




SPECIAL ISSUE ARTICLE

Palliative care facilitates the preparedness of caregivers for thoracic cancer patients

Nienke Zomerdijk^{1,2}  | Stacey Panozzo^{3,4,5}  | Linda Mileskin³ |
Jaclyn Yoong^{6,7,8,9} | Anna K. Nowak^{10,11,12} | Martin R. Stockler^{9,13} |
Jennifer Philip^{3,4,5,14} 

¹Melbourne School of Psychological Sciences, University of Melbourne, Parkville, Victoria, Australia

²Victorian Comprehensive Cancer Centre Alliance, Parkville, Victoria, Australia

³Peter MacCallum Cancer Centre, Parkville, Victoria, Australia

⁴Department of Medicine, University of Melbourne, Parkville, Victoria, Australia

⁵St Vincent's Hospital, Melbourne, Victoria, Australia

⁶Monash University, Melbourne, Victoria, Australia

⁷Monash Health, Melbourne, Victoria, Australia

⁸Northern Health, Melbourne, Victoria, Australia

⁹NHMRC Clinical Trials Centre, University of Sydney, Camperdown, New South Wales, Australia

¹⁰Medical School, The University of Western Australia, Perth, Western Australia, Australia

¹¹Department of Medical Oncology, Sir Charles Gairdner Hospital, Nedlands, Western Australia, Australia

¹²National Centre for Asbestos Related Diseases, Institute for Respiratory Health, Perth, Western Australia, Australia

¹³Department of Medical Oncology, Chris O'Brien Lifehouse, Sydney, New South Wales, Australia

¹⁴Royal Melbourne Hospital, Melbourne, Victoria, Australia

Correspondence

Nienke Zomerdijk, School of Psychological Sciences, University of Melbourne, Parkville, Victoria 3052, Australia.

Email: nienke.zomerdijk@unimelb.edu.au

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Abstract

Objective: Palliative care improves outcomes for patients with thoracic cancer; however, limited evidence exists for the benefits of this approach for caregivers. This study aimed to advance understanding of the experiences of palliative care described by bereaved caregivers.

Methods: Fifteen adult caregivers completed semi-structured interviews following prior participation in a randomised controlled trial of early referral to palliative care versus discretionary referral to palliative care. Interviews explored caregiver experiences of palliative care delivery. Interview transcripts were thematically analysed.

Results: Four related themes about the experiences of palliative care were identified, each of which required sufficient time between palliative care first contact and death: 'relationship building'; 'clear communication and information'; 'access to practical support'; and 'access to psychosocial support'. The core category underpinning these themes was *palliative care facilitates caregiver preparedness*. Caregivers noted that palliative care played a critical role in preparing them for the future and described a

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sense of practical and emotional 'relief' associated with the support services made available to them.

Conclusion: Our findings emphasise that palliative care can have a positive impact on caregivers' preparedness for providing the care needed by thoracic cancer patients and that this can improve the experiences of both caregivers and patients.

KEYWORDS

caregivers, palliative care, qualitative research, supportive care, thoracic cancer

1 | INTRODUCTION

Thoracic cancers, encompassing lung cancer and malignant pleural mesothelioma, are the leading causes of cancer death, accounting for 2.2 million new diagnoses and 1.8 million deaths worldwide (Sung et al., 2021). Despite improvements in diagnostics and treatments, prognosis for thoracic cancers remains poor and the symptom burden high (Lutz et al., 2001). This burden, which includes symptoms such as pain, fatigue, and shortness of breath, can have a considerable impact on patients' quality of life (QoL). Alongside the experiences of patients, caregivers are also adversely affected by the illness. Caregivers of patients with thoracic cancer are often faced with complex situations and may feel inadequately prepared for the responsibilities being asked of them, which can negatively influence their own wellbeing and their ability to give care (Braun et al., 2007; Hannon et al., 2013; Northouse et al., 2012). Having well-prepared caregivers and promoting their wellbeing are core elements of a palliative care approach (Levy et al., 2012).

