The GDI (continuous)	ANOVA
	Change MSAS Information Needs (continuous)	ANOVA
	Change SCNS Information Needs (continuous)	ANOVA

Caregivers potential predictors (predictors of information need, or symptoms, etc.)

Variable	Variable Type
Caregiver characteristics	
Age	Continuous (Normally distributed)
Gender	Binary
Marital status	Categorical
Education level	Categorical
Working status	Binary
Career	Categorical
Income	Categorical
Relationship	Categorical
Smoking history	Categorical
Smoking type	Categorical

Outcomes for caregivers (information need, MSAS total score, MSAS sub-domain scores, etc.)

Outcome	Variable Type	RQ	Potential predictors
Total Caregiver MSAS	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
Caregiver MSAS subdomains			
The Caregiver PHYS	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
The Caregiver PSYCH	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
The Caregiver GDI	Continuous (nonnormal distribution)	1 (Symptoms)	Age, gender, etc.
Caregiver MSAS Information Needs	Continuous (nonnormal distribution)	3 (Information)	Age, gender, etc.
Caregiver SCNS P&C Information Needs	Continuous (nonnormal distribution)	3 (Information)	Age, gender, etc.
Zarit Caregiver Burden	Continuous (nonnormal distribution)	2 (Burden)	Age, gender, etc.
Change MSAS subdomains			
Change The PHYS	Continuous (normal distribution)	1 (Symptoms)	Age, gender, etc.
Change The PSYCH	Continuous (normal distribution)	1 (Symptoms)	Age, gender, etc.
Change The GDI	Continuous (normal distribution)	1 (Symptoms)	Age, gender, etc.
Change MSAS Information Needs	Continuous (normal distribution)	3 (Information)	Age, gender, etc.
Change SCNS-P&C Information Needs	Continuous (normal distribution)	3 (Information)	Age, gender, etc.
Change Zarit Caregiver Burden	Continuous (normal distribution)	2 (Burden)	Age, gender, etc.

Different associations for caregiver

Variable	Outcome	Test
Patient characteristics		

Age (continuous)	Total MSAS (continuous) nonnormal distributed	Correlation (Spearman)
	MSAS subdomains (continuous) nonnormal distributed	Correlation (Spearman)
	MSAS Information Needs (continuous) nonnormal distributed	Correlation (Spearman)
	SCNS Information Needs (continuous) nonnormal distributed	Correlation (Spearman)
	Zarit Caregiver Burden (continuous) nonnormal distributed	Correlation (Spearman)
	Change The PHYS (continuous) normal distributed	Correlation (Pearson)
	Change The PSYCH (continuous) normal distributed	Correlation (Pearson)
	Change The GDI (continuous) normal distributed	Correlation (Pearson)
	Change MSAS Information Needs (continuous) normal distributed	Correlation (Pearson)
	Change SCNS Information Needs (continuous) normal distributed	Correlation (Pearson)
	Change Zarit Caregiver Burden (continuous) normal distributed	Correlation (Pearson)
Gender (Binary)	Total MSAS (continuous) nonnormal distributed	Mann Whitney test
	MSAS subdomains (continuous) nonnormal distributed	Mann Whitney test
	MSAS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	SCNS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	Zarit Caregiver Burden (continuous) nonnormal distributed	Mann Whitney test
	Change The PHYS (continuous) normal distributed	Independent T-test
	Change The PSYCH (continuous) normal distributed	Independent T-test
	Change The GDI (continuous) normal distributed	Independent T-test
	Change MSAS Information Needs (continuous) normal distributed	Independent T-test
	Change SCNS Information Needs (continuous) normal distributed	Independent T-test
	Change Zarit Caregiver Burden (continuous) normal distributed	Independent T-test
Marital status (Categorical)	Total MSAS (continuous) nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Zarit Caregiver Burden (continuous) nonnormal distributed	Kruskal Wallis
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
	Change Zarit Caregiver Burden (continuous) normal distributed	ANOVA
Education level (Categorical)	Total MSAS (continuous) nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Zarit Caregiver Burden (continuous) nonnormal distributed	Kruskal Wallis
	Change The PHYS (continuous) normal distributed	ANOVA

	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
	Change Zarit Caregiver Burden (continuous) normal distributed	ANOVA
Working status (Binary)	Total MSAS (continuous) nonnormal distributed	Mann Whitney test
	MSAS subdomains (continuous) nonnormal distributed	Mann Whitney test
	MSAS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	SCNS Information Needs (continuous) nonnormal distributed	Mann Whitney test
	Zarit Caregiver Burden (continuous) nonnormal distributed	Mann Whitney test
	Change The PHYS (continuous) normal distributed	Independent T-test
	Change The PSYCH (continuous) normal distributed	Independent T-test
	Change The GDI (continuous) normal distributed	Independent T-test
	Change MSAS Information Needs (continuous) normal distributed	Independent T-test
	Change SCNS Information Needs (continuous) normal distributed	Independent T-test
	Change Zarit Caregiver Burden (continuous) normal distributed	Independent T-test
Career (Categorical)	Total MSAS (continuous) nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Zarit Caregiver Burden (continuous) nonnormal distributed	Kruskal Wallis
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
	Change Zarit Caregiver Burden (continuous) normal distributed	ANOVA
Income (Categorical)	Total MSAS (continuous) nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Zarit Caregiver Burden (continuous) nonnormal distributed	Kruskal Wallis
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
	Change Zarit Caregiver Burden (continuous) normal distributed	ANOVA
	Total MSAS (continuous) nonnormal distributed	Kruskal Wallis

Relationship (Categorical)	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Zarit Caregiver Burden (continuous) nonnormal distributed	Kruskal Wallis
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
	Change Zarit Caregiver Burden (continuous) normal distributed	ANOVA
Smoking history (Categorical)	Total MSAS (continuous) nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Zarit Caregiver Burden (continuous) nonnormal distributed	Kruskal Wallis
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
	Change Zarit Caregiver Burden (continuous) normal distributed	ANOVA
Smoking type (Categorical)	Total MSAS (continuous) nonnormal distributed	Kruskal Wallis
	MSAS subdomains (continuous) nonnormal distributed	Kruskal Wallis
	MSAS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	SCNS Information Needs (continuous) nonnormal distributed	Kruskal Wallis
	Zarit Caregiver Burden (continuous) nonnormal distributed	Kruskal Wallis
	Change The PHYS (continuous) normal distributed	ANOVA
	Change The PSYCH (continuous) normal distributed	ANOVA
	Change The GDI (continuous) normal distributed	ANOVA
	Change MSAS Information Needs (continuous) normal distributed	ANOVA
	Change SCNS Information Needs (continuous) normal distributed	ANOVA
	Change Zarit Caregiver Burden (continuous) normal distributed	ANOVA

Attrition rate and characteristics

Attrition rate and characteristics of the patients at the 4 time points

	Visit 1	**Visit 2**	**Visit 3**	**Visit 4**	**P-Value**
	N=56	**N=54**	**N=51**	**N=42**	
Age					0.8994[3]
Means	59.357	58.778	59.216	57.667	
SD	1.622	1.602	1.675	1.630	
Gender					0.976[1]
Male	31	31	30	25	
Female	25	23	21	17	
Marital status					0.992[2]
Single	3	3	3	2	
Married	46	46	43	38	
Divorce	2	2	2	1	
Widow	5	3	3	1	
Education					1.000[2]
Primary	22	20	19	16	
Secondary	4	4	4	3	
High School	11	11	10	7	
Bachelor	18	18	17	15	
Master	1	1	1	1	
Working					0.962[1]
Working	37	36	33	26	
Not working	19	18	18	16	
Career					1.000[2]
Employee	14	14	13	9	
Owner	2	2	2	1	
Farmer	6	5	4	4	
Police	2	2	2	2	
Official	5	5	5	5	
Teacher	1	1	1	1	
Merchant	6	6	5	4	
Driver	1	1	1	1	
Technician	1	1	1	0	

Not work	18	17	17	15	
Income (Thai Bath)					1.000[2]
0-1,000	6	5	5	5	
1,001-5,000	9	8	8	5	
5,001-10,000	8	8	7	6	
10,000-30,000	22	22	22	18	
30,000-50,000	6	6	4	4	
50,000-100,000	3	3	3	2	
>100,000	2	2	2	2	
Smoking history					1.000[2]
light smoker (≤ 10 cigarettes daily)	1	0	0	0	
moderate smoker (≤20 cigarettes daily)	1	1	1	1	
heavy smoker (>20cigarettes daily)	28	28	27	22	
Second hand	5	4	4	3	
Not smoke	21	21	19	16	
Smoking type					1.000[2]
Cigarette	27	26	25	21	
Tobacco	2	2	2	1	
Cigarette and cigar	1	1	1	1	
None	26	25	23	19	

[1] chi-square, [2] fisher' exact and [3] one-way anova

Attrition rate and characteristics of the family caregiver at the 4 time points

	Visit 1	Visit 2	Visit 3	Visit 4	P-Value
	N=56	**N=54**	**N=51**	**N=42**	
Age					0.940[3]
Means	46.304	46.304	45.320	44.905	
SD	13.626	13.626	13.648	13.338	
Gender					0.815[1]
Male	18	18	17	17	
Female	38	38	33	25	
Marital status					1.000[1]

Single	17	17	15	13	
Married	39	39	35	29	
Divorce	0	0	0	0	
Widow	0	0	0	0	
Education					1.000[2]
Primary	9	9	8	7	
Secondary	0	0	0	0	
High School	14	14	11	9	
Bachelor	31	31	29	24	
Master	2	2	2	2	
Working					0.971[1]
Work	48	48	44	37	
Not working	8	8	6	5	
Career					1.000[2]
Employee	19	19	18	15	
Owner	6	6	5	5	
Farmer	5	5	4	4	
Official	5	5	5	4	
Teacher	1	1	1	1	
Merchant	11	11	10	7	
Lawyer	1	1	1	1	
Not work	8	8	6	5	
Income (Thai Bath)					1.000[2]
0-1,000	0	0	0	0	
1,001-5,000	3	3	3	2	
5,001-10,000	4	4	2	3	
10,000-30,000	23	23	22	18	
30,000-50,000	12	12	11	9	
50,000-100,000	12	12	11	10	
>100,000	2	2	1	0	
Smoking history					1.000[2]
light smoker (≤ 10 cigarettes daily)	2	2	1	1	
moderate smoker (≤20 cigarettes daily)	0	0	0	0	

heavy smoker (>20cigarettes daily)	5	5	4	4	
Second hand	0	0	0	0	
Not smoke	49	49	45	37	
Smoking type					1.000[2]
Cigarette	6	6	5	5	
Tobacco	1	1	0	0	
Cigarette and cigar	0	0	0	0	
None	49	49	45	37	

[1] chi-square, [2] fisher' exact and [3] one-way anova

Comparing baseline patient characteristics for those remaining in the study by visit 4 and those that were not in the study by visit 4.

		Still in at visit 4	**Dropped out by visit 4**	**P-Value**
		N=42	**N=14**	
Age				0.071[1]
	Means	57.667	64.430	
	SD	1.630	15.301	
Gender				0.277[2]
	Male	25	6	
	Female	17	8	
Marital status				0.008[3]
	Single	2	1	
	Married	38	8	
	Divorce	1	1	
	Widow	1	4	
Education				0.775[3]
	Primary	16	6	
	Secondary	3	1	
	High School	7	4	
	Bachelor	15	3	
	Master	1	0	
Working				0.338[3]
	Working	26	11	

Not working	16	3	
Career			0.488[3]
Employee	9	5	
Owner	1	1	
Farmer	4	2	
Police	2	0	
Official	5	0	
Teacher	1	0	
Merchant	4	0	
Driver	1	0	
Vendor	0	2	
Technician	0	1	
Not work	15	3	
Income (Thai Bath)			0.750[3]
0-1,000	5	1	
1,001-5,000	5	4	
5,001-10,000	6	2	
10,000-30,000	18	4	
30,000-50,000	4	2	
50,000-100,000	2	1	
>100,000	2	0	
Smoking history			0.441[3]
light smoker (≤ 10 cigarettes daily)	0	1	
moderate smoker (≤20 cigarettes daily)	1	0	
heavy smoker (>20cigarettes daily)	22	6	
Second hand	3	2	
Not smoke	16	5	
Smoking type			0.661[3]
Cigarette	21	6	
Tobacco	1	1	
Cigarette and cigar	1	0	
None	19	7	

[1] t-test, [2] Chi-square [3] fisher' exact

Comparing baseline patient characteristics for those remaining in the study by visit 4 and those that were not in the study by visit 4.

	Still in at visit 4	Dropped out by visit 4	P-Value
	N=42	N=14	
Age			**0.071[1]**
Means	57.667	64.430	
SD	1.630	15.301	
Gender			**0.277[2]**
Male	25	6	
Female	17	8	
Marital status			**0.473[3]**
Married	38	8	
Not Married	4	6	
Education			**0.520[2]**
Primary	16	6	
Secondary	10	5	
University	16	3	
Working			**0.338[3]**
Working	26	11	
Not working	16	3	
Career			**0.145[2]**
None	15	3	
Employee	9	5	
Other	18	6	
Income (Thai Bath)			**0.680[2]**
0-10,000	16	7	
10,001-30,000	18	4	
>30,000	8	3	
Smoking history			**0.301[3]**
None	20	8	
Smoker	22	6	
Smoking type			**0.572[2]**
Cigarette	21	6	
Other	1	1	
None	20	7	

Symptoms experiences (Symptom prevalence, Symptom frequency, Symptom Severity, Symptom Distress

Symptom prevalence at each visit.

Symptom Prevalence	Mean (Standard Deviations)			
	1st Visit	2nd Visit	3rd Visit	4th Visit
Difficulty concentrating	0.46(0.50)	0.44(0.50)	0.57(0.50)	0.48(0.50)
Pain	0.62(0.48)	0.59(0.49)	0.61(0.49)	0.52(0.50)
Lack of energy	0.71(0.45)	0.76(0.43)	0.86(0.34)	0.86(0.35)
Cough	0.59(0.49)	0.54(0.50)	0.49(0.50)	0.38(0.49)
Feeling nervous	0.27(0.44)	0.26(0.44)	0.20(0.40)	0.19(0.39)
Dry mouth	0.54(0.50)	0.35(0.48)	0.31(0.46)	0.21(0.41)
Nausea	0.30(0.46)	0.33(0.47)	0.24(0.42)	0.19(0.39)
Feeling drowsy	0.46(0.50)	0.43(0.49)	0.39(0.49)	0.38(0.49)
Numbness/tingling in hands/feet	0.55(0.50)	0.54(0.50)	0.43(0.50)	0.50(0.50)
Difficulty sleeping	0.48(0.50)	0.50(0.50)	0.65(0.48)	0.50(0.50)
Feeling bloated	0.27(0.44)	0.17(0.37)	0.16(0.36)	0.26(0.44)
Problems with urination	0.20(0.40)	0.15(0.35)	0.16(0.36)	0.17(0.37)
Vomiting	0.16(0.37)	0.13(0.33)	0.08(0.27)	0.14(0.35)
Shortness of breath	0.45(0.50)	0.41(0.49)	0.39(0.49)	0.24(0.43)
Diarrhoea	0.09(0.28)	0.09(0.29)	0.10(0.30)	0.07(0.26)
Feeling sad	0.30(0.46)	0.35(0.48)	0.43(0.50)	0.26(0.44)
Sweats	0.04(0.18)	0.00(0.00)	0.06(0.23)	0.07(0.26)
Worrying	0.39(0.49)	0.46(0.50)	0.51(0.50)	0.50(0.50)
Problems with sexual interest or activity	0.07(0.26)	0.06(0.23)	0.10(0.30)	0.12(0.32)
Itching	0.36(0.48)	0.20(0.40)	0.18(0.38)	0.21(0.41)
Lack of appetite	0.52(0.50)	0.54(0.50)	0.78(0.41)	0.43(0.50)
Dizziness	0.54(0.50)	0.59(0.49)	0.51(0.50)	0.29(0.45)
Difficulty swallowing	0.30(0.46)	0.26(0.44)	0.27(0.45)	0.19(0.39)
Feeling irritable	0.29(0.45)	0.35(0.48)	0.29(0.46)	0.33(0.47)
Chest tightness	0.18(0.38)	0.15(0.35)	0.18(0.38)	0.14(0.35)
difficulty breathing	0.27(0.44)	0.30(0.46)	0.27(0.45)	0.21(0.41)
Mouth sores	0.09(0.28)	0.04(0.19)	0.06(0.23)	0.14(0.35)
Change in the way food tastes	0.30(0.46)	0.33(0.47)	0.22(0.41)	0.24(0.43)
Weight loss	0.59(0.49)	0.61(0.49)	0.76(0.42)	0.52(0.50)
Hair loss	0.23(0.42)	0.24(0.43)	0.41(0.49)	0.38(0.49)

Constipation	0.46(0.50)	0.41(0.49)	0.37(0.48)	0.29(0.45)
Swelling of arms or legs	0.15(0.35)	0.15(0.35)	0.12(0.32)	0.10(0.29)
I don't look like myself	0.57(0.49)	0.44(0.50)	0.49(0.50)	0.38(0.49)
Changes in skin	0.18(0.38)	0.20(0.40)	0.27(0.45)	0.24(0.43)
Hoarseness	0.14(0.35)	0.04(0.19)	0.00(0.00)	0.02(0.15)
Hemiplegia	0.02(0.13)	-	-	-
A lot of saliva	-	-	0.02(0.14)	-

Symptom Frequency at each visit

Symptom Frequency	**Mean (Standard Deviations)**			
	1st Visit	**2nd Visit**	**3rd Visit**	**4th Visit**
Difficulty concentrating	0.89(1.05)	0.78(0.94)	1.04(1.01)	0.81(0.99)
Pain	1.38(1.25)	1.26(1.23)	0.92(0.93)	0.86(1.00)
Lack of energy	1.48(1.19)	1.56(1.09)	1.65(0.93)	1.45(0.88)
Cough	1.32(1.26)	1.11(1.22)	0.82(0.99)	0.57(0.88)
Feeling nervous	0.43(0.75)	0.44(0.81)	0.33(0.71)	0.31(0.71)
Dry mouth	1.11(1.26)	0.65(0.97)	0.49(0.83)	0.33(0.68)
Nausea	0.54(0.87)	0.50(0.81)	0.39(0.80)	0.31(0.71)
Feeling drowsy	0.79(0.98)	0.70(0.92)	0.69(0.96)	0.62(0.88)
Numbness/tingling in hands/feet	1.30(1.42)	1.19(1.31)	0.80(1.05)	0.98(1.11)
Difficulty sleeping	1.00(1.19)	1.00(1.11)	1.24(1.08)	0.95(1.10)
Feeling bloated	0.45(0.80)	0.28(0.68)	0.22(0.54)	0.43(0.88)
Problems with urination	0.29(0.65)	0.30(0.74)	0.31(0.78)	0.29(0.67)
Vomiting	0.23(0.57)	0.19(0.55)	0.10(0.36)	0.19(0.55)
Shortness of breath	0.71(0.88)	0.74(0.99)	0.67(0.93)	0.38(0.79)
Diarrhoea	0.13(0.42)	0.15(0.49)	0.16(0.54)	0.10(0.37)
Feeling sad	0.61(1.02)	0.52(0.77)	0.69(0.86)	0.45(0.88)
Sweats	0.05(0.29)	0.00(0.00)	0.08(0.33)	0.12(0.45)
Worrying	0.66(0.90)	0.78(0.94)	0.92(0.99)	0.79(0.89)
Problems with sexual interest or activity	0.09(0.34)	0.07(0.32)	0.12(0.38)	0.14(0.41)
Itching	0.61(0.96)	0.31(0.69)	0.25(0.59)	0.26(0.54)
Lack of appetite	1.05(1.19)	1.06(1.12)	1.33(0.86)	0.81(1.17)

Dizziness	0.96(1.02)	1.06(0.97)	0.82(0.93)	0.45(0.86)
Difficulty swallowing	0.61(1.05)	0.54(0.96)	0.43(0.75)	0.33(0.84)
Feeling irritable	0.55(0.95)	0.54(0.84)	0.57(0.96)	0.55(0.91)
Chest tightness	0.27(0.61)	0.28(0.71)	0.22(0.50)	0.19(0.50)
difficulty breathing	0.45(0.78)	0.52(0.92)	0.43(0.78)	0.36(0.79)

Symptom severity at each visit.

Symptom Severity	**Mean (Standard Deviations)**			
	1st Visit	**2nd Visit**	**3rd Visit**	**4th Visit**
Difficulty concentrating	0.77(0.89)	0.65(0.82)	0.76(0.79)	0.60(0.73)
Pain	1.29(0.14)	1.07(0.04)	0.90(0.90)	0.76(0.93)
Lack of energy	1.20(0.92)	1.26(0.91)	1.33(0.73)	1.10(0.65)
Cough	1.02(0.00)	0.89(0.98)	0.73(0.91)	0.50(0.74)
Feeling nervous	0.43(0.75)	0.33(0.61)	0.27(0.63)	0.29(0.67)
Dry mouth	0.82(0.87)	0.50(0.77)	0.39(0.63)	0.29(0.59)
Nausea	0.45(0.73)	0.44(0.71)	0.29(0.57)	0.24(0.57)
Feeling drowsy	0.70(0.85)	0.63(0.85)	0.51(0.75)	0.48(0.67)
Numbness/tingling in hands/feet	1.02(0.10)	0.89(0.96)	0.61(0.77)	0.76(0.87)
Difficulty sleeping	0.91(0.03)	0.89(0.02)	0.96(0.87)	0.79(0.95)
Feeling bloated	0.45(0.82)	0.26(0.65)	0.18(0.43)	0.43(0.88)
Problems with urination	0.34(0.74)	0.30(0.74)	0.24(0.58)	0.26(0.62)
Vomiting	0.27(0.64)	0.20(0.59)	0.08(0.27)	0.36(0.69)
Shortness of breath	0.66(0.83)	0.63(0.89)	0.61(0.87)	0.07(0.26)
Diarrhoea	0.11(0.36)	0.09(0.29)	0.14(0.49)	0.40(0.82)
Feeling sad	0.57(0.95)	0.43(0.63)	0.55(0.70)	0.10(0.37)
Sweats	0.05(0.29)	0.00(0.00)	0.08(0.33)	0.62(0.69)
Worrying	0.63(0.84)	0.70(0.90)	0.73(0.85)	0.14(0.41)
Problems with sexual interest or activity	0.09(0.34)	0.06(0.23)	0.10(0.30)	0.26(0.54)
Itching	0.55(0.87)	0.26(0.58)	0.22(0.50)	0.60(0.85)
Lack of appetite	0.89(0.09)	1.02(0.09)	1.08(0.71)	0.43(0.83)
Dizziness	0.91(0.94)	0.85(0.85)	0.65(0.79)	0.31(0.74)
Difficulty swallowing	0.59(0.98)	0.52(0.96)	0.33(0.58)	0.50(0.86)
Feeling irritable	0.45(0.76)	0.48(0.72)	0.51(0.90)	0.19(0.50)
Chest tightness	0.27(0.61)	0.24(0.61)	0.20(0.44)	0.31(0.68)
difficulty breathing	0.43(0.75)	0.43(0.74)	0.39(0.72)	0.14(0.35)

Mouth sores	0.09(0.28)	0.06(0.30)	0.08(0.33)	0.33(0.65)
Change in the way food tastes	0.43(0.75)	0.44(0.71)	0.31(0.64)	0.76(0.98)
Weight loss	1.02(0.05)	0.87(0.84)	0.98(0.67)	0.62(0.08)
Hair loss	0.38(0.79)	0.31(0.63)	0.47(0.61)	0.40(0.73)
Constipation	1.00(0.23)	0.74(0.04)	0.61(0.89)	0.14(0.47)
Swelling of arms or legs	0.30(0.76)	0.28(0.78)	0.14(0.40)	0.67(0.02)
I don't look like myself	1.05(0.08)	0.72(0.94)	0.75(0.89)	0.33(0.65)
Changes in skin	0.32(0.76)	0.28(0.59)	0.33(0.58)	0.60(0.73)

Symptom distress at each visit

Symptom Distress	**Mean (Standard Deviations)**			
	1st Visit	**2nd Visit**	**3rd Visit**	**4th Visit**
Difficulty concentrating	1.29(069)	1.27(066)	1.32(057)	1.21(060)
Pain	1.76(096)	1.61(082)	1.44(071)	1.43(088)
Lack of energy	1.85(100)	1.72(085)	1.68(058)	1.54(045)
Cough	1.59(084)	1.41(082)	1.33(075)	1.13(060)
Feeling nervous	1.14(065)	1.09(059)	1.01(054)	1.02(060)
Dry mouth	1.35(067)	1.14(068)	1.00(045)	1.02(055)
Nausea	1.23(074)	1.10(052)	1.02(048)	1.02(057)
Feeling drowsy	1.25(065)	1.23(070)	1.13(066)	1.24(075)
Numbness/tingling in hands/feet	1.52(091)	1.50(089)	1.22(063)	1.50(095)
Difficulty sleeping	1.65(107)	1.45(086)	1.48(076)	1.40(080)
Feeling bloated	1.16(075)	0.99(046)	0.89(031)	1.17(078)
Problems with urination	1.09(069)	1.04(069)	0.96(055)	1.02(060)
Vomiting	1.00(049)	0.92(036)	0.83(016)	0.96(052)
Shortness of breath	1.29(071)	1.27(073)	1.22(065)	1.07(052)
Diarrhoea	0.86(021)	0.86(021)	0.85(025)	0.82(012)
Feeling sad	1.26(082)	1.13(053)	1.20(059)	1.15(076)
Sweats	0.83(015)	0.80(000)	0.83(022)	0.90(036)
Worrying	1.32(080)	1.35(074)	1.35(072)	1.33(060)
Problems with sexual interest or activity	0.87(028)	0.84(018)	0.85(019)	0.90(032)
Itching	1.23(079)	1.01(055)	0.93(033)	1.00(051)
Lack of appetite	1.52(093)	1.56(093)	1.58(057)	1.33(084)
Dizziness	1.51(081)	1.40(067)	1.29(072)	1.12(064)
Difficulty swallowing	1.29(087)	1.17(081)	1.00(042)	1.04(058)

Feeling irritable	1.14(066)	1.18(062)	1.14(065)	1.27(080)
Chest tightness	1.00(046)	0.99(049)	0.94(038)	0.95(040)
difficulty breathing	1.16(070)	1.13(060)	1.05(049)	1.06(058)
Mouth sores	0.89(029)	0.83(015)	0.82(011)	0.91(038)
Change in the way food tastes	1.14(063)	1.13(058)	0.97(043)	1.06(058)
Weight loss	1.52(080)	1.42(057)	1.48(057)	1.31(070)
Hair loss	1.09(068)	1.01(051)	1.11(045)	1.21(074)
Constipation	1.51(100)	1.36(085)	1.25(077)	1.13(077)
Swelling of arms or legs	1.01(061)	1.04(069)	0.86(022)	0.92(050)
I don't look like myself	1.46(085)	1.37(080)	1.33(071)	1.27(079)
Changes in skin	1.01(060)	1.01(055)	0.99(038)	1.01(043)
Hoarseness	1.00(051)	0.86(031)	0.80(000)	0.82(012)
Hemiplegia	0.85(037)	-	-	-
A lot of saliva	-	-	0.82(011)	-

Caregiver burden

Level of the caregiver burden at four visits

Zarit burden interview	Response	1stVisit N(%)	2ndVisit N(%)	3rdVisit N(%)	4thVisit N(%)
Do you feel that your relative asks for more help than he/she needs?	Never	30(53.6)	29(51.8)	32(64.0)	31(73.8)
	Rarely	14(25.0)	17(30.4)	9(18.0)	7(16.7)
	Sometimes	9(16.1)	7(12.5)	9(18.0)	3(7.1)
	Quite frequently	2(3.6)	2(3.6)	0(0.0)	1(2.4)
	Nearly always	1(1.8)	1(1.8)	0(0.0)	0(0.0)
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	Never	27(48.2)	30(53.6)	23(46.0)	31(78.8)
	Rarely	14(25.0)	15(26.8)	19(38.0)	8(19.1)
	Sometimes	9(16.1)	9(16.1)	7(14.0)	3(7.1)
	Quite frequently	2(3.6)	1(1.8)	1(2.0)	0(0.0)
	Nearly always	1(1.8)	1(1.8)	0(0.0)	0(0.0)
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	Never	18(32.1)	23(41.1)	23(46.0)	31(78.8)
	Rarely	19(33.9)	18(32.1)	18(36.0)	6(14.3)
	Sometimes	13(23.2)	12(21.4)	7(14.0)	4(9.5)
	Quite frequently	4(7.1)	2(3.6)	1(2.0)	1(2.4)
	Nearly always	2(3.6)	1(1.8)	1(2.0)	0(0.0)

Do you feel embarrassed over your relative's behaviour?	Never	38(67.9)	37(66.1)	35(70.0)	34(80.9)
	Rarely	9(16.1)	12(21.4)	11(22.0)	7(16.7)
	Sometimes	9(16.1)	7(12.5)	4(8.0)	1(2.4)
	Quite frequently	0(0.0)	0(0.0)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
Do you feel angry when you are around your relative?	Never	42(75.0)	45(80.4)	42(84.0)	39(92.9)
	Rarely	10(17.9)	9(16.1)	7(14.0)	3(7.1)
	Sometimes	4(7.1)	2(3.6)	1(2.0)	0(0.0)
	Quite frequently	0(0.0)	0(0.0)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	Never	51(91.1)	48(85.7)	42(84.0)	39(92.9)
	Rarely	4(7.1)	7(12.5)	8(16.0)	3(7.1)
	Sometimes	1(1.8)	1(1.8)	0(0.0)	0(0.0)
	Quite frequently	0(0.0)	0(0.0)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
Are you afraid what the future holds for your relative?	Never	9(16.1)	8(14.3)	5(10.0)	11(26.2)
	Rarely	7(12.5)	8(14.3)	4(8.0)	3(7.1)
	Sometimes	14(25.0)	18(32.1)	20(40.0)	17(40.5)
	Quite frequently	15(26.8)	15(26.8)	18(36.0)	7(16.7)
	Nearly always	11(19.6)	7(12.5)	3(6.0)	4(9.5)
Do you feel your relative is dependent on you?	Never	13(23.2)	12(21.4)	12(24.0)	19(45.2)
	Rarely	15(26.8)	20(35.7)	17(34.0)	7(16.7)
	Sometimes	12(21.4)	8(14.3)	11(22.0)	12(28.6)
	Quite frequently	8(14.3)	7(12.5)	5(10.0)	3(7.1)
	Nearly always	8(14.3)	9(16.1)	5(10.0)	1(2.4)
Do you feel strained when you are around your relative?	Never	37(66.1)	35(62.5)	38(76.0)	33(78.6)
	Rarely	15(26.8)	13(23.2)	10(20.0)	9(21.4)
	Sometimes	3(5.4)	8(14.3)	2(4.0)	0(0.0)
	Quite frequently	1(1.8)	0(0.0)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
Do you feel your health has suffered because of your involvement with your relative?	Never	41(73.2)	42(75.0)	43(86.0)	39(92.9)
	Rarely	7(12.5)	7(12.5)	5(10.0)	3(7.1)
	Sometimes	5(8.9)	6(10.7)	2(4.0)	0(0.0)
	Quite frequently	2(3.6)	1(1.8)	0(0.0)	0(0.0)
	Nearly always	1(1.8)	0(0.0)	0(0.0)	0(0.0)
	Never	42(75.0)	43(76.8)	38(76.0)	35(83.3)

Do you feel that you don’t have as much privacy as you would like because of your relative?	Rarely	6(10.7)	5(6.8)	8(16.0)	7(16.7)
	Sometimes	6(10.7)	6(10.7)	2(4.0)	0(0.0)
	Quite frequently	0(0.0)	1(1.8)	2(4.0)	0(0.0)
	Nearly always	2(3.6)	1(1.8)	0(0.0)	0(0.0)
Do you feel that your social life has suffered because you are caring for your relative?	Never	47(83.9)	46(82.1)	40(80.0)	36(85.7)
	Rarely	5(8.9)	5(8.9)	6(12.0)	5(11.9)
	Sometimes	2(3.6)	4(7.1)	2(4.0)	1(2.4)
	Quite frequently	2(3.6)	0(0.0)	1(2.0)	0(0.0)
	Nearly always	0(0.0)	1(1.8)	1(2.0)	0(0.0)
Do you feel uncomfortable about having friends over because of your relative?	Never	46(82.1)	48(85.7)	42(84.0)	37(88.1)
	Rarely	5(8.9)	3(5.4)	3(6.0)	3(7.1)
	Sometimes	4(7.1)	3(5.4)	3(6.0)	2(4.8)
	Quite frequently	1(1.8)	0(0.0)	2(4.0)	0(0.0)
	Nearly always	0(0.0)	2(3.6)	0(0.0)	0(0.0)
Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	Never	23(41.1)	27(48.2)	25(50.0)	28(66.7)
	Rarely	10(17.9)	12(21.4)	10(20.0)	9(21.4)
	Sometimes	10(17.9)	7(12.5)	4(8.0)	3(7.1)
	Quite frequently	6(10.7)	5(8.9)	6(12.0)	2(4.8)
	Nearly always	7(12.5)	5(8.9)	5(10.0)	0(0.0)
Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?	Never	30(53.6)	32(57.1)	30(60.0)	30(71.4)
	Rarely	9(16.1)	11(19.6)	12(24.0)	7(16.7)
	Sometimes	8(14.3)	7(12.5)	4(8.0)	1(2.4)
	Quite frequently	4(7.1)	3(5.4)	1(2.0)	1(2.4)
	Nearly always	5(8.9)	3(5.4)	3(6.0)	3(7.1)
Do you feel that you will be unable to take care of your relative much longer?	Never	52(92.9)	53(94.6)	46(92.0)	41(97.6)
	Rarely	1(1.8)	2(3.6)	3(6.0)	1(2.4)
	Sometimes	2(3.6)	1(1.8)	1(2.0)	0(0.0)
	Quite frequently	1(1.8)	0(0.0)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
Do you feel you have lost control of your life since your relative’s illness?	Never	45(80.4)	48(85.7)	45(90.0)	39(92.9)
	Rarely	9(16.1)	8(14.3)	4(8.0)	3(7.1)
	Sometimes	1(1.8)	0(0.0)	1(2.0)	0(0.0)
	Quite frequently	1(1.8)	0(0.0)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
	Never	54(96.4)	53(94.6)	47(94.0)	42(100.0)

Do you wish you could leave the care of your relative to someone else?	Rarely	2(3.6)	2(3.6)	3(6.0)	0(0.0)
	Sometimes	0(0.0)	0(0.0)	0(0.0)	0(0.0)
	Quite frequently	0(0.0)	1(1.8)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
Do you feel uncertain about what to do about your relative?	Never	36(64.3)	37(66.1)	33(66.0)	33(78.6)
	Rarely	7(12.5)	9(16.1)	7(14.0)	2(4.8)
	Sometimes	7(12.5)	5(8.9)	5(10.0)	3(7.1)
	Quite frequently	2(3.6)	1(1.8)	1(2.0)	1(2.4)
	Nearly always	4(7.1)	4(7.1)	4(8.0)	3(7.1)
Do you feel you should be doing more for your relative?	Never	45(80.4)	47(83.9)	41(82.0)	38(90.5)
	Rarely	3(5.4)	4(7.1)	9(18.0)	4(9.5)
	Sometimes	8(14.3)	4(7.1)	0(0.0)	0(0.0)
	Quite frequently	0(0.0)	1(1.8)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	0(0.0)	0(0.0)	0(0.0)
Do you feel you could do a better job in caring for your relative?	Never	30(53.6)	30(53.6)	30(60.0)	30(71.4)
	Rarely	11(19.6)	11(19.6)	9(18.0)	8(19.1)
	Sometimes	8(14.3)	10(17.9)	8(16.0)	1(2.4)
	Quite frequently	5(8.9)	0(0.0)	1(2.0)	0(0.0)
	Nearly always	2(3.6)	5(8.9)	2(4.0)	3(7.1)
Overall, how burdened do you feel in caring for your relative?	Never	49(87.50	50(89.3)	43(86.0)	40(95.2)
	Rarely	6(10.7)	5(8.9)	6(12.0)	2(4.8)
	Sometimes	1(1.8)	0(0.0)	0(0.0)	0(0.0)
	Quite frequently	0(0.0)	0(0.0)	0(0.0)	0(0.0)
	Nearly always	0(0.0)	1(1.8)	1(2.0)	0(0.0)

The mean and standard deviation of caregiver burden were calculated for four visits, and the statistically significant results are as follows.