Caregivers are a highly important group who enable patients to remain at home and provide support that is crucial to both their physical and psychological wellbeing. Although many caregivers find personal satisfaction and accomplishment from this role, it can also be challenging or even overwhelming (Braun et al., 2007; Northouse et al., 2012). Caregiving can involve multiple tasks, including but not limited to complex medical management, such as identifying and reporting side effects, administering medications, care coordination, and household tasks. This can lead to increasing stress over time, with a significant physical, psychological, and social impact for the caregiver. A recent cross-sectional study of 43 dyads of people with lung cancer and their caregivers reported that the prevalence of anxiety and depression was 47% and 28% respectively, and in some cases, the distress of caregivers exceeded that of patients (Tan et al., 2018). Notably, a meta-analysis of 21 studies involving people with cancer and their caregivers found positive associations between patient and caregiver psychological outcomes (Hodges et al., 2005), suggesting that patients' wellbeing directly affects caregivers' distress and vice versa. This mutuality of risk suggests that the focus of care should include the caregiver.

Palliative care is defined as multidisciplinary care that aims to enhance QoL and improve quality of care for patients and their families, including caregivers (Ringdal et al., 2002; World Health Organization, 2020). As previous studies have indicated, thoracic cancer patients and their caregivers represent a cohort that can greatly

benefit from an intervention with a palliative care strategy. Research undertaken to determine the effects of palliative care early in the course of thoracic cancer have demonstrated significant improvements in patient outcomes, including QoL, timely end of life planning, symptom control and, in some cases, survival (Bakitas et al., 2009; Temel et al., 2010; Yoong et al., 2013; Zimmermann et al., 2014). In contrast, evidence for the benefits of this approach for caregivers of patients with thoracic cancer has received limited attention to date.

In-depth understanding of the experiences of palliative care for caregivers of thoracic cancer patients has the potential to cultivate awareness of the role of this approach to care, and its possible lessening of the burden upon caregivers. The present study is part of a multi-centre phase three randomised controlled trial of early referral to palliative care versus discretionary referral (usual care) to palliative care for patients with recently (within 60 days) diagnosed, advanced thoracic cancer. Bereaved caregivers of patients from both study arms were interviewed 2–3 months following the patient's death. The aim of this qualitative study was to advance understanding of the experiences of palliative care described by bereaved caregivers of people who died from thoracic cancers.

2 | METHODS

2.1 | Design and participants

This study is a substudy of a randomised controlled clinical trial examining the effects of early referral to palliative care on outcomes for patients with advanced thoracic cancers, registered with the Australian New Zealand Clinical Trials Registry (ACTRN12617000166370). The methods and results of this trial are reported elsewhere (Mileshkin et al., 2018).

Eligible patients were adults aged ≥ 18 years with a diagnosis within the last 60 days of either (i) advanced non-small lung cancer (NSCLC), including de novo stage IV disease, recurrent NSCLC, and locally advanced disease not planned for curative treatment, or (ii) extensive stage small cell lung cancer (SCLC), or (iii) advanced malignant pleural mesothelioma (MPM) not planned for extrapleural pneumonectomy or pleurectomy decortication, a Karnofsky performance status of 50 to 100 at the time of randomisation, and had sufficient English literacy to provide written and informed consent. Patients who required immediate referral to palliative care had already

been referred to palliative care or had a life expectancy of less than 3 months were excluded. Recruited patients were asked to nominate their primary caregiver, who was approached with the patient's consent for trial-specific caregiver participation in the research. This study was approved by the institutional Human Research and Ethics Committee (HREC/16/RPAH/467). Consolidated criteria for reporting qualitative research were used to guide the reporting of this research (Tong et al., 2007).

2.2 | Intervention and control

The palliative care intervention in this trial consisted of standard oncological care plus early referral (within 60 days of diagnosis) to a palliative care service. The intervention included (i) an initial palliative care consultation with a hospital-based palliative care service, (ii) a case conference between the hospital-based palliative care service and the patient's general practitioner within 28 days of the initial palliative care consultation, and (iii) a regular follow-up with the hospital-based palliative care service after the initial consultation according to the patient's needs every 3–4 weeks. The content of the consultations was based on the National Comprehensive Cancer Network guidelines for palliative care (Levy et al., 2012). Consultations consisted of an assessment of patients' physical, psychological, social, and spiritual needs. The control arm received standard oncological care and referral to a hospital-based palliative care service at the treating clinician's discretion.

2.3 | Qualitative caregiver study

At 2–3 months following the patient's death, a subset of caregivers in each trial arm was identified to participate in a qualitative semi-structured telephone interview. Consecutive sampling of caregivers was utilised and supplemented by purposive sampling to ensure representation across age, gender, diagnoses, and regionality. Caregivers were initially contacted by a trials nurse or site coordinator and invited to participate in an interview. Author SP then contacted interested caregivers by telephone to schedule an interview.

2.4 | Sample and data collection

Eligible patient and caregiver participants were recruited between June 2017 and December 2021 from 15 sites across three states in Australia. Of the 78 caregivers recruited to the trial, 15 (19%) agreed to participate in this substudy. Written and verbal-informed consent was obtained prior to the interviews.

Interviews were conducted by author SP (Research Fellow, PhD, experienced in qualitative research methods) between April 2019 and July 2021. A question guide was developed by the investigators based on the existing literature but not subjected to pilot testing, which consisted of semi-structured and open-ended questions to elicit and

TABLE 1 Interview guide

| Topic | Questions |
|--|---|
| Perceived patient issues or concerns | Can you tell me about the few weeks leading up to <patient's> death? What were the biggest issues or concerns for <patient> in the last few weeks? |
| Caregiver issues or concerns | What were the biggest issues/concerns for you in the last few weeks? What things were helpful for you at this time? What things did you think were not helpful? |
| Timeliness and usefulness of palliative care | What are your reflections on the care/palliative care that <patient> received? |
| Suggestions for improvement | Are there other things that you want to tell us about this time for <patient> and for you? Things we should know, suggestions for doing things better? |

explore caregiver experiences and perceptions of palliative care delivery (Table 1). Prompts were used to elicit further detail, follow-up experiences, and viewpoints emerging dependent on participants' responses. Telephone interviews were an average 44 min duration (range 28 to 71 min).

2.5 | Data analysis

Interviews were audio-recorded, transcribed verbatim, transcriptions checked for accuracy by authors NZ and SP, and deidentified. Analysis involved immersion in the data with repeated listening of recordings and reading of interview transcriptions using Braun and Clarke's six-stage reflexive thematic analysis method (Braun et al., 2018; Braun & Clarke, 2006). During the analysis, the authors employed an inductive approach to thematic analysis and worked within a realist epistemology. That is, the authors were not committed to any pre-existing coding frameworks or preconceptions and instead sought to report experiences, meanings, and the reality of caregivers, which aligns clearly with the exploratory nature of the present study. Familiarisation and initial coding of a subset of the transcripts were conducted independently by authors NZ, JP and SP. Coding of remaining transcripts was performed by NZ, and codes were refined into themes. The themes were formally defined and subsequently summarised with extracts from the transcripts. Codes and themes were reviewed and verified by co-authors.