Questions	1stVisit Mean(±SD)	2ndVisit Mean(±SD)	3rdVisit Mean(±SD)	4thVisit Mean(±SD)	Sig
Do you feel that your relative asks for more help than he/she needs?	0.75(0.977)	0.73(0.944)	0.54(0.788)	0.38(0.731)	**0.023**
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0.87(1.046)	0.71(0.929)	0.69(0.769)	0.33(0.612)	**0.006**
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	1.16(1.075)	0.93(0.970)	0.78(0.910)	0.40(0.767)	**<0.001**
Do you feel embarrassed over your relative's behaviour?	0.48(0.763)	0.46(0.713)	0.38(0.635)	0.21(0.470)	0.053
Do you feel angry when you are around your relative?	0.32(0.606)	0.23(0.504)	0.18(0.438)	0.07(0.261)	**0.003**
Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0.11(0.366)	0.16(0.417)	0.16(0.370)	0.07(0.261)	0.099
Are you afraid what the future holds for your relative?	2.21(1.345)	2.09(1.225)	2.20(1.030)	1.76(1.284)	0.099
Do you feel your relative is dependent on you?	1.70(1.345)	1.66(1.379)	1.48(1.249)	1.05(1.125)	**0.011**
Do you feel strained when you are around your relative?	0.43(0.684)	0.52(0.738)	0.28(0.536)	0.21(0.415)	0.060
Do you feel your health has suffered because of your involvement with your relative?	0.48(0.934)	0.39(0.755)	0.18(0.482)	0.07(0.261)	**0.000**

Do you feel that you don't have as much privacy as you would like because of your relative?	0.46(0.953)	0.43(0.892)	0.36(0.749)	0.17(377)	0.179
Do you feel that your social life has suffered because you are caring for your relative?	0.27(0.7)	0.30(0.761)	0.34(0.823)	0.17(0.437)	0.121
Do you feel uncomfortable about having friends over because of your relative?	0.29(0.68)	0.30(0.872)	0.30(0.763)	0.17(0.490)	0.225
Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	1.36(1.432)	1.09(1.339)	1.12(1.409)	0.50(0.834)	<0.001
Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	1.02(1.342)	0.82(1.177)	0.70(1.111)	0.57(1.151)	0.000
Do you feel that you will be unable to take care of your relative much longer?	0.14(0.554)	0.07(0.322)	0.10(0.364)	0.02(0.154)	0.120
Do you feel you have lost control of your life since your relative's illness?	0.25(0.580)	0.14(0.353)	0.12(0.385)	0.07(0.261)	0.075
Do you wish you could leave the care of your relative to someone else?	0.04(0.187)	0.09(0.438)	0.06(0.240)	0.00(0.000)	0.304
Do you feel uncertain about what to do about your relative?	0.77(1.236)	0.68(1.177)	0.72(1.230)	0.55(1.194)	0.645
Do you feel you should be doing more for your relative?	0.34(0.721)	0.27(0.674)	0.18(0.388)	0.10(0.297)	0.105
Do you feel you could do a better job in caring for your relative?	0.89(1.171)	0.91(1.240)	0.72(1.070)	0.52(1.087)	0.081
Overall, how burdened do you feel in caring for your relative?	0.14(0.401)	0.16(0.596)	0.20(0.639)	0.05(0.216)	0.255

Information need

Information need at each visit (MSAS)

Symptoms	Baseline (%)	Visit 2(%)	Visit 3(%)	Visit 4(%)	Summary
Difficulty concentrating	44.64	44.44	52.94	45.24	46.80
Pain	58.93	53.70	50.98	42.86	52.22
Lack of energy	66.07	62.96	76.47	78.57	70.44
Cough	53.57	46.30	41.18	33.33	44.33
Feeling nervous	23.21	22.22	15.69	19.05	20.20
Dry mouth	48.21	29.63	25.49	19.05	31.53
Nausea	26.79	27.78	21.57	19.05	24.14
Feeling drowsy	41.07	35.19	31.37	33.33	35.47
Numbness/tingling in hands/feet	55.36	51.85	39.22	45.24	48.28
Difficulty sleeping	44.64	44.44	54.90	42.86	46.80
Feeling bloated	23.21	14.81	11.76	26.19	18.72
Problems with urination	17.86	12.96	11.76	14.29	14.29
Vomiting	14.29	9.26	5.88	14.29	10.84
Shortness of breath	41.07	35.19	33.33	21.43	33.50
Diarrhoea	7.14	7.41	5.88	7.14	6.90
Feeling sad	28.57	29.63	35.29	23.81	29.56
Sweats	3.57	0.00	3.92	7.14	3.45
Worrying	37.50	40.74	41.18	45.24	40.89
Problems with sexual interest or activity	7.14	5.56	7.84	11.90	7.88
Itching	33.93	20.37	13.73	21.43	22.66
Lack of appetite	48.21	48.15	68.63	35.71	50.74
Dizziness	50.00	57.41	47.06	26.19	46.31
Difficulty swallowing	25.00	22.22	19.61	19.05	21.67
Feeling irritable	26.79	33.33	21.57	26.19	27.09
chest tightness	17.86	11.11	11.76	11.90	13.30
difficulty breathing	23.21	25.93	21.57	19.05	22.66
Mouth sores	8.93	3.70	3.92	14.29	7.39
Change in the way food tastes	28.57	29.63	17.65	23.81	25.12
Weight loss	51.79	57.41	66.67	47.62	56.16
Hair loss	23.21	22.22	35.29	30.95	27.59
Constipation	42.86	37.04	31.37	26.19	34.98

Swelling of arms or legs	46.43	12.96	7.84	9.52	20.20
I don't look like myself	16.07	38.89	37.25	30.95	30.54
Changes in skin	14.29	18.52	19.61	21.43	18.23
Hoarseness	14.29	3.70	0.00	2.38	5.42
Hemiplegia	1.79	0.00	0.00	0.00	0.00
	31.00%	29.00%	28.30%	26.20%	

Information need subscale from the Supportive Care Needs Survey - Patient version (SCNS)

	Baseline		**Second visit**		**Third visit**		**Fourth visit**	
	Some need	**No need**	**Some need**	**No need**	**Some need**	**No need**	**Some need**	**No need**
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
To be given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	35 (63)	21 (36)	16 (30)	38 (70)	8 (16)	43 (84)	4 (10)	38 (90)
To be adequately informed about the benefits and side-effects of treatments before you choose to have them	37 (66)	19 (34)	28 (52)	26 (48)	18 (35)	33 (65)	10 (24)	32 (76)
To be informed about your test results as soon as feasible	38 (68)	18 (32)	15 (28)	39 (72)	9 (18)	42 (82)	3 (7)	39 (93)
To be informed about cancer which is under control or diminishing (that is, remission)	39 (70)	17 (30)	21 (39)	33 (61)	14 (27)	37 (73)	4 (10)	38 (90)
To be informed about things you can do to help yourself get well	43 (77)	13 (23)	23 (43)	31 (57)	15 (29)	36 (71)	5 (12)	37 (88)
To be informed about support groups in your area	36 (64)	20 (36)	31 (57)	23 (43)	24 (47)	27 (53)	13 (31)	29 (69)
	228	108	134	190	88	218	39	213

Information need subscale from the Supportive Care Needs Survey – Partners and caregivers version (SCNS-P&C)

Information caregiver needs	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**

	Some need	No need	Some need	No need	Some need	No need	Some need	No need
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Information caregiver needs	41 (73)	15 (27)	26 (46)	30 (54)	12 (24)	38 (76)	9 (21)	33 (79)
Information prognosis	45 (80)	11 (20)	27 (48)	29 (52)	13 (26)	37 (74)	10 (24)	32 (76)
Information support services	46 (82)	10 (18)	30 (54)	26 (46)	15 (30)	35 (70)	10 (24)	32 (76)
Information alternative therapies	48 (86)	8 (14)	42 (75)	14 (25)	36 (72)	14 (28)	25 (60)	17 (40)
Information patient physical needs	47 (84)	9 (16)	29 (52)	27 (48)	15 (30)	35 (70)	12 (29)	30 (71)
Information about the benefits and side-effects of treatment	47 (84)	9 (16)	28 (50)	28 (50)	14 (28)	36 (72)	10 (24)	32 (76)
Information local health care services	88 (79)	12 (21)	35 (62)	21 (38)	24 (48)	26 (52)	19 (45)	23 (55)

Mean and standard deviation of Information need subscale from the Supportive Care Needs Survey - Patient version (SCNS)

Questions	**Mean (±Standard Deviation)**			
	1st Visit	2nd Visit	3rd Visit	4th Visit
To be given written information about the important aspects of your care	3.77±1.44	2.74±1.24	2.37±0.91	2.14±0.52
To be given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	3.77±1.46	3.30±1.40	2.84±1.25	2.52±1.11
To be adequately informed about the benefits and side-effects of treatments before you choose to have them	3.91±1.41	2.72±1.29	2.47±1.04	2.17±0.62
To be informed about your test results as soon as feasible	4.04±1.42	2.96±1.33	2.69±1.19	2.17±0.58

To be informed about cancer which is under control or diminishing (that is, remission)	4.18±1.32	3.06±1.35	2.73±1.20	2.24±0.79
To be informed about things you can do to help yourself get well	3.96±1.27	3.07±1.24	2.96±1.19	2.71±1.21

Mean and standard deviation of Information need subscale from the Supportive Care Needs Survey - Partners and caregivers version (SCNS-P&C)

Questions	Mean (±Standard Deviation)				Average
	1st Visit	2nd Visit	3rd Visit	4th Visit	
Information caregiver needs	4.02±1.31	3.21±1.38	2.66±1.20	2.43±0.91	3.08
Information prognosis	4.20±1.21	3.21±1.34	2.64±1.15	2.48±0.96	3.13
Information support services	4.18±1.19	3.36±1.36	2.68±1.15	2.50±0.99	3.18
Information alternative therapies	3.98±1.13	3.48±1.17	3.30±1.12	2.88±1.01	3.41
Information patient physical needs	4.23±1.16	3.32±1.36	2.74±1.20	2.55±1.06	3.21
Information for decision making	4.23±1.14	3.30±1.38	2.64±1.12	2.52±1.04	3.21
Information local health care services	4.00±1.22	3.34±1.35	3.02±1.27	2.79±1.07	3.29

Nonparametric test and parametric test with change scores.

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
ThePSYCH	.200	42	<.001	.864	42	<.001
ThePSYCH2	.155	42	.013	.906	42	.002
ThePSYCH3	.125	42	.098	.934	42	.018
ThePSYCH4	.171	42	.003	.803	42	<.001
ThePHYS	.133	42	.060	.931	42	.014
ThePHYS2	.161	42	.008	.804	42	<.001
ThePHYS3	.195	42	<.001	.915	42	.004
ThePHYS4	.270	42	<.001	.808	42	<.001
TheGDI	.140	42	.037	.905	42	.002
TheGDI2	.122	42	.122	.916	42	.005
TheGDI3	.142	42	.033	.944	42	.039
TheGDI4	.223	42	<.001	.800	42	<.001
TotalMSAS1	.187	42	<.001	.909	42	.003
TotalMSAS2	.178	42	.002	.883	42	<.001
TotalMSAS3	.203	42	<.001	.853	42	<.001
TotalMSAS4	.198	42	<.001	.803	42	<.001

a. Lilliefors Significance Correction

The Predictors of Symptom experiences

Correlation analysis: Patients characteristics and symptom experiences

The univariate and multivariate analysis correlations were tested.

Age

Spearman’s rho correlation coefficient was used to assess the relationship between age and the total MSAS and MSAS subscale. There was no significant correlation between the age and total MSAS and MSAS subscale at four visits.

Correlation between age and change in symptom experiences.

Baseline			**The PSYCH**	**The PHYS**	**The GDI**	**MSAS**
Spearman’s rho	Age	Correlation Coefficient	-0.032	0.042	-0.077	0.004
		Sig. (2-tailed)	0.816	0.757	0.574	0.978
		N	56	56	56	56
Second visit			**The PSYCH**	**The PHYS**	**The GDI**	**MSAS**
Spearman’s rho	Age	Correlation Coefficient	0.111	-0.001	-0.009	0.038
		Sig. (2-tailed)	0.423	0.992	0.946	0.784
		N	54	54	54	54
Third visit			**The PSYCH**	**The PHYS**	**The GDI**	**MSAS**
Spearman’s rho	Age	Correlation Coefficient	0.077	0.109	0.093	0.103
		Sig. (2-tailed)	0.592	0.445	0.515	0.473
		N	51	51	51	51
Fourth visit			**The PSYCH**	**The PHYS**	**The GDI**	**MSAS**
Spearman’s rho	Age	Correlation Coefficient	-0.118	-0.205	-0.149	-0.178
		Sig. (2-tailed)	0.457	0.193	0.347	0.26
		N	42	42	42	42

Pearson’s correlation was used to assess the relationship between age and change the total MSAS and MSAS subscale. The age and change the PHYS3 were found to be strongly correlated, *r* (40) = -.40, *p* = .01 and the age and change MSAS 3 were found to be statistically significant *r* (40) = -.31, *p* = .048.

Change 1 (Second baseline)	**Change The PSYCH**	**Change The PHYS**	**Change The GDI**	**Change MSAS**

Age	Pearson Correlation	0.168	-0.07	0.053	-0.022
	Sig. (2-tailed)	0.224	0.615	0.702	0.877
	N	54	54	54	54
Change 2 (Third baseline)		Change The PSYCH	Change The PHYS	Change The GDI	Change MSAS
Age	Pearson Coefficient	0.168	-0.017	0.175	0.064
	Sig. (2-tailed)	0.238	0.906	0.22	0.656
	N	51	51	51	51
Change 3 (Fourth baseline)		Change The PSYCH	Change The PHYS	Change The GDI	Change MSAS
Age	Pearson n Coefficient	-0.191	-.395**	-0.221	-.306*
	Sig. (2-tailed)	0.226	0.01	0.159	0.048
	N	42	42	42	42

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Gender

A Mann-Whitney U test showed that there was a significant difference between the male or female and the total MSAS at fourth visit in male group was statistically significantly higher than female (U = 135, *p* = 0.047)

Baseline	**The PSYCH**	**The PHYS**	**The GDI**	**Total MSAS**
Mann-Whitney U	324.000	375.000	375.000	354.500
Z	-1.052	-.206	-.206	-.544
Sig	.293	.837	.837	.586
Second Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	303.500	264.500	354.000	315.000
Z	-.932	-1.610	-.044	-.726
Sig	.352	.107	.965	.468
Third Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	249.000	290.000	265.000	309.000
Z	-1.264	-.479	-.959	-.115
Sig	.206	.632	.338	.909
Fourth Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	144.000	144.500	165.500	135.000
Z	-1.764	-1.743	-1.207	-1.986

Sig	.078	.081	.227	.047

Independent T- test showed that there wasn't a significant difference between the male or female and the change of total MSAS and MSAS subscale.

		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
CHANGESMSAS1	1	0.907	0.345	-1.429	52	0.159	-0.14776	0.10341	-0.35526	0.05975
	2			-1.446	49.413	0.155	-0.14776	0.10222	-0.35312	0.05761
CHANGESMSAS2	1	3.917	0.053	-0.84	49	0.405	-0.085637	0.101912	-0.290437	0.119163
	2			-0.903	48.855	0.371	-0.085637	0.094878	-0.276316	0.105042
CHANGESMSAS3	1	0.87	0.357	-1.358	40	0.182	-0.19226	0.14157	-0.47838	0.09386
	2			-1.426	39.216	0.162	-0.19226	0.13485	-0.46498	0.08046
CHANGESPSYCH1	1	1.031	0.315	-0.672	52	0.505	-0.09448	0.14068	-0.37677	0.18781
	2			-0.696	51.822	0.489	-0.09448	0.13566	-0.36673	0.17776
CHANGESPSYCH2	1	2.301	0.136	0.049	49	0.961	0.00873	0.17812	-0.34922	0.36668
	2			0.051	48.407	0.959	0.00873	0.17034	-0.33369	0.35115
CHANGESPSYCH3	1	0.595	0.445	-1.549	40	0.129	-0.34214	0.22087	-0.78853	0.10425
	2			-1.614	38.702	0.115	-0.34214	0.21199	-0.77104	0.08675
CHANGESPHYS1	1	0.104	0.749	-1.195	52	0.237	-0.1821	0.15235	-0.48781	0.12361
	2			-1.213	49.872	0.231	-0.1821	0.1501	-0.48359	0.1194
CHANGESPHYS2	1	1.762	0.191	-0.755	49	0.454	-0.08954	0.11852	-0.32772	0.14864
	2			-0.814	48.72	0.42	-0.08954	0.10997	-0.31057	0.13149
CHANGESPHYS3	1	1.697	0.2	-1.073	40	0.29	-0.18129	0.16893	-0.52271	0.16012
	2			-1.16	39.973	0.253	-0.18129	0.15628	-0.49715	0.13456
CHANGESGDI	1	1.019	0.317	-0.478	52	0.634	-0.06264	0.13094	-0.32539	0.20012
	2			-0.495	51.767	0.622	-0.06264	0.12642	-0.31635	0.19108
CHANGESGDI2	1	0.963	0.331	0.287	49	0.775	0.0381	0.13266	-0.22849	0.30468
	2			0.297	47.686	0.767	0.0381	0.12805	-0.21941	0.2956
CHANGESGDI3	1	0.123	0.727	-0.903	40	0.372	-0.15078	0.16698	-0.48826	0.18671
	2			-0.945	39.015	0.351	-0.15078	0.15956	-0.47352	0.17197

1 Equal variance assumed.

2 Equal variances not assumed.

Marital status

Kruskal-Wallis Test was conducted to examine the differences on marital status according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (Married, Single, Divorce, Separate, Widowed).

Test Statistics $^{a, b}$

	The PSYCH	The PHYS	The GDI	Total MSAS1
Kruskal-Wallis H	2.482	1.795	0.578	3.238
df	3	3	3	3
Asymp. Sig.	0.479	0.616	0.901	0.356
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	1.85	2.062	1.82	3.876
df	3	3	3	3
Asymp. Sig.	0.604	0.56	0.611	0.275
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	6.741	2.603	4.666	5.946
df	3	3	3	3
Asymp. Sig.	0.081	0.457	0.198	0.114
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	4.498	1.753	3.578	2.38
df	3	3	3	3
Asymp. Sig.	0.212	0.625	0.311	0.497

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

		Sum of Squares	df	Mean Square	F	Sig.
CHANGESMSAS1	Between Groups	0.026	3	0.009	0.056	0.982
	Within Groups	7.604	50	0.152		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.132	3	0.044	0.332	0.802
	Within Groups	6.245	47	0.133		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	0.185	3	0.062	0.283	0.837
	Within Groups	8.301	38	0.218		

	Total	8.486	41			
CHANGESPSYCH1	Between Groups	0.278	3	0.093	0.345	0.793
	Within Groups	13.427	50	0.269		
	Total	13.706	53			
CHANGESPSYCH2	Between Groups	0.394	3	0.131	0.328	0.805
	Within Groups	18.812	47	0.4		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	1.397	3	0.466	0.906	0.447
	Within Groups	19.533	38	0.514		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	0.082	3	0.027	0.084	0.969
	Within Groups	16.291	50	0.326		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	0.227	3	0.076	0.424	0.736
	Within Groups	8.375	47	0.178		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	0.104	3	0.035	0.112	0.953
	Within Groups	11.779	38	0.31		
	Total	11.883	41			
CHANGESGDI	Between Groups	0.08	3	0.027	0.113	0.952
	Within Groups	11.744	50	0.235		
	Total	11.824	53			
CHANGESGDI2	Between Groups	0.987	3	0.329	1.596	0.203
	Within Groups	9.683	47	0.206		
	Total	10.67	50			
CHANGESGDI3	Between Groups	0.853	3	0.284	1.013	0.398
	Within Groups	10.663	38	0.281		
	Total	11.516	41			
CHANGESMSASC1	Between Groups	0.596	3	0.199	0.989	0.405
	Within Groups	10.448	52	0.201		
	Total	11.044	55			
CHANGESMSASC2	Between Groups	0.533	3	0.178	0.739	0.534
	Within Groups	11.064	46	0.241		
	Total	11.597	49			
CHANGESMSASC3	Between Groups	0.608	3	0.203	0.916	0.443
	Within Groups	8.418	38	0.222		

Total	9.027	41

Education level

Kruskal-Wallis Test was conducted to examine the differences on education level according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. Significant difference was found among the seven categories of participants (None, Primary, Secondary, High school, Bachelor, Master, PhD) and The PHYS at fourth visit (Chi square = 10.965, p = .027, df = 4)

Test Statistics $^{a, b}$

	The PSYCH	**The PHYS**	**The GDI**	**Total MSAS1**
Kruskal-Wallis H	7.53	3.55	4.899	5.416
df	4	4	4	4
Asymp. Sig.	0.11	0.47	0.298	0.247
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	8.13	7.541	7.417	9.324
df	4	4	4	4
Asymp. Sig.	0.087	0.11	0.115	0.053
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	8.63	4.089	8.009	5.865
df	4	4	4	4
Asymp. Sig.	0.071	0.394	0.091	0.209
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	7.135	10.965	5.336	8.984
df	4	4	4	4
Asymp. Sig.	0.129	**0.027**	0.255	0.061

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

		Sum of Squares	df	Mean Square	F	Sig.
CHANGESMSAS1	Between Groups	0.243	4	0.061	0.403	0.806
	Within Groups	7.387	49	0.151		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.167	4	0.042	0.31	0.87
	Within Groups	6.21	46	0.135		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	1.186	4	0.297	1.503	0.221
	Within Groups	7.3	37	0.197		
	Total	8.486	41			
CHANGESPSYCH1	Between Groups	0.116	4	0.029	0.104	0.981
	Within Groups	13.59	49	0.277		
	Total	13.706	53			
CHANGESPSYCH2	Between Groups	0.23	4	0.057	0.139	0.967
	Within Groups	18.976	46	0.413		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	1.249	4	0.312	0.587	0.674
	Within Groups	19.68	37	0.532		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	0.835	4	0.209	0.658	0.624
	Within Groups	15.538	49	0.317		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	0.13	4	0.032	0.176	0.949
	Within Groups	8.472	46	0.184		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	1.299	4	0.325	1.135	0.355
	Within Groups	10.584	37	0.286		
	Total	11.883	41			
CHANGESGDI	Between Groups	0.198	4	0.05	0.209	0.932
	Within Groups	11.625	49	0.237		
	Total	11.824	53			
CHANGESGDI2	Between Groups	0.243	4	0.061	0.268	0.897
	Within Groups	10.426	46	0.227		
	Total	10.67	50			
CHANGESGDI3	Between Groups	0.155	4	0.039	0.126	0.972
	Within Groups	11.361	37	0.307		

	Total	11.516	41			
CHANGESMSASC1	Between Groups	0.25	4	0.062	0.295	0.88
	Within Groups	10.795	51	0.212		
	Total	11.044	55			
CHANGESMSASC2	Between Groups	0.231	4	0.058	0.228	0.921
	Within Groups	11.366	45	0.253		
	Total	11.597	49			
CHANGESMSASC3	Between Groups	0.1	4	0.025	0.103	0.981
	Within Groups	8.927	37	0.241		
	Total	9.027	41			

Employment status

A Mann-Whitney U test showed that there wasn’t a significant difference between the patients who still work or not work and the MSAS subscale.