3 | RESULTS

3.1 | Participant characteristics

A total of 15 caregivers (9 intervention and 6 control), with a median age of 63 years (range 40–85), completed interviews between April 2018 and July 2021. Most caregivers were women and acted as the

TABLE 2 Participant characteristics (N = 15)

| | Intervention (N = 9) n (%) | Control (N = 6) n (%) |
|------------------------------|-------------------------------|--------------------------|
| Age in years, median (range) | 64 (43–85) | 63 (40–79) ^a |
| Gender | | |
| Women | 6 (67) | 5 (83) |
| Men | 3 (33) | 1 (17) |
| Relationship to patient | | |
| Spouse | 7 (78) | 4 (67) |
| Daughter | 2 (22) | 2 (33) |
| Patient place of death | | |
| Hospital | 7 (78) | 4 (67) |
| Hospice | 1 (11) | - |
| Home | 1 (11) | 2 (33) |

^aReflection of 14 participants, rather than all 15.

caregiver for their spouse (73% respectively) (Table 2). Caregivers were interviewed an average of 2 months after the patient's death (range = 2–4 months).

3.2 | Overview of themes

Analysis of the qualitative data resulted in the overarching theme that *palliative care facilitates caregiver preparedness*. This sense of preparedness was seen as a core task of palliative care and was achieved through four major areas of activity, each of which required sufficient time between first point of contact with palliative care staff and the patient's death: 'Relationship building', 'Clear communication and information', 'Access to practical support' and 'Access to psychosocial support'.

3.2.1 | Relationship building

Palliative care staff focused on building relationships with patients and caregivers by establishing an understanding of their needs and care preferences. Palliative care staff included caregivers in conversations, ensuring the caregivers felt informed and prepared for how to help their loved one. In such encounters, caregivers described feeling comfortable asking questions and conveying their needs and concerns. Participant descriptions revealed the importance of the relationship that was built between palliative care staff and caregivers.

They were very good to us, you know, in that way, and like whatever if I wanted, anything, I just had to ask. (Caregiver #3, Intervention)

Building this relationship early in the illness course facilitated smoother transitions at times of disease progression later

on. Participants described a familiarity with palliative care staff, providing caregivers with a sense of comfort and peace when patients approached the end of their life.

And I found it was quite good because it meant that the palliative care specialist knew her quite well by the time we got to that stage. It wasn't a long battle, by any means. But it was nice to already have that connection with the palliative care specialist before hitting that stage. (Caregiver #6, Intervention)

However, when there was a lack of continuity between the palliative care staff, this limited the opportunities for establishing such a relationship, and as a result, preparedness was not achieved.

The only thing I wasn't happy about is that he didn't see someone, like the people he knew, he had seen before. You know? It would have been nice to have one of them come down and see him, even if it was only for five minutes. (Caregiver #3, Intervention)

3.2.2 | Clear communication and information

The importance of clear communication and information from all members of the care team was emphasised by caregivers. Palliative care highlighted the patient's poor prognosis in a sensitive manner, avoided false optimism, and set realistic expectations about the illness, which were highlighted as important to caregivers. This allowed caregivers to prepare for death, both practically and emotionally. For example, caregivers described having discussions with the patient about their end of life wishes, informing other family members about the possibility of death, and making funeral arrangements.

Both of them were very honest with us and very good doctors. I'm quite analytical, so the doctors told me this and that's what it was. I had come to the conclusion that she was terminal, and that's what it was. So I knew where she stood. (Caregiver #6, Intervention)

Clear communication about the patient's prognosis also appeared to facilitate the caregivers' adjustment to bereavement. Caregivers described positive reflections of their time with the patient leading up to the death. In contrast, a lack of timely and clear communication regarding the patient's prognosis negatively impacted caregiver experiences. Shock, sadness, and anger were common reactions among caregivers who reported feeling unprepared for the patient's death. Some caregivers were not present at the time of death itself. However, it was not the bedside presence itself that was highlighted by caregivers but the ability to prepare and spend meaningful time prior to death. A lack of preparedness led carers to reflect on their regret about time spent with the patient before death and appeared to negatively affect their adjustment to bereavement.