Baseline	**The PSYCH**	**The PHYS**	**The GDI**	**Total MSAS**
Mann-Whitney U	275	346.5	344.5	313.5
Z	-1.331	-0.087	-0.121	-0.658
Sig	0.183	0.931	0.903	0.511
Second Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	230	295	310.5	318
Z	-1.733	-0.532	-0.248	-0.11
Sig	0.083	0.595	0.804	0.912
Third Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	207	248	234.5	233.5
Z	-1.776	-0.966	-1.235	-1.252
Sig	0.076	0.334	0.217	0.211
Fourth Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	195.5	190.5	201	193
Z	-0.325	-0.453	-0.182	-0.389
Sig	0.745	0.65	0.856	0.698

Independent T-test showed that there wasn’t a significant difference between the patients who still work or not work and the change of MSAS subscale.

		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
CHANGESMSAS1	1	0.878	0.353	1.383	52	0.173	0.15015	0.1086	-0.06777	0.36807
	2			1.55	45.819	0.128	0.15015	0.0969	-0.04492	0.34523
CHANGESMSAS2	1	0.199	0.657	0.184	49	0.855	0.019467	0.105672	-0.192888	0.231823
	2			0.176	30.727	0.861	0.019467	0.110651	-0.206288	0.245223
CHANGESMSAS3	1	0.052	0.821	1.288	40	0.205	0.18475	0.14341	-0.10509	0.47459
	2			1.235	27.747	0.227	0.18475	0.14954	-0.12171	0.4912
CHANGESPSYCH1	1	1.104	0.298	-0.025	52	0.98	-0.0037	0.1482	-0.30109	0.29369
	2			-0.023	27.699	0.982	-0.0037	0.16097	-0.33359	0.32618
CHANGESPSYCH2	1	0.02	0.889	-0.721	49	0.475	-0.13148	0.18248	-0.49819	0.23523
	2			-0.713	33.996	0.481	-0.13148	0.18444	-0.50632	0.24336
CHANGESPSYCH3	1	0.075	0.785	1.344	40	0.186	0.30219	0.22482	-0.15219	0.75657
	2			1.29	27.796	0.208	0.30219	0.23432	-0.17795	0.78233
CHANGESPHYS1	1	0	0.992	1.249	52	0.217	0.19938	0.15961	-0.1209	0.51966
	2			1.279	36.317	0.209	0.19938	0.1559	-0.1167	0.51547
CHANGESPHYS2	1	1.964	0.167	0.153	49	0.879	0.01877	0.12274	-0.22789	0.26543
	2			0.137	25.685	0.892	0.01877	0.13736	-0.26375	0.30129
CHANGESPHYS3	1	0.319	0.575	1.047	40	0.302	0.17885	0.17086	-0.16648	0.52417
	2			0.965	24.287	0.344	0.17885	0.18537	-0.20351	0.5612
CHANGESGDI	1	0.005	0.943	0.538	52	0.593	0.07389	0.13727	-0.20157	0.34934
	2			0.527	32.235	0.602	0.07389	0.14026	-0.21173	0.35951
CHANGESGDI2	1	0.227	0.636	-0.379	49	0.706	-0.05172	0.13653	-0.32609	0.22266
	2			-0.366	31.742	0.717	-0.05172	0.14134	-0.33971	0.23627
CHANGESGDI3	1	0.532	0.47	1.245	40	0.22	0.20827	0.16728	-0.12982	0.54636
	2			1.185	27.02	0.246	0.20827	0.17581	-0.15245	0.56899

1 Equal variance assumed

2 Equal variances not assumed

Careers

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the ten categories of participants (None, Employee, Owner, Farmer, Police, Official, Teacher, Vendor, Driver, and Technician).

Test Statistics $^{a, b}$

	The PSYCH	The PHYS	The GDI	Total MSAS1
Kruskal-Wallis H	11.038	11.156	8.069	12.154
df	9	9	9	9
Asymp. Sig.	0.273	0.265	0.527	0.205
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	10.289	10.181	9.234	9.296
df	9	9	9	9
Asymp. Sig.	0.328	0.336	0.416	0.41
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	12.223	13.873	10.171	9.85
df	9	9	9	9
Asymp. Sig.	0.201	0.127	0.337	0.363
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	7.958	13.283	13.148	12.91
df	8	8	8	8
Asymp. Sig.	0.438	0.102	0.107	0.115

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Baseline		Sum of squares	df	Mean Square	F	Sig.
CHANGESMSAS1	Between Groups	1.783	9	0.198	1.491	0.181
	Within Groups	5.847	44	0.133		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.927	9	0.103	0.775	0.64
	Within Groups	5.45	41	0.133		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	2.369	8	0.296	1.597	0.164
	Within Groups	6.118	33	0.185		
	Total	8.486	41			
CHANGESPSYCH1	Between Groups	1.941	9	0.216	0.806	0.613
	Within Groups	11.765	44	0.267		

	Total	13.706	53			
CHANGESPSYCH2	Between Groups	3.459	9	0.384	1.001	0.455
	Within Groups	15.747	41	0.384		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	5.531	8	0.691	1.482	0.202
	Within Groups	15.399	33	0.467		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	4.281	9	0.476	1.731	0.11
	Within Groups	12.093	44	0.275		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	1.064	9	0.118	0.643	0.754
	Within Groups	7.538	41	0.184		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	1.676	8	0.209	0.677	0.708
	Within Groups	10.207	33	0.309		
	Total	11.883	41			
CHANGESGDI	Between Groups	2.648	9	0.294	1.411	0.213
	Within Groups	9.176	44	0.209		
	Total	11.824	53			
CHANGESGDI2	Between Groups	1.725	9	0.192	0.878	0.552
	Within Groups	8.945	41	0.218		
	Total	10.67	50			
CHANGESGDI3	Between Groups	2.441	8	0.305	1.109	0.382
	Within Groups	9.075	33	0.275		
	Total	11.516	41			

Income

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. Significant differences and Chi square = 16.298, p = .012, df = 6) were found among seven categories of participants (0-1,000, 1,001-5,000, 5,001-10,000, 10,001-30,000, 30,001-50,000, 50,001-100,000, >100,000).) at third visit and The GDI (Chi square = 16.298, p = .012, df = 6) and Total MSAS (Chi square = 12.823, p = .046, df = 6).

Test Statistics [a, b]

	The PSYCH	The PHYS	The GDI	Total MSAS1
Kruskal-Wallis H	7.777	6.993	4.243	8.83
df	6	6	6	6
Asymp. Sig.	0.255	0.322	0.644	0.183
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	3.607	1.939	2.991	3.242
df	6	6	6	6
Asymp. Sig.	0.73	0.925	0.81	0.778
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	12.629	9.753	16.298	12.823
df	6	6	6	6
Asymp. Sig.	0.049	0.135	**0.012**	**0.046**
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	2.109	5.216	3.041	3.069
df	6	6	6	6
Asymp. Sig.	0.909	0.516	0.804	0.8

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Baseline		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
CHANGESMSAS1	Between Groups	0.953	6	0.159	1.118	0.367
	Within Groups	6.677	47	0.142		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	1.403	6	0.234	2.069	0.076
	Within Groups	4.974	44	0.113		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	1.47	6	0.245	1.222	0.319
	Within Groups	7.017	35	0.2		
	Total	8.486	41			
CHANGESPSYCH1	Between Groups	1.06	6	0.177	0.656	0.685
	Within Groups	12.646	47	0.269		
	Total	13.706	53			

CHANGESPSYCH2	Between Groups	4.009	6	0.668	1.935	0.096
	Within Groups	15.197	44	0.345		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	3.406	6	0.568	1.134	0.364
	Within Groups	17.524	35	0.501		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	1.595	6	0.266	0.845	0.542
	Within Groups	14.779	47	0.314		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	1.07	6	0.178	1.041	0.412
	Within Groups	7.532	44	0.171		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	1.988	6	0.331	1.172	0.343
	Within Groups	9.895	35	0.283		
	Total	11.883	41			
CHANGESGDI	Between Groups	0.755	6	0.126	0.534	0.779
	Within Groups	11.069	47	0.236		
	Total	11.824	53			
CHANGESGDI2	Between Groups	2.314	6	0.386	2.03	0.082
	Within Groups	8.356	44	0.19		
	Total	10.67	50			
CHANGESGDI3	Between Groups	1.636	6	0.273	0.966	0.463
	Within Groups	9.88	35	0.282		
	Total	11.516	41			

Smoking history

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. Significant differences were found among the five categories of participants (None, Light smoker, Moderate smoker, and Heavy smoker) and The PSYCH at second visit (Chi square = 6.483, p = .09, df = 3) and The PSYCH at fourth visit (Chi square = 9.477, p = .024, df = 3).

Test Statistics [a, b]

	The PSYCH	The PHYS	The GDI	Total MSAS1

Kruskal-Wallis H	2.885	6.199	5.061	5.007
df	4	4	4	4
Asymp. Sig.	0.577	0.185	0.281	0.287
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	6.483	2.235	2.385	0.611
df	3	3	3	3
Asymp. Sig.	**0.09**	0.525	0.496	0.894
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	2.67	3.362	1.406	1.075
df	3	3	3	3
Asymp. Sig.	0.445	0.339	0.704	0.783
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	9.477	4.179	4.071	5.439
df	3	3	3	3
Asymp. Sig.	**0.024**	0.243	0.254	0.142

a Kruskal Wallis Test

b Grouping Variable: Marital status

There was a statistically significant difference between groups as determined by one-way ANOVA in Change PHYS at second visit (F (3,47) =5.109, *p*=0.004).

Baseline		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
CHANGESMSAS1	Between Groups	0.384	3	0.128	0.883	0.456
	Within Groups	7.246	50	0.145		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.525	3	0.175	1.405	0.253
	Within Groups	5.852	47	0.125		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	0.284	3	0.095	0.438	0.727
	Within Groups	8.202	38	0.216		
	Total	8.486	41			
CHANGESPSYCH1	Between Groups	0.733	3	0.244	0.942	0.428

	Within Groups	12.973	50	0.259		
	Total	13.706	53			
CHANGESPSYCH2	Between Groups	0.622	3	0.207	0.524	0.668
	Within Groups	18.584	47	0.395		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	0.238	3	0.079	0.145	0.932
	Within Groups	20.692	38	0.545		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	1.617	3	0.539	1.826	0.154
	Within Groups	14.756	50	0.295		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	2.115	3	0.705	5.109	0.004
	Within Groups	6.487	47	0.138		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	0.953	3	0.318	1.104	0.359
	Within Groups	10.931	38	0.288		
	Total	11.883	41			
CHANGESGDI	Between Groups	0.711	3	0.237	1.066	0.372
	Within Groups	11.113	50	0.222		
	Total	11.824	53			
CHANGESGDI2	Between Groups	1.358	3	0.453	2.285	0.091
	Within Groups	9.312	47	0.198		
	Total	10.67	50			
CHANGESGDI3	Between Groups	1.064	3	0.355	1.29	0.292
	Within Groups	10.452	38	0.275		
	Total	11.516	41			

Smoking type

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. Significant differences were found among the five categories of participants (Cigarette, Tobacco, Cigar, Cigarette and Cigar, None) and The PHYS at second visit (Chi square = 8.507, p = .037, df = 3).

Test Statistics [a, b]

	The PSYCH	The PHYS	The GDI	Total MSAS1
Kruskal-Wallis H	5.119	1.936	3.61	3.295
df	3	3	3	3
Asymp. Sig.	0.163	0.586	0.307	0.348
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	0.582	8.507	2.467	4.053
df	3	3	3	3
Asymp. Sig.	0.901	**0.037**	0.481	0.256
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	1.836	0.978	1.268	0.614
df	3	3	3	3
Asymp. Sig.	0.607	0.807	0.737	0.893
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	5.456	3.219	1.883	5.238
df	3	3	3	3
Asymp. Sig.	0.141	0.359	0.597	0.155

a Kruskal Wallis Test

b Grouping Variable: Marital status

There was a statistically significant difference between groups as determined by one-way ANOVA and ChangeMSAS1 (F (3,50 = 2.503, p=0.07) and ChangePHYS1 (F (3,50) =3.127, p=0.034) and ChangeGDI1 (F (3,50= 2.848, p=0.047).

Baseline		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
CHANGESMSAS1	Between Groups	0.996	3	0.332	2.503	0.07
	Within Groups	6.634	50	0.133		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.547	3	0.182	1.469	0.235

	Within Groups	5.83	47	0.124		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	0.056	3	0.019	0.083	0.969
	Within Groups	8.431	38	0.222		
	Total	8.486	41			
CHANGESPSYCH1	Between Groups	1.843	3	0.614	2.59	0.063
	Within Groups	11.863	50	0.237		
	Total	13.706	53			
CHANGESPSYCH2	Between Groups	1.974	3	0.658	1.795	0.161
	Within Groups	17.231	47	0.367		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	0.276	3	0.092	0.169	0.917
	Within Groups	20.654	38	0.544		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	2.586	3	0.862	3.127	0.034
	Within Groups	13.787	50	0.276		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	0.455	3	0.152	0.876	0.46
	Within Groups	8.147	47	0.173		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	0.11	3	0.037	0.118	0.949
	Within Groups	11.773	38	0.31		
	Total	11.883	41			
CHANGESGDI	Between Groups	1.726	3	0.575	2.848	0.047
	Within Groups	10.098	50	0.202		
	Total	11.824	53			
CHANGESGDI2	Between Groups	1.412	3	0.471	2.389	0.081
	Within Groups	9.258	47	0.197		
	Total	10.67	50			
CHANGESGDI3	Between Groups	0.029	3	0.01	0.032	0.992
	Within Groups	11.487	38	0.302		
	Total	11.516	41			

Pathology

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. Significant differences found among the five categories of participants (Squamous, Adenocarcinoma, NSCLC, Unspecified, SCLC, other) and The PSYCH at baseline (Chi square = 11.268, p = 0.046, df = 5).

Test Statistics [a, b]

	The PSYCH	The PHYS	The GDI	Total MSAS1
Kruskal-Wallis H	11.268	3.226	7.357	5.618
df	5	5	5	5
Asymp. Sig.	**0.046**	0.665	0.195	0.345
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	4.265	5.121	5.429	6.848
df	5	5	5	5
Asymp. Sig.	0.512	0.401	0.366	0.232
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	6.541	1.511	0.635	2.057
df	5	5	5	5
Asymp. Sig.	0.257	0.912	0.986	0.841
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	2.745	7.434	3.088	7.468
df	5	5	5	5
Asymp. Sig.	0.739	0.19	0.686	0.188

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Baseline		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
CHANGESMSAS1	Between Groups	0.748	5	0.15	1.043	0.403
	Within Groups	6.882	48	0.143		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.821	5	0.164	1.329	0.269
	Within Groups	5.556	45	0.123		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	1.435	5	0.287	1.466	0.225
	Within Groups	7.051	36	0.196		

	Total	8.486	41			
CHANGESPSYCH1	Between Groups	2.232	5	0.446	1.868	0.118
	Within Groups	11.474	48	0.239		
	Total	13.706	53			
CHANGESPSYCH2	Between Groups	1.828	5	0.366	0.947	0.46
	Within Groups	17.378	45	0.386		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	2.843	5	0.569	1.132	0.361
	Within Groups	18.087	36	0.502		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	1.107	5	0.221	0.696	0.629
	Within Groups	15.266	48	0.318		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	0.693	5	0.139	0.789	0.563
	Within Groups	7.909	45	0.176		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	1.834	5	0.367	1.314	0.28
	Within Groups	10.049	36	0.279		
	Total	11.883	41			
CHANGESGDI	Between Groups	2.261	5	0.452	2.269	0.062
	Within Groups	9.563	48	0.199		
	Total	11.824	53			
CHANGESGDI2	Between Groups	1.266	5	0.253	1.211	0.319
	Within Groups	9.404	45	0.209		
	Total	10.67	50			
CHANGESGDI3	Between Groups	1.173	5	0.235	0.816	0.546
	Within Groups	10.343	36	0.287		
	Total	11.516	41			

Radiotherapy type

A Mann-Whitney U test showed that there was a significant difference between the 2D or 3D and the total MSAS at third visit (U = 235, Z = -1.696, p = 0.09).

Baseline	**The PSYCH**	**The PHYS**	**The GDI**	**Total MSAS**
Mann-Whitney U	360.5	347.5	349	306.5
Z	-0.511	-0.722	-0.698	-1.394
Sig	0.609	0.471	0.485	0.163
Second Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	336.5	300.5	342	316
Z	-0.478	-1.099	-0.381	-0.831
Sig	0.632	0.272	0.703	0.406
Third Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	254.5	246.5	280.5	235
Z	-1.33	-1.48	-0.84	-1.696
Sig	0.184	0.139	0.401	0.09
Fourth Visit	The PSYCH	The PHYS	The GDI	Total MSAS
Mann-Whitney U	158.5	171	169	167
Z	-1.469	-1.144	-1.198	-1.245
Sig	0.142	0.253	0.231	0.213

Radiotherapy dose

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the seven categories of participants (20Gy/4-5F, 25Gy/5-7F, 30Gy/10F, 35Gy/15F, 60Gy/30F).

Test Statistics [a, b]

	The PSYCH	**The PHYS**	**The GDI**	**Total MSAS1**
Kruskal-Wallis H	1.724	3.048	2.634	1.996
df	4	4	4	4
Asymp. Sig.	0.786	0.55	0.621	0.737
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	3.459	4.083	5.42	3.501

df	4	4	4	4
Asymp. Sig.	0.484	0.395	0.247	0.478
	The PSYCH3	**ThePHYS3**	**TheGDI3**	**Total MSAS3**
Kruskal-Wallis H	3.741	2.258	7.025	2.806
df	4	4	4	4
Asymp. Sig.	0.442	0.688	0.135	0.591
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	3.417	4.583	4.171	3.892
df	4	4	4	4
Asymp. Sig.	0.491	0.333	0.383	0.421

a Kruskal Wallis Test

b Grouping Variable: Marital status

There was a statistically significant difference between groups as determined by one-way ANOVA in changesMSAS1 (F (4,49) = 5.616, p = 0.001), ChangesPSYCH1 (F (4,49) = 2.631, p = 0.045), ChangesPSYCH2 (F (4,46) = 2.151, p = 0.09) ChangesPHYS1 (F (4,49) = 4.194, p = 0.005) and ChangesGDI1 (F (4,49) = 2.318, p = 0.07).