They said to me, 'You know, have you got a funeral director?' I said, 'No, we haven't even talked about that'. (Caregiver #7, Control)

If I had known that, we could have probably handled her situation a lot better. So you can arrange your life a bit better or take that holiday, take that chance when you've got it, instead of sort of being too late. That was one of the major things that was upsetting. (Caregiver #4, Intervention)

The retrospective perspectives shared by caregivers indicated that conversations about the prognosis were influenced by patient readiness. There appeared to be different information priorities for patients and caregivers, which was consistent among both trial arms. While most caregivers desired frank and early discussions about the illness, some patients avoided discussions about end of life. This was particularly evident among caregivers who described the patients as maintaining hope while undergoing active treatment.

I often think whether we would have had a bit more quality time at the end if he hadn't kept on pushing to, you know, try the study trial stuff that really hit him, whether he mightn't have been quite so sick, you know, we'd have had a bit more quality time. But, you know, he was just willing to keep trying something else. (Caregiver #2, Control)

3.2.3 | Access to practical support

Palliative care was described as seeking to ensure that patients and their caregivers had access to needed practical services, including facilitating those from other providers such as home equipment, nursing and/or cleaning services. Community palliative care was the most frequently mentioned service in this context. Timely and regular involvement of community palliative care relieved caregivers of a number of practical carer responsibilities such as showering, providing medications, and transportation. Others expressed a need for greater psychosocial support.

The people that came in, they're... Yeah, I don't think we could've managed without any of this. (Caregiver #12, Intervention)

Yeah, they were wonderful. All of them were really helpful, and it was really... They would ring me every morning, and if you didn't want help, I'd just say, 'Look, no, I'm okay today, at this point in time'. So they'd leave it and then someone would ring in the afternoon and maybe they'd come and see him. (Caregiver #15, Intervention)

3.2.4 | Access to psychosocial support

Palliative care staff were also reported to relieve caregivers from much of the emotional burden of caregiving. Caregivers described staff as being gentle, kind, warm, and having an open manner. This was said to help the patients to feel at ease and facilitated discussion about any psychosocial concerns. This provided 'relief' for caregivers, some of whom struggled to get patients to open up, or patients who wanted to 'protect' caregivers from hurt or worry by concealing their psychosocial concerns. Caregivers experienced a positive downstream effect, making it easier for them to provide care as illness worsened.

One-on-one he (*patient*) wouldn't relate to me. But if I'd say something, they would then say something to (*patient*) in a different way that would still get me sort of an understanding of how he was feeling. If I had said to him, 'How are you feeling? Better?' 'Yeah, I'm fine'. But he would say that to everybody. Probably the palliative care people were the only ones who could get him to open up. (Caregiver #12, Intervention)

When asked about the timeliness of palliative care, majority of caregivers (four out of six) in the control group wished palliative care had been involved earlier on in the patient's illness trajectory. Specifically, they noted earlier access to the aspects of palliative care that focused more on the psychosocial aspects of the patient's advanced disease would have been helpful. For instance, one caregiver felt that earlier palliative care could have helped the patient to better cope with their deteriorating health status, and this may have affected their mental health.

He perhaps should have had someone he was talking to, not just the oncologist, but yeah, some sort of counselling. Something, you know? Regards to how he was feeling and how much pain he was in or better ways of getting through it or yeah. Yeah, perhaps it should have start that a bit earlier. (Caregiver #2, Control)

4 | DISCUSSION

This study provides an in-depth qualitative account of caregiver experiences, highlighting that a core task of palliative care for caregivers of people with thoracic cancer is to facilitate a sense of preparedness. While clinical practice guidelines clearly state that the needs of caregivers should be responded to with relevant psychosocial and practical supports and information provision (Howell et al., 2012; Hudson et al., 2012; National Comprehensive Cancer Network, 2022), there is evidence that their implementation into routine clinical care is limited and that the support needs of caregivers are often unmet (Dilworth et al., 2014; Wang et al., 2018). This may be because psychosocial aspects of care are not seen as central to the scope of practice for

busy clinicians and lack of confidence about addressing psychosocial concerns (Dilworth et al., 2014). However, our results suggest that preparing caregivers through providing information and access to practical and psychosocial supports is meaningfully realised in clinical practice by palliative care.