Baseline		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
CHANGESMSAS1	Between Groups	2.398	4	0.6	5.616	0.001
	Within Groups	5.232	49	0.107		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.781	4	0.195	1.605	0.189
	Within Groups	5.596	46	0.122		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	0.071	4	0.018	0.078	0.988
	Within Groups	8.415	37	0.227		
	Total	8.486	41			
CHANGESPSYCH1	Between Groups	2.424	4	0.606	2.631	0.045
	Within Groups	11.282	49	0.23		
	Total	13.706	53			
CHANGESPSYCH2	Between Groups	3.026	4	0.757	2.151	0.09
	Within Groups	16.18	46	0.352		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	0.173	4	0.043	0.077	0.989
	Within Groups	20.757	37	0.561		

	Total	20.93	41			
CHANGESPHYS1	Between Groups	4.176	4	1.044	4.194	0.005
	Within Groups	12.197	49	0.249		
	Total	16.373	53			
CHANGESPHYS2	Between Groups	1.124	4	0.281	1.729	0.16
	Within Groups	7.478	46	0.163		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	0.196	4	0.049	0.155	0.96
	Within Groups	11.688	37	0.316		
	Total	11.883	41			
CHANGESGDI	Between Groups	1.881	4	0.47	2.318	0.07
	Within Groups	9.943	49	0.203		
	Total	11.824	53			
CHANGESGDI2	Between Groups	1.236	4	0.309	1.507	0.216
	Within Groups	9.434	46	0.205		
	Total	10.67	50			
CHANGESGDI3	Between Groups	0.188	4	0.047	0.154	0.96
	Within Groups	11.328	37	0.306		
	Total	11.516	41			

Area of radiotherapy

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (Chest, Mediastinum, Bone, Brain, Other).

Test Statistics $^{a, b}$

	The PSYCH	**The PHYS**	**The GDI**	**Total MSAS1**
Kruskal-Wallis H	3.176	0.936	4.529	1.249
df	4	4	4	4
Asymp. Sig.	0.529	0.919	0.339	0.87
	The PSYCH2	**The PHYS2**	**The GDI2**	**Total MSAS2**
Kruskal-Wallis H	3.318	1.378	5.884	2.981
df	4	4	4	4
Asymp. Sig.	0.506	0.848	0.208	0.561

	The PSYCH3	ThePHYS3	TheGDI3	Total MSAS3
Kruskal-Wallis H	1.547	3.774	4.083	1.975
df	4	4	4	4
Asymp. Sig.	0.818	0.437	0.395	0.74
	The PSYCH4	**The PHYS4**	**The GDI4**	**Total MSAS4**
Kruskal-Wallis H	1.415	2.013	3.628	1.264
df	4	4	4	4
Asymp. Sig.	0.842	0.733	0.459	0.867

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Baseline		Sum of squares	df	Mean Square	F	Sig.
CHANGESMSAS1	Between Groups	0.719	4	0.18	1.274	0.293
	Within Groups	6.911	49	0.141		
	Total	7.63	53			
CHANGESMSAS2	Between Groups	0.25	4	0.062	0.469	0.758
	Within Groups	6.127	46	0.133		
	Total	6.377	50			
CHANGESMSAS3	Between Groups	0.049	4	0.012	0.054	0.994
	Within Groups	8.437	37	0.228		
	Total	8.486	41			
CHANGESPSYCH1	Between Groups	1.97	4	0.493	2.056	0.101
	Within Groups	11.736	49	0.24		
	Total	13.706	53			
CHANGESPSYCH2	Between Groups	0.202	4	0.051	0.122	0.974
	Within Groups	19.004	46	0.413		
	Total	19.206	50			
CHANGESPSYCH3	Between Groups	0.193	4	0.048	0.086	0.986
	Within Groups	20.736	37	0.56		
	Total	20.93	41			
CHANGESPHYS1	Between Groups	1.215	4	0.304	0.982	0.426
	Within Groups	15.159	49	0.309		

	Total	16.373	53			
CHANGESPHYS2	Between Groups	0.681	4	0.17	0.989	0.423
	Within Groups	7.921	46	0.172		
	Total	8.602	50			
CHANGESPHYS3	Between Groups	0.303	4	0.076	0.242	0.912
	Within Groups	11.58	37	0.313		
	Total	11.883	41			
CHANGESGDI	Between Groups	0.992	4	0.248	1.122	0.357
	Within Groups	10.832	49	0.221		
	Total	11.824	53			
CHANGESGDI2	Between Groups	0.509	4	0.127	0.576	0.681
	Within Groups	10.161	46	0.221		
	Total	10.67	50			
CHANGESGDI3	Between Groups	0.322	4	0.08	0.266	0.898
	Within Groups	11.194	37	0.303		
	Total	11.516	41			

The Predictors associated with increased caregivers' burden

Age

Spearman's rho correlation coefficient was used to assess the relationship between age and the caregivers' burden. There was no significant correlation between the age and information needs at four visits.

Zarit Burden Interview			**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Spearman's rho	Age	Correlation Coefficient	0.147	0.127	0.134	0.122
		Sig. (2-tailed)	0.28	0.35	0.36	0.44
		N	56	56	50	42

Pearson correlation coefficient was used to assess the relationship between age and the change of caregivers' burden. There was no significant correlation between the age and information needs at four visits.

			Change 1	**Change 2**	**Change 3**

Pearson	Age	Pearson Correlation	-0.46	-0.088	-0.046
		Sig. (2-tailed)	0.734	0.545	0.772
		N	56	50	42

Gender

A Mann-Whitney U test showed that there wasn’t a significant difference between the male or female and the caregivers’ burden from ZBI.

ZBI	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Mann-Whitney U	467.5	449.5	396	273
Z	2.204	1.890	2.372	1.557
Sig	0.28	0.059	0.018	0.119

Independent 9:12 PM-test showed that there wasn’t a significant difference between the male or female and the change of caregivers’ burden from ZBI.

		F	**Sig.**	**t**	**df**	**Sig. (2-tailed)**	**Mean Difference**	**Std. Error Difference**	**95% Confidence Interval of the Difference**	
									Lower	Upper
ChangeZ1	1	0.724	0.399	0.888	54	0.189	0.379	1.21053	1.36355	-1.52322
	2			0.983	43.45	0.166	0.331	1.21053	1.23198	-1.27326
ChangeZ2	1	1.526	0.223	0.724	48	0.236	0.473	1.28164	1.77122	-2.27965
	2			0.85	47.061	0.2	0.4	1.28164	1.50852	-1.753
ChangeZ3	1	0.004	0.952	0.793	40	0.216	0.432	1.87294	2.36092	-2.89866
	2			0.793	34.53	0.216	0.433	1.87294	2.36068	-2.92183

Marital status

Kruskal-Wallis Test was conducted to examine the differences on according to the ZBI at four period of times. No significant differences were found among the five categories of participants (Married, Single, Divorce, Separate, Widowed).

ZBI	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**

Kruskal-Wallis H	28.288	17.448	27.344	13.137
df	28	25	22	16
Asymp. Sig.	0.449	0.865	0.198	0.663

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Caregivers' burden		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	38.914	1	38.914	1.743	0.192
	Within groups	1205.3	54	22.32		
	Total	1244.214	55			
ChangeIN2	Between groups	27.849	1	27.849	0.796	0.377
	Within groups	1680.171	48	35.004		
	Total	1708.02	49			
ChangeIN3	Between groups	8.834	1	8.834	0.155	0.696
	Within groups	2282.785	40	57.07		
	Total	2291.619	41			

Education level

Kruskal-Wallis Test was conducted to examine the differences on according to The ZBI at four period of times. No significant differences were found among the seven categories of participants (None, Primary, Secondary, High school, Bachelor, Master, PhD).

ZBI	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	33.426	26.497	24.743	19.061
df	28	25	22	16
Asymp. Sig.	0.220	0.381	0.310	0.266

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Caregivers' burden		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	3.709	3	1.236	0.052	0.984
	Within groups	1240.506	52	23.856		
	Total	1244.214	55			
ChangeIN2	Between groups	9.337	3	3.112	0.084	0.968
	Within groups	1698.683	46	36.928		
	Total	1708.02	49			
ChangeIN3	Between groups	280.071	3	93.357	1.764	0.171
	Within groups	2011.548	38	52.935		
	Total	2291.619	41			

Employment status

A Mann-Whitney U test showed that there wasn't a significant difference between the male or female and the information need from modified MSAS.

Information needs from modified MSAS	Baseline	Second visit	Third visit	Fourth visit
Mann-Whitney U	228	212	118.5	146.5
Z	0844	0.469	1.691	2.107
Sig	0.413	0.654	0.092	0.33

Independent t-test showed that there wasn't a significant difference between the male or female and the change of information need from modified MSAS.

		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ChangeIN1	1	0.572	0.453	0.998	54	0.161	0.323	1.8125	1.8164	-1.82916
	2			0.926	9.005	0.189	0.379	1.8125	1.95719	-2.61462
ChangeIN2	1	0.162	0.689	0.085	48	0.466	0.933	0.2197	2.59583	-4.99957
	2			0.112	8.206	0.457	0.913	0.2197	1.95785	-4.27542
ChangeIN3	1	0.091	0.765	-1.073	40	0.145	0.29	-3.81622	3.55562	-11.0024
	2			-0.988	4.915	0.185	0.369	-3.81622	3.86396	-13.8007

Career

Kruskal-Wallis Test was conducted to examine the differences on according to The ZBI at four period of times. No significant differences were found among the ten categories of participants (None, Employee, Owner, Farmer, Police, Official, Teacher, Vendor, Driver and Technician).

ZBI	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	24.487	110759	16.178	17.453
df	28	25	22	16
Asymp. Sig.	0.656	0.988	0.807	0.357

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Caregivers’ burden		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	241.489	7	34.498	1.651	0.144
	Within groups	1002.726	48	20.89		
	Total	1244.214	55			
ChangeIN2	Between groups	415.209	7	59.316	1.927	0.089
	Within groups	1292.811	42	30.781		
	Total	1708.02	49			
ChangeIN3	Between groups	262.571	7	37.51	0.629	0.729
	Within groups	2029.048	34	59.678		
	Total	2291.619	41			

Income

Kruskal-Wallis Test was conducted to examine the differences on according to The ZBI at four period of times. No significant differences were found among the seven categories of participants (0-1,000, 1,001-5,000, 5,001-10,000, 10,001-30,000, 30,001-50,000, 50,001-100,000, >100,000).

Information needs from modified MSAS	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	34.711	34.654	24.787	12.815

df	28	22	22	16
Asymp. Sig.	0.178	0.095	0.307	0.686

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Caregivers’ burden		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	126.229	5	25.246	1.129	0.357
	Within groups	1117.986	50	22.36		
	Total	1244.214	55			
ChangeIN2	Between groups	30.702	5	6.14	0.161	0.975
	Within groups	1677.318	44	38.121		
	Total	1708.02	49			
ChangeIN3	Between groups	84.886	4	21.221	0.356	0.838
	Within groups	2206.733	37	59.641		
	Total	2291.619	41			

Smoking history

Kruskal-Wallis Test was conducted to examine the differences on according to The ZBI at four period of times. No significant differences were found among the five categories of participants (None, Light smoker, Moderate smoker and Heavy smoker).

ZBI	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	19.842	23.660	13.113	15.781
df	28	25	22	16
Asymp. Sig.	0.870	0.539	0.930	0.468

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Caregivers’ burden		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	6.892	2	3.446	0.148	0.863
	Within groups	1237.322	53	23.346		

	Total	1244.214	55			
ChangeIN2	Between groups	10.242	2	5.121	0.142	0.868
	Within groups	1697.778	47	36.123		
	Total	1708.02	49			
ChangeIN3	Between groups	50.592	2	25.296	0.44	0.647
	Within groups	2241.027	39	57.462		
	Total	2291.619	41			

Smoking type

Kruskal-Wallis Test was conducted to examine the differences on according to The ZBI at four period of times. No significant differences were found among the five categories of participants (Cigarette, Tobacco, Cigar, Cigarette and Cigar, None).

ZBI	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	20.699	25.470	13.248	15.248
df	28	25	22	16
Asymp. Sig.	0.838	0.436	0.926	0.507

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Caregivers’ burden		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	9.259	2	4.629	0.199	0.82
	Within groups	1234.956	53	23.301		
	Total	1244.214	55			
ChangeIN2	Between groups	3.042	1	3.042	0.086	0.771
	Within groups	1704.978	48	35.52		
	Total	1708.02	49			
ChangeIN3	Between groups	49.792	1	49.792	0.888	0.352
	Within groups	2241.827	40	56.046		
	Total	2291.619	41			

Relationships

Kruskal-Wallis Test was conducted to examine the differences on according to The ZBI at four period of times. No significant differences were found among the five categories of participants (Cigarette, Tobacco, Cigar, Cigarette and Cigar, None).

ZBI	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	22.398	21.856	22.311	12.975
df	28	25	22	16
Asymp. Sig.	0.763	0.644	0.441	0.675

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Caregivers’ burden		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	86.224	4	21.556	0.949	0.443
	Within groups	1157.99	51	22.706		
	Total	1244.214	55			
ChangeIN2	Between groups	27.169	4	6.792	0.182	0.947
	Within groups	1680.851	45	37.352		
	Total	1708.02	49			
ChangeIN3	Between groups	74.136	4	18.534	0.309	0.87
	Within groups	2217.483	37	59.932		
	Total	2291.619	41			

The Predictors associated with increased information need in patients

Age

Spearman's rho correlation coefficient was used to assess the relationship between age and the information needs. There was no significant correlation between the age and information needs at four visits.

Information needs from modified MSAS			**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Spearman's rho	Age	Correlation Coefficient	0.144	-0.005	0.032	-0.03
		Sig. (2-tailed)	0.29	0.97	0.826	0.853
		N	56	54	50	42
SCNS (information need subscale)			Baseline	Second visit	Third visit	Fourth visit
Spearman's rho	Age	Correlation Coefficient	-0.037	-0.04	-0.041	-0.09
		Sig. (2-tailed)	0.788	0.777	0.778	0.569
		N	56	54	51	42

Pearson correlation coefficient was used to assess the relationship between age and the change of information needs. There was no significant correlation between the age and information needs at four visits.

Information needs from modified MSAS			**Change 1**	**Change 2**	**Change 3**
Pearson	Age	Pearson Correlation	-0.182	-0.176	-0.262
		Sig. (2-tailed)	0.189	0.222	0.094
		N	54	50	42
SCNS (information need subscale)			Change 1	Change 2	Change 3
Pearson	Age	Pearson Correlation	0.033	0.057	0.18
		Sig. (2-tailed)	0.81	0.693	0.253
		N	54	51	42

Gender

A Mann-Whitney U test showed that there wasn't a significant difference between the male or female and the information need from modified MSAS.

Information needs from modified MSAS	Baseline	Second visit	Third visit	Fourth visit
Mann-Whitney U	362.5	340	303	142.5
Z	-0.413	-0.289	-0.03	-1.798
Sig	0.68	0.772	0.976	0.072
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Mann-Whitney U	376	340.5	271.5	194
Z	-0.199	-0.288	-0.895	-0.543
Sig	0.842	0.774	0.371	0.587

Independent t-test showed that there wasn't a significant difference between the male or female and the change of information need from modified MSAS.

		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ChangeIN1	1	0.696	0.408	1.442	52	0.155	2.36111	1.63753	-0.92482	5.64705
	2			1.596	44.482	0.118	2.36111	1.47977	-0.62026	5.34249
ChangeIN2	1	0.252	0.618	0.853	48	0.398	1.69519	1.98618	-2.2983	5.68868
	2			0.772	25.005	0.448	1.69519	2.19679	-2.82913	6.21951
ChangeIN3	1	0.171	0.681	1.395	40	0.171	3.9375	2.82191	-1.7658	9.6408
	2			1.448	35.652	0.156	3.9375	2.71842	-1.57758	9.45258
ChangeSCNS1	1	0.859	0.358	0.163	52	0.871	0.36111	2.21586	-4.08534	4.80756
	2			0.165	35.447	0.87	0.36111	2.18407	-4.07078	4.79301
ChangeSCNS2	1	0.254	0.617	-1.066	49	0.292	-2.57071	2.41114	-7.41607	2.27466
	2			-1.021	30.967	0.315	-2.57071	2.51781	-7.70603	2.56461
ChangeSCNS3	1	3.652	0.063	-0.027	40	0.979	-0.0625	2.3322	-4.77605	4.65105
	2			-0.028	35.705	0.978	-0.0625	2.24541	-4.6177	4.4927

Marital status

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (Married, Single, Divorce, Separate, Widowed).

Information needs from modified MSAS	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	3.067	2.12	4.686	2.292
df	3	3	3	3
Asymp. Sig.	0.381	0.548	0.196	0.514
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	5.686	0.291	3.896	5.383
df	3	3	3	3
Asymp. Sig.	0.128	0.962	0.273	0.146

a Kruskal Wallis Test

b Grouping Variable: Marital status

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Information need		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	23.547	3	7.849	0.229	0.876
	Within groups	1716.601	50	34.332		
	Total	1740.148	53			
ChangeIN2	Between groups	104.701	3	34.9	0.782	0.51
	Within groups	2052.119	46	44.611		
	Total	2156.82	49			
ChangeIN3	Between groups	33.237	3	11.079	0.129	0.943
	Within groups	3275.263	38	86.191		
	Total	3308.5	41			
ChangeSCNS1	Between groups	208.933	3	69.644	1.219	0.313
	Within groups	2856.493	50	57.13		
	Total	3065.426	53			
ChangeSCNS2	Between groups	214.482	3	71.494	1.057	0.377
	Within groups	3180.341	47	67.667		
	Total	3394.824	50			
ChangeSCNS3	Between groups	117.476	3	39.159	0.73	0.54
	Within groups	2037.5	38	53.618		
	Total	2154.976	41			

Education level

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the seven categories of participants (None, Primary, Secondary, High school, Bachelor, Master, PhD).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	4.353	5.283	2.042	7.308
df	4	4	4	4
Asymp. Sig.	0.36	0.259	0.728	0.12
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	2.909	4.271	3.491	3.701
df	4	4	4	4
Asymp. Sig.	0.573	0.371	0.479	0.448

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	117.161	4	29.29	0.884	0.48
	Within groups	1622.987	49	33.122		
	Total	1740.148	53			
ChangeIN2	Between groups	237.098	4	59.275	1.389	0.253
	Within groups	1919.722	45	42.66		
	Total	2156.82	49			
ChangeIN3	Between groups	595.055	4	148.764	2.029	0.11
	Within groups	2713.445	37	73.336		
	Total	3308.5	41			
ChangeSCNS1	Between groups	515.016	4	128.754	2.474	0.056
	Within groups	2550.41	49	52.049		
	Total	3065.426	53			
ChangeSCNS2	Between groups	545.727	4	136.432	2.203	0.083
	Within groups	2849.097	46	61.937		
	Total	3394.824	50			

ChangeSCNS3	Between groups	276.529	4	69.132	1.362	0.266
	Within groups	1878.448	37	50.769		
	Total	2154.976	41			

Employment status

A Mann-Whitney U test showed that there wasn’t a significant difference between the male or female and the information need from modified MSAS.

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Mann-Whitney U	286	300.5	225	170.5
Z	-1.136	-0.432	-1.142	-0.974
Sig	0.256	0.666	0.253	0.33
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Mann-Whitney U	303	280.5	259.5	207
Z	-0.882	-0.82	-0.794	-0.03
Sig	0.378	0.412	0.427	0.976

Independent t-test showed that there wasn’t a significant difference between the male or female and the change of information need from modified MSAS.

		F	**Sig.**	**t**	**df**	**Sig. (2-tailed)**	**Mean Difference**	**Std. Error Difference**	**95% Confidence Interval of the Difference**	
									Lower	Upper
ChangeIN1	1	0.696	0.408	1.442	52	0.155	2.36111	1.63753	-0.92482	5.64705
	2			1.596	44.482	0.118	2.36111	1.47977	-0.62026	5.34249
ChangeIN2	1	0.252	0.618	0.853	48	0.398	1.69519	1.98618	-2.2983	5.68868
	2			0.772	25.005	0.448	1.69519	2.19679	-2.82913	6.21951
ChangeIN3	1	0.171	0.681	1.395	40	0.171	3.9375	2.82191	-1.7658	9.6408
	2			1.448	35.652	0.156	3.9375	2.71842	-1.57758	9.45258
ChangeSCNS1	1	0.859	0.358	0.163	52	0.871	0.36111	2.21586	-4.08534	4.80756
	2			0.165	35.447	0.87	0.36111	2.18407	-4.07078	4.79301
ChangeSCNS2	1	0.254	0.617	-1.066	49	0.292	-2.57071	2.41114	-7.41607	2.27466

	2			-1.021	30.967	0.315	-2.57071	2.51781	-7.70603	2.56461
ChangeSCNS3	1	3.652	0.063	-0.027	40	0.979	-0.0625	2.3322	-4.77605	4.65105
	2			-0.028	35.705	0.978	-0.0625	2.24541	-4.6177	4.4927

Career

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the ten categories of participants (None, Employee, Owner, Farmer, Police, Official, Teacher, Vendor, Driver, and Technician).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	6.758	8.104	6.799	9.739
df	9	9	9	8
Asymp. Sig.	0.662	0.524	0.658	0.284
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	9.118	6.656	9.582	2.335
df	9	9	9	8
Asymp. Sig.	0.426	0.673	0.385	0.969

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	411.04	9	45.671	1.512	0.174
	Within groups	1329.108	44	30.207		
	Total	1740.148	53			
ChangeIN2	Between groups	442.843	9	49.205	1.148	0.353
	Within groups	1713.977	40	42.849		
	Total	2156.82	49			
ChangeIN3	Between groups	1021.844	8	127.731	1.843	0.104
	Within groups	2286.656	33	69.293		
	Total	3308.5	41			
ChangeSCNS1	Between groups	598.529	9	66.503	1.186	0.328
	Within groups	2466.897	44	56.066		
	Total	3065.426	53			

ChangeSCNS2	Between groups	744.747	9	82.75	1.28	0.277
	Within groups	2650.077	41	64.636		
	Total	3394.824	50			
ChangeSCNS3	Between groups	666.904	8	83.363	1.849	0.103
	Within groups	1488.072	33	45.093		
	Total	2154.976	41			

Income

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the seven categories of participants (0-1,000, 1,001-5,000, 5,001-10,000, 10,001-30,000, 30,001-50,000, 50,001-100,000, >100,000).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	10.648	4.906	9.443	5.367
df	6	6	6	6
Asymp. Sig.	0.1	0.556	0.15	0.498
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	5.606	3.882	7.731	8.757
df	6	6	6	6
Asymp. Sig.	0.469	0.693	0.259	0.188

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	202.519	6	33.753	1.032	0.417
	Within groups	1537.63	47	32.716		
	Total	1740.148	53			
ChangeIN2	Between groups	483.333	6	80.556	2.07	0.077
	Within groups	1673.487	43	38.918		
	Total	2156.82	49			
ChangeIN3	Between groups	611.867	6	101.978	1.324	0.273
	Within groups	2696.633	35	77.047		

	Total	3308.5	41			
ChangeSCNS1	Between groups	341.808	6	56.968	0.983	0.447
	Within groups	2723.618	47	57.949		
	Total	3065.426	53			
ChangeSCNS2	Between groups	516.323	6	86.054	1.315	0.271
	Within groups	2878.5	44	65.42		
	Total	3394.824	50			
ChangeSCNS3	Between groups	226.843	6	37.807	0.686	0.662
	Within groups	1928.133	35	55.09		
	Total	2154.976	41			

Smoking history

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, the PHYS, the GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (None, Light smoker, Moderate smoker, and Heavy smoker).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	4.189	0.207	2.302	2.581
df	4	3	3	3
Asymp. Sig.	0.381	0.976	0.512	0.461
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	1.383	1.846	3.581	3.388
df	4	3	3	3
Asymp. Sig.	0.847	0.605	0.31	0.336

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	21.481	3	7.16	0.208	0.89
	Within groups	1718.667	50	34.373		
	Total	1740.148	53			
ChangeIN2	Between groups	77.83	3	25.943	0.574	0.635

	Within groups	2078.99	46	45.195		
	Total	2156.82	49			
ChangeIN3	Between groups	86.941	3	28.98	0.342	0.795
	Within groups	3221.559	38	84.778		
	Total	3308.5	41			
ChangeSCNS1	Between groups	113.009	3	37.67	0.638	0.594
	Within groups	2952.417	50	59.048		
	Total	3065.426	53			
ChangeSCNS2	Between groups	207.426	3	69.142	1.02	0.393
	Within groups	3187.397	47	67.817		
	Total	3394.824	50			
ChangeSCNS3	Between groups	38.599	3	12.866	0.231	0.874
	Within groups	2116.377	38	55.694		
	Total					

Smoking type

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (Cigarette, Tobacco, Cigar, Cigarette and Cigar, None).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	1.115	3.176	1.547	1.87
df	3	3	3	3
Asymp. Sig.	0.773	0.365	0.672	0.6
SCNS (information need subscale)	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	1.196	6.186	2.586	1.14
df	3	3	3	3
Asymp. Sig.	0.754	0.103	0.46	0.767

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	204.247	3	68.082	2.216	0.098
	Within groups	1535.902	50	30.718		
	Total	1740.148	53			
ChangeIN2	Between groups	71.492	3	23.831	0.526	0.667
	Within groups	2085.328	46	45.333		
	Total	2156.82	49			
ChangeIN3	Between groups	63.021	3	21.007	0.246	0.864
	Within groups	3245.479	38	85.407		
	Total	3308.5	41			
ChangeSCNS1	Between groups	171.08	3	57.027	0.985	0.407
	Within groups	2894.346	50	57.887		
	Total	3065.426	53			
ChangeSCNS2	Between groups	16.685	3	5.562	0.077	0.972
	Within groups	3378.138	47	71.875		
	Total	3394.824	50			
ChangeSCNS3	Between groups	181.076	3	60.359	1.162	0.337
	Within groups	1973.9	38	51.945		
	Total	2154.976	41			

Pathology

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the six categories of participants (Squamous, Adenocarcinoma, NSCLC, Unspecified, SCLC, other).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	4.491	8.873	4.878	3.862
df	5	5	5	5
Asymp. Sig.	0.481	0.114	0.431	0.569
SCNS (information need subscale)	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	7.286	3.92	3.455	1.184
df	5	5	5	5
Asymp. Sig.	0.2	0.561	0.63	0.946

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	24.196	5	4.839	0.135	0.983
	Within groups	1715.952	48	35.749		
	Total	1740.148	53			
ChangeIN2	Between groups	175.92	5	35.184	0.782	0.568
	Within groups	1980.9	44	45.02		
	Total	2156.82	49			
ChangeIN3	Between groups	573.368	5	114.674	1.509	0.211
	Within groups	2735.132	36	75.976		
	Total	3308.5	41			
ChangeSCNS1	Between groups	72.072	5	14.414	0.231	0.947
	Within groups	2993.354	48	62.362		
	Total	3065.426	53			
ChangeSCNS2	Between groups	146.564	5	29.313	0.406	0.842
	Within groups	3248.26	45	72.184		
	Total	3394.824	50			
ChangeSCNS3	Between groups	271.113	5	54.223	1.036	0.411
	Within groups	1883.863	36	52.33		
	Total	2154.976	41			

Radiotherapy type

A Mann-Whitney U test showed that there wasn't a significant difference between the male or female and the information need from modified MSAS.

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Mann-Whitney U	238.5	331.5	309	210
Z	-2.515	-0.564	-0.059	-0.153
Sig	0.012	0.573	0.953	0.879
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Mann-Whitney U	359.5	346.5	284.5	182

Z	-0.551	-0.311	-0.82	-0.99
Sig	0.581	0.756	0.412	0.322

Independent t-test showed that there wasn't a significant difference between the male or female and the change of information need from modified MSAS.

		F	**Sig.**	**t**	**df**	**Sig. (2-tailed)**	**Mean Difference**	**Std. Error Difference**	**95% Confidence Interval of the Difference**	
									Lower	Upper
ChangeIN1	1	2.179	0.146	-1.251	52	0.216	-1.94231	1.55232	-5.05727	1.17265
	2			-1.233	42.636	0.225	-1.94231	1.5759	-5.12119	1.23657
ChangeIN2	1	1.716	0.196	-1.675	48	0.1	-3.08974	1.84434	-6.79803	0.61854
	2			-1.644	37.266	0.109	-3.08974	1.87961	-6.89728	0.71779
ChangeIN3	1	3.064	0.088	-1.629	40	0.111	-4.47222	2.74617	-10.02245	1.078
	2			-1.783	35.058	0.083	-4.47222	2.50844	-9.56433	0.61989
ChangeSCNS1	1	0.803	0.374	-0.283	52	0.779	-0.59066	2.0895	-4.78354	3.60222
	2			-0.281	48.841	0.78	-0.59066	2.10375	-4.81865	3.63734
ChangeSCNS2	1	0.831	0.366	-0.018	49	0.986	-0.04154	2.33151	-4.72689	4.64381
	2			-0.018	48.683	0.986	-0.04154	2.33341	-4.73147	4.6484
ChangeSCNS3	1	3.157	0.083	-0.659	40	0.514	-1.5	2.2763	-6.10057	3.10057
	2			-0.677	39.557	0.502	-1.5	2.21484	-5.97792	2.97792

Radiotherapy dose

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the seven categories of participants (20Gy/4-5F, 25Gy/5-7F, 30Gy/10F, 35Gy/15F, 60Gy/30F).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**

Kruskal-Wallis H	1.959	4.148	2.959	1.943
df	4	4	4	4
Asymp. Sig.	0.743	0.386	0.565	0.746
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	4.531	1.547	4.209	10.625
df	4	4	4	4
Asymp. Sig.	0.339	0.818	0.378	0.031

There was a statistically significant difference between groups as determined by one-way ANOVA in ChangeIN1 (F (4,49) = 3.854, p = 0.008).

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	416.448	4	104.112	3.854	0.008
	Within groups	1323.7	49	27.014		
	Total	1740.148	53			
ChangeIN2	Between groups	117.218	4	29.304	0.647	0.632
	Within groups	2039.602	45	45.324		
	Total	2156.82	49			
ChangeIN3	Between groups	59.25	4	14.813	0.169	0.953
	Within groups	3249.25	37	87.818		
	Total	3308.5	41			
ChangeSCNS1	Between groups	221.681	4	55.42	0.955	0.441
	Within groups	2843.744	49	58.036		
	Total	3065.426	53			
ChangeSCNS2	Between groups	466.119	4	116.53	1.83	0.139
	Within groups	2928.705	46	63.667		
	Total	3394.824	50			
ChangeSCNS3	Between groups	395.697	4	98.924	2.081	0.103
	Within groups	1759.279	37	47.548		
	Total	2154.976	41			

Area of radiotherapy

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences found among the five categories of participants (Chest, Mediastinum, Bone, Brain, Other).

Information needs from modified MSAS	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	2.236	3.881	3.491	1.63
df	4	4	4	4
Asymp. Sig.	0.692	0.422	0.479	0.803
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	3.08	6.312	3.265	6.231
df	4	4	4	4
Asymp. Sig.	0.545	0.177	0.514	0.183

There was a statistically significant difference between groups as determined by one-way ANOVA in the ChangeSCNS1 (F (4,49) = 2.575, p = 0.049.

Information need		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	164.667	4	41.167	1.28	0.291
	Within groups	1575.481	49	32.153		
	Total	1740.148	53			
ChangeIN2	Between groups	105.831	4	26.458	0.581	0.678
	Within groups	2050.989	45	45.578		
	Total	2156.82	49			
ChangeIN3	Between groups	13.756	4	3.439	0.039	0.997
	Within groups	3294.744	37	89.047		
	Total	3308.5	41			
ChangeSCNS1	Between groups	532.401	4	133.1	2.575	0.049
	Within groups	2533.025	49	51.694		
	Total	3065.426	53			
ChangeSCNS2	Between groups	44.75	4	11.188	0.154	0.96
	Within groups	3350.073	46	72.828		
	Total	3394.824	50			
ChangeSCNS3	Between groups	12.76	4	3.19	0.055	0.994
	Within groups	2142.217	37	57.898		
	Total	2154.976	41			

The Predictors associated with increased information need in caregivers.

Age

Spearman's rho correlation coefficient was used to assess the relationship between age and the information needs. There was no significant correlation between the age and information needs at four visits.

Information needs from modified MSAS			**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Spearman's rho	Age	Correlation Coefficient	0.08	-0.062	0.027	-0.046
		Sig. (2-tailed)	0.556	0.649	0.851	0.773
		N	56	56	50	42
SCNS (information need subscale)			**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Spearman's rho	Age	Correlation Coefficient	0.16	0.109	0.164	0.194
		Sig. (2-tailed)	0.237	0.423	0.255	0.219
		N	56	56	50	42

Pearson correlation coefficient was used to assess the relationship between age and the change of information needs. There was no significant correlation between the age and information needs at four visits.

Information needs from modified MSAS			**Change 1**	**Change 2**	**Change 3**
Pearson	Age	Pearson Correlation	-0.055	-0.032	-0.142
		Sig. (2-tailed)	0.689	0.828	0.37
		N	56	50	42
SCNS (information need subscale)			Change 1	Change 2	Change 3
Pearson	Age	Pearson Correlation	-0.135	-0.108	-0.061
		Sig. (2-tailed)	0.321	0.455	0.7
		N	56	50	42

Gender

A Mann-Whitney U test showed that there wasn’t a significant difference between the male or female and the information need from modified MSAS, and the information need from the SCNS.

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Mann-Whitney U	287	291.5	233.5	205
Z	-0.967	-0.598	-0.967	-0.193
Sig	0.333	0.55	0.333	0.847
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Mann-Whitney U	302	281	254.5	190.5
Z	-0.737	-0.811	-0.741	-0.646
Sig	0.461	0.417	0.459	0.518

Independent t-test showed that there wasn’t a significant difference between the male or female and the change of information need from modified MSAS.

		F	**Sig.**	**t**	**df**	**Sig. (2-tailed)**	**Mean Difference**	**Std. Error Difference**	**95% Confidence Interval of the Difference**	
									Lower	Upper
ChangeIN1	1	0.001	0.972	-0.663	54	0.51	-1.55848	2.3499	-6.26974	3.15279
	2			-0.672	34.563	0.506	-1.55848	2.32015	-6.27077	3.15381
ChangeIN2	1	0	0.989	-1.647	48	0.106	-4.46702	2.7115	-9.91887	0.98482
	2			-1.621	31.04	0.115	-4.46702	2.75556	-10.08673	1.15269
ChangeIN3	1	2.513	0.121	-1.689	40	0.099	-4.60235	2.72463	-10.10905	0.90434
	2			-1.564	25.392	0.13	-4.60235	2.94302	-10.65887	1.45417
ChangeSCNS1	1	1.598	0.212	0.401	54	0.69	0.89474	2.23258	-3.58132	5.37079

	2			0.416	36.785	0.68	0.89474	2.15153	-3.46554	5.25501
ChangeSCNS2	1	4.754	0.034	-0.355	48	0.724	-0.84135	2.37231	-5.6112	3.92849
	2			-0.381	39.248	0.706	-0.84135	2.21076	-5.31214	3.62943
ChangeSCNS3	1	0.009	0.925	0.94	40	0.353	2.41882	2.57254	-2.78048	7.61812
	2			0.939	34.382	0.354	2.41882	2.57545	-2.81299	7.65063

Marital status

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (Married, Single, Divorce, Separate, Widowed).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	1.629	0.879	2.207	2.472
df	1	1	1	1
Asymp. Sig.	0.202	0.349	0.137	0.116
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	2.15	0.384	0.885	0.477
df	1	1	1	1
Asymp. Sig.	0.143	0.536	0.347	0.49

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	0.029	1	0.029	0	0.984
	Within groups	3671.81	54	67.996		
	Total	3671.839	55			
ChangeIN2	Between groups	6.72	1	6.72	0.077	0.782
	Within groups	4176.8	48	87.017		
	Total	4183.52	49			

ChangeIN3	Between groups	21.392	1	21.392	0.268	0.608
	Within groups	3197.751	40	79.944		
	Total	3219.143	41			
ChangeSCNS1	Between groups	67.749	1	67.749	1.133	0.292
	Within groups	3229.608	54	59.808		
	Total	3297.357	55			
ChangeSCNS2	Between groups	22.004	1	22.004	0.35	0.557
	Within groups	3016.876	48	62.852		
	Total	3038.88	49			
ChangeSCNS3	Between groups	2.732	1	2.732	0.04	0.843
	Within groups	2735.172	40	68.379		
	Total	2737.905	41			

Education level

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the seven categories of participants (None, Primary, Secondary, High school, Bachelor, Master, PhD) and Information need from modified MSAS (Chi square = 8.272, p = 0.041, df = 3).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	3.621	5.597	6.126	8.272
df	3	3	3	3
Asymp. Sig.	0.305	0.133	0.106	0.041
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	12.894	5.053	6.68	6.476
df	3	3	3	3
Asymp. Sig.	0.005	0.168	0.083	0.091

There wasn't a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	10.447	3	3.482	0.049	0.985

	Within groups	3661.393	52	70.411		
	Total	3671.839	55			
ChangeIN2	Between groups	24.228	3	8.076	0.089	0.966
	Within groups	4159.292	46	90.419		
	Total	4183.52	49			
ChangeIN3	Between groups	154.105	3	51.368	0.637	0.596
	Within groups	3065.038	38	80.659		
	Total	3219.143	41			
ChangeSCNS1	Between groups	114.232	3	38.077	0.622	0.604
	Within groups	3183.125	52	61.214		
	Total	3297.357	55			
ChangeSCNS2	Between groups	202.044	3	67.348	1.092	0.362
	Within groups	2836.836	46	61.67		
	Total	3038.88	49			
ChangeSCNS3	Between groups	352.357	3	117.452	1.871	0.151
	Within groups	2385.548	38	62.778		
	Total	2737.905	41			

Employment status

A Mann-Whitney U test showed that there was a significant difference between the male or female and the information need from modified MSAS at second visit (U = 87, Z = -2, p = 0.045).

Information needs from modified MSAS	*Baseline*	*Second visit*	*Third visit*	*Fourth visit*
Mann-Whitney U	160.5	87	137.5	55
Z	-0.739	-2	-0.365	-1.46
Sig	0.46	0.045	0.715	0.144
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Mann-Whitney U	191.5	143	140	73.5
Z	-0.012	-0.569	-0.412	-0.846
Sig	0.99	0.569	0.681	0.398

Independent t-test showed that there was a significant difference between the male or female and the change of SCNS information need subscale (t (54) = 2.201, p = 0.032).