In addition, palliative care served an important role in helping caregivers to cope with their loved one's deteriorating health status and death. These perceptions indicate that palliative care recognised the critical role of caregivers in helping patients cope with the effects of thoracic cancer and their need for preparation. This need for preparation is particularly salient for caregivers of advanced thoracic cancer patients, who have complex clinical and care needs that differ from those with earlier stage cancer or curable disease (Hart et al., 2022). This requires intensive and prolonged home-based caregiving, which can become physically and emotionally overwhelming and negatively impact caregiver QoL (Tan et al., 2018). Thus, having well-prepared caregivers and promoting their wellbeing is critical. Our findings suggest that palliative care plays a critical role in facilitating preparedness and builds on previous literature that attests to the benefits of quality palliative care for patients (Bakitas et al., 2009; Ringdal et al., 2002; Temel et al., 2010; Yoong et al., 2013; Zimmermann et al., 2014).

This study revealed that building a relationship with caregivers was key for achieving caregiver preparedness. Understanding the needs and preferences of caregivers early in the disease trajectory appeared to form the basis for the relationship between palliative care staff and caregivers. In end of life settings, when the patients' health status rapidly declined, and stakes were high, these relationships assisted caregivers during stressful experiences. The importance of building relationships has similarly been highlighted in early palliative care intervention studies with patients. Yoong et al. (2013) commenting on lung cancer patients suggested that continuity of care and rapport between patients, family members, and palliative care clinicians facilitate smoother transitions at later stages of the patient's disease when more challenging discussions about end of life are necessary. Our findings demonstrate that relationship building is equally important for caregivers and suggest that important outcomes, such as caregiver experiences, engagement in decision-making, and transitions of care, may be influenced by relationships with caregivers in the early phases of illness. This suggests that palliative care is applicable already early after the diagnosis of advanced cancer and contradicts studies and common perceptions that this approach may be physically and/or psychologically harmful (Collins et al., 2017; Haun et al., 2017; Shen & Wellman, 2019; Touzet et al., 2019). This knowledge should reassure members of the healthcare team who have concerns about the timing for introducing palliative care services (Schofield et al., 2006).

Our findings also suggest that provision of clear prognostic information facilitates caregivers' preparedness for death, which strongly impacts caregiver experiences both pre- and post-death. Avoidance of false optimism and setting realistic expectations allowed caregivers to be prepared for the future, to make plans for spending meaningful time with their loved one leading up to the death and, in turn, facilitated their adjustment to bereavement, as evidenced by their

acceptance of the patient's death. Lack of preparedness for death is a risk factor for complicated grief (Wen et al., 2021). Complicated grief is associated with many physical and mental health problems including increased rates of depression, anxiety, suicide, and substance abuse (Latham & Prigerson, 2004; Sung et al., 2011). As such, timely palliative care, which facilitates preparation, is also a public health matter. Our results demonstrate that clear information about what to expect in the future is a vital task accomplished by palliative care that may serve to prevent complicated grief. However, results also indicate that there can be a discord between patient and caregiver priorities for information and desire to discuss the prognosis. These information priorities can remain unspoken in the presence of patients who experience difficulties coming to terms with their changing health status and avoid discussions about end of life. Such discussions, however, are essential for achieving caregiver preparedness and need to be sensitively handled (Schofield et al., 2006; Steinhäuser et al., 2015).