		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
ChangeIN1	1	0.087	0.77	0.631	54	0.531	1.97917	3.13747	-4.31107	8.26941
	2			0.757	11.291	0.464	1.97917	2.61364	-3.75541	7.71374
ChangeIN2	1	0.008	0.931	-0.366	48	0.716	-1.48485	4.05722	-9.64243	6.67273
	2			-0.402	6.862	0.7	-1.48485	3.6966	-10.26179	7.29209
ChangeIN3	1	0.092	0.764	0.548	40	0.586	2.33514	4.25846	-6.27154	10.94181
	2			0.578	5.319	0.587	2.33514	4.0406	-7.86721	12.53748
ChangeSCNS1	1	2.487	0.121	2.201	54	0.032	6.29167	2.85864	0.56043	12.0229
	2			1.849	8.502	0.099	6.29167	3.40303	-1.47588	14.05921
ChangeSCNS2	1	0.215	0.645	-0.333	48	0.741	-1.15152	3.45874	-8.10578	5.80275
	2			-0.29	5.99	0.782	-1.15152	3.97717	-10.88734	8.58431
ChangeSCNS3	1	0.035	0.853	0.352	40	0.727	1.38378	3.93594	-6.57104	9.33861
	2			0.347	5.104	0.742	1.38378	3.98723	-8.80294	11.57051

Career

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the ten categories of participants (None, Employee, Owner, Farmer, Police, Official, Teacher, Vendor, Driver and Technician).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	3.641	7.602	5.14	2.809
df	6	6	6	6
Asymp. Sig.	0.725	0.269	0.526	0.832
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	2.685	4.043	2.197	6.266
df	6	6	6	6
Asymp. Sig.	0.847	0.671	0.901	0.394

There was a statistically significant difference between groups as determined by one-way ANOVA in the ChangeIN3 (F (7,34) = 3.347, p = 0.008) and the changeSCNS3 (F (7,34) = 2.504, p = 0.035).

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	429.373	7	61.339	0.908	0.508
	Within groups	3242.467	48	67.551		
	Total	3671.839	55			
ChangeIN2	Between groups	571.437	7	81.634	0.949	0.48
	Within groups	3612.083	42	86.002		
	Total	4183.52	49			
ChangeIN3	Between groups	1313.336	7	187.619	3.347	0.008
	Within groups	1905.807	34	56.053		
	Total	3219.143	41			
ChangeSCNS1	Between groups	442.558	7	63.223	1.063	0.401
	Within groups	2854.799	48	59.475		
	Total	3297.357	55			
ChangeSCNS2	Between groups	274.952	7	39.279	0.597	0.755
	Within groups	2763.928	42	65.808		
	Total	3038.88	49			
ChangeSCNS3	Between groups	931.364	7	133.052	2.504	0.035
	Within groups	1806.54	34	53.134		
	Total	2737.905	41			

Income

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the seven categories of participants (0-1,000, 1,001-5,000, 5,001-10,000, 10,001-30,000, 30,001-50,000, 50,001-100,000, >100,000).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	6.557	8.895	5.671	8.391
df	5	5	5	4
Asymp. Sig.	0.256	0.113	0.34	0.078

SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	1.672	5.47	3.711	7.128
df	5	5	5	4
Asymp. Sig.	0.892	0.361	0.592	0.129

There was a statistically significant difference between groups as determined by one-way ANOVA in ChangeIN1 (F (5,50) = 2.849, p = 0.024.

Information need		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	814.18	5	162.836	2.849	0.024
	Within groups	2857.659	50	57.153		
	Total	3671.839	55			
ChangeIN2	Between groups	629.762	5	125.952	1.559	0.191
	Within groups	3553.758	44	80.767		
	Total	4183.52	49			
ChangeIN3	Between groups	107.487	4	26.872	0.32	0.863
	Within groups	3111.656	37	84.099		
	Total	3219.143	41			
ChangeSCNS1	Between groups	265.879	5	53.176	0.877	0.503
	Within groups	3031.478	50	60.63		
	Total	3297.357	55			
ChangeSCNS2	Between groups	198.698	5	39.74	0.616	0.688
	Within groups	2840.182	44	64.55		
	Total	3038.88	49			
ChangeSCNS3	Between groups	135.083	4	33.771	0.48	0.75
	Within groups	2602.822	37	70.347		
	Total	2737.905	41			

Relationship

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the six categories of participants (Spouse/partner, Child, Friend, Relative, Sister, Brother, Grandchild).

Information needs from modified MSAS	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	3.4	2.066	1.629	3.293
df	4	4	4	4
Asymp. Sig.	0.493	0.724	0.804	0.51
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	6.111	2.523	0.959	6.61
df	4	4	4	4
Asymp. Sig.	0.191	0.641	0.916	0.158

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Information need		Sum of squares	df	Mean Square	F	Sig.
ChangeIN1	Between groups	167.049	4	41.762	0.608	0.659
	Within groups	3504.79	51	68.721		
	Total	3671.839	55			
ChangeIN2	Between groups	386.734	4	96.683	1.146	0.347
	Within groups	3796.786	45	84.373		
	Total	4183.52	49			
ChangeIN3	Between groups	674.26	4	168.565	2.451	0.063
	Within groups	2544.883	37	68.781		
	Total	3219.143	41			
ChangeSCNS1	Between groups	248.317	4	62.079	1.038	0.397
	Within groups	3049.04	51	59.785		
	Total	3297.357	55			
ChangeSCNS2	Between groups	428.41	4	107.103	1.846	0.137
	Within groups	2610.47	45	58.01		
	Total	3038.88	49			
ChangeSCNS3	Between groups	404.421	4	101.105	1.603	0.194
	Within groups	2333.483	37	63.067		
	Total	2737.905	41			

Smoking history

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (None, Light smoker, Moderate smoker and Heavy smoker).

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	0.104	0.439	2.424	2.302
df	2	2	2	2
Asymp. Sig.	0.949	0.803	0.298	0.316
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	0.368	2.5	1.774	1.582
df	2	2	2	2
Asymp. Sig.	0.832	0.286	0.412	0.454

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	78.435	2	39.218	0.578	0.564
	Within groups	3593.404	53	67.8		
	Total	3671.839	55			
ChangeIN2	Between groups	13.526	2	6.763	0.076	0.927
	Within groups	4169.994	47	88.723		
	Total	4183.52	49			
ChangeIN3	Between groups	31.062	2	15.531	0.19	0.828
	Within groups	3188.081	39	81.746		
	Total	3219.143	41			
ChangeSCNS1	Between groups	65.21	2	32.605	0.535	0.589
	Within groups	3232.147	53	60.984		
	Total	3297.357	55			
ChangeSCNS2	Between groups	126.969	2	63.484	1.025	0.367
	Within groups	2911.911	47	61.956		
	Total	3038.88	49			
ChangeSCNS3	Between groups	92.128	2	46.064	0.679	0.513
	Within groups	2645.777	39	67.84		

	Total	2737.905	41

Smoking type

Kruskal-Wallis Test was conducted to examine the differences on according to the PSYCH, The PHYS, The GDI and Total MSAS at four period of times. No significant differences were found among the five categories of participants (Cigarette, Tobacco, Cigar, Cigarette and Cigar, None). At third and fourth visit, there is only one non-empty group so the Kruskal-Wallis Test cannot be performed.

Information needs from modified MSAS	**Baseline**	**Second visit**	**Third visit**	**Fourth visit**
Kruskal-Wallis H	1	1		
df	1	1		
Asymp. Sig.	0.317	0.317		
SCNS (information need subscale)	Baseline	Second visit	Third visit	Fourth visit
Kruskal-Wallis H	1.591	1.62		
df	1	1		
Asymp. Sig.	0.207	0.203		

There wasn’t a statistically significant difference between groups as determined by one-way ANOVA.

Information need		**Sum of squares**	**df**	**Mean Square**	**F**	**Sig.**
ChangeIN1	Between groups	3.635	2	1.818	0.026	0.974
	Within groups	3668.204	53	69.211		
	Total	3671.839	55			
ChangeIN2	Between groups	2.276	1	2.276	0.026	0.872
	Within groups	4181.244	48	87.109		
	Total	4183.52	49			
ChangeIN3	Between groups	26.062	1	26.062	0.326	0.571
	Within groups	3193.081	40	79.827		
	Total	3219.143	41			
ChangeSCNS1	Between groups	37.177	2	18.588	0.302	0.74
	Within groups	3260.18	53	61.513		
	Total	3297.357	55			

ChangeSCNS2	Between groups	123.769	1	123.769	2.038	0.16
	Within groups	2915.111	48	60.731		
	Total	3038.88	49			
ChangeSCNS3	Between groups	91.678	1	91.678	1.386	0.246
	Within groups	2646.227	40	66.156		
	Total	2737.905	41			

The Linear regression result

Predictor associated with information need in patients.

Outcome: Change in MSAS information need subscale (follow-up visit 1)

Univariable linear regression showed that there were no statistically significant predictors found between patient's characteristics and the change of IN at follow up visit 1. Multivariable linear regression results were qualitatively similar.

Univariable and multivariable result of Change in information need at visit 2 from baseline.

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.088(-0.222,0.045);0.189		-0.124 (-0.394, 0.146);0.358	
Gender				
Male	-2.025(-5.170, 1.119); 0.202		-7.674 (-18.086, 2.738); 0.144	
Female (Reference)	-		-	
Marital status				
Single	-0.223(-4.669, 4.223); 0.920		-0.723 (-7.018, 5.571); 0.817	
No single (Reference)	-		-	
Education Level		0.271		0.304
Primary	-0.716(-4.378, 2.946); 0.696		0.490 (-5.783, 6.762); 0.875	
Secondary	-3.116(-7.064, 0.832); 0.119		-3.161 (-8.309, 1.987); 0.221	
University (Reference)	-		-	
Employment status				
Work (Reference)				
Not work	-2.361(-5.647, 0.925); 0.155		-2.293 (-18.613, 14.028); 0.777	
Career		0.302		0.852
None	-2.874(-7.008, 1.260); 0.169		1.486 (-15.311, 18.283); 0.858	
Other	-0.460(-4.342, 3.423); 0.813		1.314 (-3.993, 6.620); 0.618	
Employee (Reference)	-		-	
Income		0.758		0.784

0-10,000	-0.710(-5.051, 3.631); -0.328		-1.426 (-8.661, 5.810); 0.692	
10,001-30,000	-1.545(-5.852, 2.761); -0.720		-1.627 (-6.985, 3.731); 0.542	
>30,000 ((Reference)	-		-	
Smoking history		0.810		0.138
Some smokers	-1.410(-7.221, 4.402); 0.628		3.397 (-5.615,12.409);0.449	
Heavy smoker	-0.952(-4.324, 2.419); 0.573		7.467(-2.721,17.655);0.146	
None ((Reference)	-		-	
Pathology		0.977		0.838
Unspecified	0.381(-3.195, 3.957); 0.832		1.842 (-3.917,7.600);0.520	
Other	0.182(-4.147, 4.510); 0.933		2.084(-3.508,7.675);0.454	
Adenocarcinoma (Reference)	-		-	
RT Type				
3D	1.942(-1.173, 5.057); 0.216		0.439 (-4.417,5.295);0.855	
2D (Reference)	-		-	
RT Dose				
Other	1.111(-3.116, 5.339); 0.600		2.778(-3.236,8.792);0.355	
30Gy/10F (Reference)	-		-	
Area of treatment		0.435		0.442
Bone	-1.339(-4.966, 2.288); 0.462		-2.631(-7.870,2.607);0.315	
Other	1.470(-2.582, 5.522);0.470		1.111(-3.980,6.201);0.661	
Brain (Reference)	-		-	

Outcome: Change in MSAS information need subscale (follow-up visit 2)

Univariable linear regression showed that there were no statistically significant predictors found between patient’s characteristics and the change of IN at follow up visit 2.

Multivariable linear regression results were found statistically significant predictors found between smoking history and the change of IN at follow up visit 2. Smoking history was statistically significant predictor with heavy smoker (p = 0.017) having a bigger increase in information need than none smoking (p = 0.028)

Univariable and multivariable result of Change in information need at visit 3 from baseline.

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.097(-0.255,0.061);0.222		-0.071(-0.353,0.211);0.611	
Gender				

Male	-0.389(-4.249, 3.471);0.840		-8.125(-18.729,2.479);0.128	
Female (Reference)	-		-	
Marital status				
Single	-0.821(-6.015, 4.372); 0.752		-5.606(-12.458,1.246);0.105	
No single (Reference)	-		-	
Education Level		0.183		0.088
Primary	0.263(-4.125, 4.651); 0.904		0.017(-6.456,6.491);0.996	
Secondary	-3.714(-8.458, 1.030); 0.122		-6.173(-11.877,-0.469);0.035	
University (Reference)	-		-	
Employment status				
Work (Reference)				
Not work	-1.695(-5.689, 2.298); 0.398		1.905(-15.083,18.894);0.821	
Career		0.381		0.211
None	-0.760(-5.745, 4.225); 0.761		-1.757(-19.030,15.516);0.837	
Other	2.187(-2.525, 6.898); 0.355		3.938(-1.565,9.441);0.154	
Employee (Reference)	-		-	
Income		.0.366		0.395
0-10,000	0.175(-5.405, 5.755); 0.950		-0.031(-7.856,7.794);0.994	
10,001-30,000	-2.580(-8.087, 2.928); 0.351		-0.581(-6.569,5.408);0.845	
>30,000 ((Reference)	-		-	
Smoking history		0.803		**0.028**
Some smokers	0.484(-6.334, 7.302); 0.887		8.712(-1.026,18.450);0.078	
Heavy smoker	1.338(-2.756, 5.432); 0.514		13.173(2.502,23.843);**0.017**	
None ((Reference)	-		-	
Pathology		0.628		0.850
Unspecified	-0.600(-4.867, 3.667); 0.779		-0.573(-6.819,5.674);0.853	
Other	-2.500(-7.726, 2.726); 0.341		-2.116(-8.064,3.832);0.474	
Adenocarcinoma (Reference)	-		-	
RT Type				
3D	3.090(-0.619, 6.798); 0.100		4.658(-0.683,9.999);0.085	
2D (Reference)	-		-	
RT Dose				
Other	0.604(-4.354, 5.562); 0.807		2.099(-4.262,8.460);0.506	
30Gy/10F (Reference)	-		-	
Area of treatment		0.486		0.282
Bone	-2.589(-7.068, 1.891); 0.251		-3.197(-8.756,2.362);0.250	
Other	-1.705(-6.561, 3.150); 0.483		-3.883(-9.307,1.541);0.154	
Brain (Reference)	-		-	

Outcome: Change in MSAS information need subscale (follow-up visit 3)

Univariable linear regression showed that there were no statistically significant predictors found between patient's characteristics and the change of IN at follow up visit 3. Multivariable linear regression results were qualitatively similar.

Univariable and multivariable result of Change in IN information need at visit 4 from baseline.

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.222(-0.485,0.040);0.094		-0.030(-0.481,0.422);0.894	
Gender				
Male	-4.299(-9.911, 1.314); 0.130		-9.866(-24.646,4.915);0.181	
Female (Reference)	-		-	
Marital status				
Single	-0.829(-10.487,8.830);0.863		-1.067(-12.662,10.527);0.851	
No single (Reference)	-		-	
Education Level		0.042		0.113
Primary	-3.250(-9.323,2.823);0.286		-7.826(-17.071,1.418);0.093	
Secondary	-8.975(-15.899,-2.051);0.012		-8.809(-18.411,0.794);0.070	
University (Reference)	-		-	
Employment status				
Work (Reference)				
Not work	-3.937(-9.641,1.766);0.171		8.637(-20.977,38.252);0.552	
Career		0.329		0.456
None	-3.711(-11.345,3.923);0.332		-11.400(-39.310,16.511);0.407	
Other	0.889(-6.503,8.281);0.809		2.571(-5.594,10.736);0.521	
Employee (Reference)	-		-	
Income		0.128		0.051
0-10,000	1.688(-5.965,9.340);0.658		12.722(0.660,24.784);0.040	
10,001-30,000	-4.417(-11.926,3.093);0.241		2.530(-6.027,11.087);0.547	
>30,000 ((Reference)	-		-	
Smoking history		0.600		0.198
Some smokers	-3.312(-13.591,6.966);0.518		1.554(-16.720,19.827);0.862	
Heavy smoker	-2.858(-8.899,3.183);0.345		10.122(-5.796,26.040);0.201	
None ((Reference)	-		-	
Pathology		0.155		0.160
Unspecified	-4.921(-11.176,1.334);0.120		-1.412(-10.511,7.687);0.751	
Other	-5.977(-13.163,1.210);0.101		-9.463(-18.604,-0.322);0.043	
Adenocarcinoma (Reference)	-		-	

RT Type				
3D	4.472(-1.078,10.022);0.111		3.149(-4.110,10.407);0.379	
2D (Reference)	-		-	
RT Dose				
Other	2.625(-4.549,9.799);0.464		4.625(-4.337,13.587);0.297	
30Gy/10F (Reference)	-		-	
Area of treatment		0.984		0.556
Bone	-0.365(-7.000,6.269);0.912		1.141(-7.377,9.660);0.784	
Other	-0.639(-8.114,6.836);0.864		-3.398(-11.441,4.644);0.391	
Brain (Reference)	-		-	

Outcome: Change in SCNS subscale (follow-up visit 1)

Univariable linear regression showed that there were statistically significant predictors found between area of treatment and the change of SCNS at follow up visit 1. Area of treatment was statistically significant predictor with other area (p = 0.048) having a bigger increase in SCNS than brain (p = 0.012).