Caregivers commonly described spending substantial time with patients which involved emotional and physical sacrifices. Indeed, their role involved complex medical and nursing management. Palliative care relieved them of many tasks by ensuring timely access to practical resources and services such as home equipment, transportation, nursing and/or cleaning services. Caregivers in this study were satisfied with the practical care they had received and emphasised that this reduced their subjective burden. This accords with research showing resource shortage leads to more stressful caregiving experiences and higher burdens, whereas the availability of resources is associated with better perceived health of caregivers (Hong & Harrington, 2016; Northouse et al., 2012). Importantly, access to psychosocial support emerged as a strong aspect of palliative care that brought deep relief for both caregivers and their loved ones. Caregivers described that the provision of this support helped patients to unveil their psychological concerns and encouraged positive methods to cope with their deteriorating health status. In turn, caregivers experienced a positive downstream effect, which made it easier for them to care for their loved one. This is in line with studies suggesting patients' and caregivers' psychological distress is interdependent (Hodges et al., 2005). Additionally, caregivers' distress levels have been shown to increase as the patient's health status declines and as the patient approaches death (Northouse et al., 2012). Taken together, this evidence suggests that palliative care interventions could prevent later development of psychological distress in both members.

The present study demonstrates the importance of sufficient time between first point of contact with palliative care staff and the patient's death. While preparedness was seen as a core task of palliative care, this required sufficient time to plan and coordinate the four major areas of activity in order to achieve caregiver preparedness. It has previously been demonstrated that longer intervals between the first contact with palliative care and death are associated with better outcomes in patients with advanced cancers (Ziegler et al., 2018). Our qualitative findings suggest that the benefits of palliative care for caregivers may also be based on the interval between first point of

contact and death. That is, the longer duration of palliative care might increase opportunities for relationship building, delivering clear information and subsequent provision of effective support, and hence achieve caregiver preparedness. It remains unclear if this improves caregiver outcomes. Continued research utilising mixed-methods and validated instruments will help to further extrapolate the benefits of palliative care for caregivers and the association with duration of palliative care.

5 | STRENGTHS AND LIMITATIONS

The qualitative method used in this study enabled deeper understanding of individual caregiver perspectives in relation to their experiences of palliative care. The study also benefited from the fact that it described results obtained from 15 different centres. There are some limitations to the study. First, only a small proportion of eligible caregivers participated in this substudy, and only caregivers' perceptions were represented, resulting in the exclusion of views of persons with thoracic cancer. Second, caregivers' retrospective accounts may have reflected how they felt at the time of the interview, rather than being an accurate description of their experiences of actually delivering care during palliative care through to the end of life. Third, this study did not include detailed questions about caregivers' perspectives regarding the timeliness of palliative care. Indeed, unanswered questions remain: When is it too early for referral? When is it too late? These questions may be answered by future qualitative research exploring preferences regarding the ideal timing for palliative care referral. Fourth, an eligibility requirement that participants have sufficient English language skills is likely to have prevented the participation of individuals from culturally and linguistically diverse backgrounds, which may have affected the themes that were identified. Last, the views of those other than spouses of the patients who may take on the role of caregiver were underrepresented in our sample. As the population continues to age, a growing number of children, parents, and siblings will find themselves in the position of taking on this role. Further, consideration of these subgroups of caregivers is important as they juggle other social roles while providing care to a family member with cancer.

6 | CONCLUSION

This study demonstrated that palliative care can increase caregivers' sense of preparedness for providing the complex care needed by patients with thoracic cancer and that this can improve the experiences of both caregivers and patients. This underscores the importance for future research to extend its focus to identify possible positive aspects of palliative care for both patients and their caregivers. Finally, our findings underline the importance of integrating palliative care in routine clinical care for patients with advanced thoracic cancer, with the core goal of improving outcomes for both patients and their caregivers.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon reasonable request from the corresponding author.

ORCID

Nienke Zomerdijsk  <https://orcid.org/0000-0001-5008-6429>

Stacey Panozzo  <https://orcid.org/0000-0001-8918-3226>

Jennifer Philip  <https://orcid.org/0000-0002-3312-0645>

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