Multivariable linear regression results were statistically significant predictors found between age, area of treatment and the change of SCNS at follow up visit 1. Age was statistically significant predictor (p = 0.048), and area of treatment was statistically significant predictor with bone (p = 0.012) having a bigger reduce in SCNS than brain (p = 0.002)

Univariable and multivariable result of Change in SCNS at visit 2 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	0.022(-0.158,0.201);0.810		-0.312(-0.621,-0.003);**0.048**	
Gender				
Male	0.504(-3.734, 4.741); 0.812		15.765(-6.152,17.682);0.333	
Female (Reference)	-		-	
Marital status				
Single	5.092(-0.637, 10.822);0.080		6.002(-1.202,13.207);0.100	
No single (Reference)	-		-	
Education Level		0.099		0.101
Primary	5.147(0.382, 9.913); 0.035		0.491(-6.688,7.670);0.890	
Secondary	1.814(-3.324, 6.952); 0.482		3.627(-2.265,9.519);0.220	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	

Not work	-0.361(-4.808, 4.085); 0.871		-10.717(-29.397,7.963);0.252	
Career		0.949		0.899
None	0.542(-5.069, 6.153); 0.847		10.287(-8.939,29.512);0.285	
Other	0.854(-4.417, 6.125); 0.746		-1.667(-7.741,4.406);0.581	
Employee (Reference)	-		-	
Income		0.083		0.300
0-10,000	5.468(-0.049, 10.984);0.052		3.972(-4.310,12.254);0.337	
10,001-30,000	1.273(-4.200, 6.746); 0.643		-2.054(-8.187,4.078);0.501	
>30,000 ((Reference)	-		-	
Smoking history		0.579		0.855
Some smokers	3.990(-3.672, 11.653); 0.301		5.623(-4.691,15.938);0.276	
Heavy smoker	0.548(-3.898, 4.993); 0.806		-7.393(-19.054,4.268);0.206	
None ((Reference)	-		-	
Pathology		0.991		0.831
Unspecified	-0.305(-5.053, 4.442); 0.898		4.752(-1.839,11.343);0.152	
Other	-0.045(-5.792, 5.701); 0.987		3.943(-2.457,10.342);0.219	
Adenocarcinoma (Reference)	-		-	
RT Type				
3D	0.591(-3.602, 4.784); 0.779		-2.682(-8.240,2.876);0.334	
2D (Reference)	-		-	
RT Dose				
Other	2.111(-3.484, 7.706); 0.452		3.456(-3.427,10.340);0.315	
30Gy/10F (Reference)	-		-	
Area of treatment		**0.012**		**0.002**
Bone	-3.242(-7.732, 1.247); 0.153		-7.861(-13.857,-1.865);**0.012**	
Other	5.057(0.042, 10.072); **0.048**		5.144(-0.682,10.970);0.082	
Brain (Reference)	-		-	

Outcome: Change in SCNS subscale (follow-up visit 2)

Univariable linear regression showed that there were statistically significant predictors found between education level and the change of SCNS at follow up visit 2. Education level was statistically significant predictor with primary (p = 0.008) having a bigger increase in SCNS than university (p = 0.025)

Multivariable linear regression results were qualitatively similar. Education level was statistically significant predictor with primary having a bigger increase in SCNS than university (p = 0.027)

Univariable and multivariable result of Change in SCNS at visit 3 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	0.039(-0.158,0.237);0.693		-0.121(-0.511,0.270);0.533	
Gender				
Male	0.505(-4.252, 5.262); 0.832		-5.732(-20.436,8.972);0.433	
Female (Reference)	-		-	
Marital status				
Single	4.517(-1.791, 10.826); 0.157		6.754(-2.624,16.133);0.152	
No single (Reference)	-		-	
Education Level		**0.025**		**0.027**
Primary	7.120(1.968, 12.271); **0.008**		5.796(-3.192,14.784);0.198	
Secondary	2.492(-3.089, 8.073); 0.374		3.516(-4.257,11.289);0.364	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	
Not work	2.571(-2.275, 7.416); 0.292		-4.163(-27.729,19.403);0.721	
Career		0.485		0.906
None	3.385(-2.752, 9.521); 0.273		7.261(-16.730,31.252);0.542	
Other	0.766(-5.112, 6.644); 0.795		0.870(-6.757,8.498);0.818	
Employee (Reference)	-		-	
Income		0.099		0.741
0-10,000	5.767(-0.701, 12.235); 0.079		2.401(-8.077,12.878);0.644	
10,001-30,000	1.076(-5.300, 7.452); 0.7360		0.610(-7.456,8.677);0.878	
>30,000 ((Reference)	-		-	
Smoking history		0.302		0.921
Some smokers	6.463(-1.826, 14.753); 0.124		2.144(-11.378,15.666);0.749	
Heavy smoker	1.300(-3.638, 6.239); 0.599		2.029(-12.758,16.815);0.782	
None ((Reference)	-		-	
Pathology		0.986		0.937
Unspecified	-0.188(-5.470, 5.093); 0.943		1.378(-7.109,9.865);0.743	
Other	-0.538(-7.033, 5.957); 0.868		1.405(-6.784,9.594);0.729	
Adenocarcinoma (Reference)	-		-	
RT Type				
3D	0.042(-4.644, 4.727); 0.986		-2.202(-9.479,5.075);0.542	
2D (Reference)	-		-	
RT Dose				
Other	5.730(-0.190, 11.650);0.057		8.186(-0.512,16.883);0.064	
30Gy/10F (Reference)	-		-	
Area of treatment		0.765		0.799
Bone	1.053(-4.438, 6.545); 0.701		-2.475(-10.068,5.118);0.511	
Other	2.175(-3.909, 8.258); 0.476		-0.489(-8.018,7.041);0.896	

Brain (Reference)	-		-	

Outcome: Change in SCNS subscale (follow-up visit 3)

Univariable linear regression showed that there were no statistically significant predictors found between RT dose and the change of SCNS at follow up visit 3. RT dose was statistically significant predictor with other RT dose having a bigger increase in SCNS than 30Gy/10F (p = 0.008)

Multivariable linear regression results were qualitatively similar. RT dose was statistically significant predictor with other RT dose having a bigger increase in SCNS than 30Gy/10F (p = 0.009)

Univariable and multivariable result of Change in SCNS at visit 4 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	0.124(-0.092,0.339);0.253		0.073(-0.336,0.482);0.716	
Gender				
Male	0.336(-4.326,4.999);0.885		-5.401(-18.785,7.984);0.412	
Female (Reference)	-		-	
Marital status				
Single	5.000(-2.632,12.632); 0.193		9.742(-0.757,20.242);0.067	
No single (Reference)	-		-	
Education Level		0.208		0.166
Primary	4.562(-0.543, 9.668); 0.078		2.807(-5.564,11.179);0.495	
Secondary	2.512(-3.309, 8.334); 0.388		4.376(-4.319,13.072);0.309	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	
Not work	0.063(-4.651, 4.776); 0.979		5.800(-21.017,32.618);0.659	
Career		0.913		0.965
None	1.022(-5.302, 7.347);0.745		-3.233(-28.508,22.042);0.794	
Other	1.278(-4.846, 7.402); 0.675		1.305(-6.089,8.699);0.718	
Employee (Reference)	-			
Income		0.388		0.544
0-10,000	4.188(-2.167, 10.542); 0.190		6.018(-4.904,16.941);0.266	
10,001-30,000	1.875(-4.361, 8.111); 0.547		2.623(-5.125,10.372);0.491	
>30,000 ((Reference)	-		-	
Smoking history		0.855		0.691

Some smokers	2.187(-6.184, 10.559); 0.600		-4.768(-21.315,11.779);0.557	
Heavy smoker	0.006(-4.915, 4.926); 0.998		0.047(-14.368,14.462);0.995	
None ((Reference)	-		-	
Pathology		0.546		0.703
Unspecified	2.835(-2.380, 8.049); 0.278		3.191(-5.048,11.431);0.431	
Other	1.596(-4.394, 7.587); 0.593		-0.173(-8.451,8.105);0.966	
Adenocarcinoma (Reference)	-		-	
RT Type				
3D	1.500(-3.101, 6.101); 0.514		0.155(-6.418,6.728);0.962	
2D (Reference)	-		-	
RT Dose				
Other	7.382(2.052, 12.713); **0.008**		11.269(3.154,19.385);**0.009**	
30Gy/10F (Reference)	-		-	
Area of treatment		0.917		0.585
Bone	0.350(-4995, 5.695); 0.895		-0.971(-8.684,6.743);0.797	
Other	1.239(-4.783, 7.261); 0.680		-3.652(-10.935,3.631);0.310	
Brain (Reference)	-		-	

Predictor associated with information need in caregivers

1) Outcome: Change in MSAS information need subscale (follow-up visit 1)

Univariable linear regression showed that there were no statistically significant predictors found between caregiver's characteristics and the change of IN at follow up visit 1.

Multivariable linear regression results were qualitatively similar.

Univariable and multivariable result of Change in MSAS information need at visit 2 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.033(-0.196,0.131);0.689		-0.052(-0.297,0.193);0.670	
Gender				
Male	-1.558(-6.270, 3.153); 0.510		-2.119(-8.398,4.160);0.500	
Female (Reference)	-		-	
Marital status				
Single	0.050(-4.755, 4.855); 0.984		1.959(-5.658,9.575);0.607	
No single (Reference)	-		-	

Education Level		0.927		0.858
Primary	-0.929(-7.198, 5.340); 0.767		-0.352(-9.690,8.986);0.940	
Secondary	0.444(-4.874, 5.761); 0.868		1.489(-5.067,8.045);0.649	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	
Not work	-1.979(-8.269, 4.311); 0.531		-4.060(-12.288,4.169);0.325	
Career		0.355		0.284
None	-3.882(-10.782, 3.019); 0.264		-4.060(-12.288,4.169);0.325	
Other	-3.149(-7.981, 1.683); 0.197		-2.603(-8.549,3.342);0.382	
Employee (Reference)	-		-	
Income		0.387		0.404
0-10,000	2.610(-4.373, 9.592); 0.457		3.281(-6.409,12.970);0.498	
10,001-30,000	-2.048(-6.742, 2.645); 0.385		-1.274(-7.250,4.702);0.669	
>30,000 ((Reference)	-		-	
Smoking history		0.564		0.464
Some smokers	-5.469(-17.384, 6.445);0.361		-5.763(-18.963,7.438);0.384	
Heavy smoker	1.931(-5.823, 9.684); 0.620		4.516(-5.272,14.304);0.357	
None ((Reference)	-		-	
Relationship				
Spouse/Partner	1.746(-2.673, 6.164); 0.432		2.314(-4.473,9.102);0.495	
Other ((Reference)			-	

Outcome: Change in MSAS information need subscale (follow-up visit 2)

Univariable linear regression showed that there were no statistically significant predictors found between caregiver’s characteristics and the change of IN at follow up visit 2.

Multivariable linear regression results were qualitatively similar.

Univariable and multivariable result of Change in MSAS information need at visit 3 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.021(-0.218,0.175);0.828		0.032(-0.281;0.344);0.839	
Gender				
Male	-4.467(-9.919, 0.985); 0.106		-5.335(-12.940;2.270);0.164	
Female (Reference)	-		-	
Marital status				
Single	0.800(-4.988, 6.588); 0.782		3.035(-6.388;12.458);0.518	
No single (Reference)	-		-	
Education Level		0.873		0.636
Primary	-1.528(-9.033, 5.977); 0.684		-2.038(-13.340;9.265);0.717	
Secondary	-1.358(-8.00, 5.284); 0.683		-1.776(-10.125;6.574);0.669	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	
Not work	1.485(-6.673, 9.642); 0.716		2.224(-8.305;12.753);0.671	
Career		0.527		0.514
None	-0.333(-9.160, 8.493); 0.940		2.224(-8.305;12.753);0.671	
Other	-3.077(-8.818, 2.664); 0.286		-1.051(-8.336;6.234);0.772	
Employee (Reference)	-		-	
Income		0.520		0.614
0-10,000	2.800(-6.436, 12.036); 0.545		3.966(-8.513;16.446);0.524	
10,001-30,000	-2.091(-7.673, 3.491); 0.455		-0.740(-7.969;6.489);0.837	
>30,000 ((Reference)	-		-	
Smoking history		0.927		0.581
Some smokers	3.711(-15.447, 22.870); 0.699		9.345(-12.657;31.346);0.395	
Heavy smoker	-0.039(-9.926, 9.848); 0.994		5.450(-6.572;17.472);0.364	
None ((Reference)	-		-	
Relationship				
Spouse/Partner	3.082(-2.168, 8.333); 0.244		5.939(-2.852;14.730);0.179	
Other ((Reference)	-		-	

Outcome: *Change in MSAS information need subscale (follow-up visit 3)*

Univariable linear regression showed that there were statistically significant predictors found between relationship and the change of IN at follow up visit 3.

Relationship was statistically significant predictor with spouse/partner having a bigger increase in SCNS than other relationship (p = 0.031).

Multivariable linear regression results were statistically significant predictors found between gender, relationship, and the change of IN at follow up visit 3. Gender was statistically significant predictor with male having a bigger reduce in SCNS than female (p = 0.041). Relationship was statistically significant predictor with spouse/partner having a bigger increase in SCNS than other relationship (p = 0.021).

Univariable and multivariable result of Change in MSAS information need at visit 4 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.094(-0.304,0.116);0.370		0.024(-0.282,0.331);0.872	
Gender				
Male	-4.602(-10.109,0.904); 0.099		-7.879(-15.408,-0.350);**0.041**	
Female (Reference)	-		-	
Marital status				
Single	-1.544(-7.575, 4.488); 0.608		4.572(-4.598,13.742);0.316	
No single (Reference)	-		-	
Education Level		0.933		0.832
Primary	-1.027(-8.839, 6.784); 0.792		1.402(-9.691,12.495);0.798	
Secondary	0.671(-6.424, 7.765); 0.849		1.578(-6.772,9.928);0.702	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	
Not work	-2.335(-10.942, 6.272); 0.586		-2.703(-13.251,7.844);0.604	
Career		0.386		0.614
None	-4.600(-13.861, 4.661); 0.321		-2.703(-13.251,7.844);0.604	
Other	-3.809(-9.814, 2.196); 0.207		-0.356(-7.810,7.098);0.923	
Employee (Reference)	-		-	
Income		0.702		0.904
0-10,000	1.832(-7.322, 10.985); 0.688		0.961(-10.645,12.568);0.867	
10,001-30,000	-1.702(-7.692, 4.288); 0.569		1.585(-5.528,8.699);0.652	
>30,000 ((Reference)	-		-	
Smoking history		0.828		0.406
Some smokers	4.432(-14.101, 22.966); 0.631		6.232(-14.252,26.716);0.539	
Heavy smoker	1.932(-7.693, 11.558); 0.687		10.696(-0.418,21.809);0.059	

None ((Reference)	-		-	
Relationship				
Spouse/Partner	5.836(0.554, 11.118); **0.031**		10.613(1.713,19.514);**0.021**	
Other ((Reference)	-		-	

Outcome: Change in SCNS-P&C subscale (follow-up visit 1)

Univariable linear regression showed that there were statistically significant predictors found between employment status and the change of SCNS at follow up visit 1. Employment status was statistically significant predictors with not work having a bigger reduce in SCNS than work (p = 0.032).

Multivariable linear regression results were no statistically significant predictors found between caregiver's characteristics and the change of SCNS at follow up visit 1.

Univariable and multivariable result of Change in SCNS version at visit 2 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.077(-0.230,0.077);0.321		-0.066(-0.279,0.148);0.537	
Gender				
Male	0.895(-3.581, 5.371); 0.690		-2.554(-8.032,2.924);0.352	
Female (Reference)	-		-	
Marital status				
Single	-2.392(-6.898, 2.114); 0.292		-0.030(-6.675,6.615);0.993	
No single (Reference)	-		-	
Education Level		0.569		0.397
Primary	-1.313(-7.200, 4.573); 0.656		-4.555(-12.702,3.592);0.266	
Secondary	2.052(-2.941, 7.045); 0.413		1.216(-4.504,6.936);0.670	
University (Reference)	-			
Employment status				
Work (Reference)	-		-	
Not work	-6.292(-12.023, -0.560); **0.032**		-5.433(-12.613,1.746);0.134	
Career		0.052		0.100
None	-4.737(-11.044, 1.570); 0.138		-5.433(-12.613,1.746);0.134	
Other	2.574(-1.843, 6.990); 0.248		5.131(-0.056,10.319);0.052	
Employee (Reference)	-		-	
Income		0.567		0.125
0-10,000	1.484(-5.181, 8.148); 0.657		6.683(-1.772,15.137);0.118	
10,001-30,000	2.378(-2.103, 6.858); 0.292		4.992(-0.222,10.206);0.060	

>30,000 ((Reference)	-		-	
Smoking history		0.589		0.799
Some smokers	5.816(-5.483, 17.116); 0.307		3.641(-7.876,15.158);0.527	
Heavy smoker	0.016(-7.337, 7.370); 0.996		1.311(-7.228,9.851);0.758	
None ((Reference)	-		-	
Relationship				
Spouse/Partner	2.372(-1.790, 6.533); 0.258		0.986(-4.936,6.908);0.739	
Other ((Reference)	-		-	

Outcome: *Change in SCNS-P&C subscale (follow-up visit 2)*

Univariable linear regression showed that there were no statistically significant predictors found between caregiver's characteristics and the change of SCNS at follow up visit 2. Multivariable linear regression results were qualitatively similar.

Univariable and multivariable result of Change in SCNS version at visit 3 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.062(-0.229,0.104);0.455		-0.083(-0.352,0.185);0.533	
Gender				
Male	-0.841(-5.611, 3.928); 0.724		-0.424(-6.961,6.114);0.896	
Female (Reference)	-		-	
Marital status				
Single	-1.448(-6.367, 3.472); 0.557		-0.496(-8.597,7.604);0.902	
No single (Reference)	-		-	
Education Level		0.201		0.274
Primary	-0.165(-6.365, 6.034); 0.957		-0.735(-10.451,8.981);0.879	
Secondary	4.801(-0.686, 10.287); 0.085		5.091(-2.087,12.268);0.159	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	
Not work	1.152(-5.803, 8.106); 0.741		0.880(-8.171,9.931);0.845	
Career		0.658		0.196
None	2.389(-5.169, 9.947); 0.528		0.880(-8.171,9.931);0.845	
Other	2.094(-2.822, 7.010); 0.396		2.760(-3.503,9.022);0.378	
Employee (Reference)	-		-	

Income		0.829		0.903
0-10,000	-0.913(-8.863, 7.037); 0.818		-1.638(-12.365,9.090);0.759	
10,001-30,000	1.132(-3.672, 5.937); 0.638		0.486(-5.728,6.701);0.875	
>30,000 ((Reference)	-		-	
Smoking history		0.367		0.401
Some smokers	-6.844(-22.854, 9.165); 0.394		-10.771(-29.683,8.142);0.256	
Heavy smoker	-4.844(-13.106, 3.417); 0.244		-4.036(-14.371,6.298);0.434	
None (Reference)	-		-	
Relationship				
Spouse/Partner	0.351(-4.187, 4.889); 0.877		-1.449(-9.006,6.108);0.700	
Other ((Reference)	-		-	

Outcome: Change in SCNS P&C subscale (follow-up visit 3)

Univariable linear regression showed that there were no statistically significant predictors found between caregiver's characteristics and the change of SCNS at follow up visit 3.

Multivariable linear regression results were qualitatively similar.

Univariable and multivariable result of Change in SCNS version at visit 4 from baseline

Variable	Univariable Results Estimate (95% Confidence Interval); p-value	Univariable Results Categorical p-values	Multivariable Results Estimate (95% Confidence Interval); p-value	Multivariable Results Categorical p-values
Age	-0.038(-0.233,0.158);0.700		-0.183(-0.469,0.103);0.201	
Gender				
Male	2.419(-2.780, 7.618); 0.353		4.458(-2.559,11.474);0.204	
Female (Reference)	-		-	
Marital status				
Single	-0.552(-6.130, 5.027); 0.843		0.954(-7.592,9.500);0.821	
No single (Reference)	-		-	
Education Level		0.233		0.100
Primary	3.467(-3.485, 10.419); 0.319		4.791(-5.547,15.129);0.351	
Secondary	5.038(-1.275, 11.352); 0.115		5.432(-2.349,13.213);0.164	
University (Reference)	-		-	
Employment status				
Work (Reference)	-		-	
Not work	-1.384(-9.339, 6.571); 0.727		0.683(-9.146,10.512);0.888	
Career		0.163		0.065
None	1.667(-6.687, 10.021); 0.689		0.683(-9.146,10.512);0.888	

Other	5.130(-0.287, 10.547); 0.063		5.013(-1.933,11.960);0.151	
Employee (Reference)	-		-	
Income		0.406		0.662
0-10,000	1.758(-6.566, 10.082); 0.672		1.509(-9.308,12.325);0.777	
10,001-30,000	3.658(-1.789, 9.105); 0.182		2.730(-3.899,9.359);0.406	
>30,000 ((Reference)	-		-	
Smoking history		0.513		0.208
Some smokers	-5.162(-22.046, 11.721); 0.540		-12.493(-31.583,6.597);0.191	
Heavy smoker	-4.412(-13.181, 4.357); 0.315		-4.651(-15.008,5.705);0.366	
None ((Reference)	-		-	
Relationship				
Spouse/Partner	-0.918(-6.076, 4.240); 0.721		-0.590(-8.885,7.704);0.885	
Other ((Reference)	-		-	

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