



The role of palliative care in lung transplantation

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Abstract: Lung transplantation confers meaningful benefit for patients by extending life and improving quality of life. Palliative care is a medical specialty that likewise aims to improve the quality of life of patients enduring serious illness and their caregivers. Yet, while transplant candidates and recipients face serious illness they rarely receive palliative care, even at end of life. While limited palliative care utilization is likely multifactorial, one key reason is a limited understanding of the specialty of palliative care and evidence for palliative interventions. In this review, we address this key barrier by discussing in depth what the specialty of palliative care is and provides to patients and their caregivers. We then discuss the growing evidence for palliative care interventions to improve quality of life and reduce symptom burdens in patients with malignancy including those undergoing bone marrow transplantation and patients with chronic organ failure. We then consider what palliative care needs exist across pre and post transplantation based on studies of palliative care needs of patients with end stage lung disease, studies of quality of life after lung transplantation, and limited studies of palliative care utilization pre and post lung transplantation. Finally, we consider different models of palliative care and discuss how palliative care might optimally be incorporated in lung transplantation using a longitudinal, integrated approach to palliative care.

Keywords: Lung transplantation; palliative care; quality of life

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Introduction

Lung transplantation confers meaningful benefit for patients with end stage lung disease by extending life and improving quality of life (1-3). Palliative care is a medical specialty that aims to also improve quality of life and reduce the suffering of patients and their families facing life-threatening illness (4,5). If lung transplantation improves quality of life, is there a role for palliative care in lung transplantation?

As we will discuss in detail, palliative care is beneficial for patients with life-threatening or serious illness (6). Serious illness is “a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life, or excessively strains their

caregivers.” (5,7). Transplant candidates face poor quality of life and potential mortality while awaiting transplantation. Transplant recipients face uncertainty about life expectancy and may experience reduced quality of life due to rejection and other complications following transplantation. Thus, there may be a potential role for palliative care across the transplant trajectory.

Currently neither transplant candidates nor recipients commonly receive palliative care (8-11). Limited understanding of the specialty of palliative care and evidence for palliative interventions likely contribute to limited utilization (9,12). We aim to address this barrier by discussing in detail the specialty of palliative care and evidence for its impact on quality of life and symptom

burdens. We then consider the potential palliative care needs of lung transplant candidates and recipients and how palliative care might be optimally utilized.

What is palliative care?

According to the World Health Organization, palliative care “is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (13). Palliative care is interdisciplinary, including medical specialists, nurses, social workers, and chaplains who have trained in palliative medicine (5). Hospice and Palliative Medicine was certified as a subspecialty in 2006 and fellowship training has been required for board certification since 2014. Fellowship entails 1–2 years of interdisciplinary training with defined milestones for knowledge of serious illness, comprehensive patient assessment, addressing suffering and distress, refractory symptoms, communication skills including facilitating complex decision making, and interdisciplinary teamwork (14,15). Certification programs also exist for nurses, social workers, and chaplains (16).

What is the comprehensive palliative care assessment?

A comprehensive palliative assessment includes structured assessment of multiple domains including physical symptoms such as pain, breathlessness, fatigue, and nausea, psychiatric and cognitive symptoms including anxiety, depression, delirium, demoralization, and coping, illness comprehension and preferences regarding medical care, social and economic needs, and spiritual, religious, and existential distress (4,5,17,18). Symptom burdens and other needs are typically assessed using validated instruments such as the Edmonton Symptom and Assessment Scale for physical symptoms and the Patient Health Questionnaire for psychological symptoms. Use of validated instruments is important because symptoms and support needs are likely to be underappreciated if not assessed systemically (4,18–26). Identification of symptoms and sources of distress enables interventions to mitigate symptoms, enable better coping, alleviate distress, and assist with decision making.

When can a patient receive palliative care?

A common perception amongst transplant providers is that palliative care is equal to hospice care (9,12). While palliative care originally emerged from hospice care, it has a broader mandate and can be provided at any point along a patient’s illness trajectory while patients are receiving disease directed therapies. In summary, palliative care is an interdisciplinary medical specialty with a defined training pathway that is uniquely suited to comprehensively evaluate and treat symptoms and sources of distress at any point along an illness trajectory.

What is the evidence for palliative care interventions?

Evidence for palliative care’s impact on quality of life has grown substantially over the past two decades. Yet to date there are no trials of palliative care in solid organ transplantation. To understand the potential of palliative care we will consider evidence from trials in oncology and chronic organ failure.

A 2016 meta-analysis assessed the association between palliative care interventions and quality of life and symptom burden in randomized controlled trials (RCT) (6). Most trials included patients with cancer and about a third included patients with heart failure. Palliative care improved quality of life and reduced symptom burden though the effects were small when limited to studies at low risk of bias likely due to heterogeneity in study design. Two more recent meta-analyses examined the impact of palliative care on quality of life and the effect of early palliative care on quality of life and symptom burdens for patients with advanced cancer (27,28). Both found associations between palliative care, better quality of life, and lower symptom burdens. Trials published since these meta-analyses add additional insight.

First, early integrated outpatient palliative care improved quality of life and reduced depression for patients with non-curable lung cancer potentially through an increase in positive coping strategies (29,30). Second, integrated palliative care for patients with acute leukemia undergoing bone marrow transplantation reduced depression, anxiety and declines in quality of life during the transplant (31). At 6 months, patients receiving palliative care had less depression and PTSD potentially due to lower symptom burdens during the transplant (32). Third, outpatient palliative care for patients with advanced heart failure improved

quality of life and reduced anxiety and depression (33). Finally, a pilot RCT of embedded palliative care in a cystic fibrosis clinic found that more than 60% reported improvements in physical symptoms and quality of life (34). Collectively, these studies suggest that integrated palliative care improves quality of life and reduces symptom burdens.

Other outcomes assessed in RTCs include advanced care planning, satisfaction with care, caregiver outcomes, and survival. A systematic review found a consistent association of palliative care with improvements in advance care planning, patient and caregiver satisfaction, and lower health care utilization (6). Evidence regarding the impact of palliative care on health care expenditures and caregiver outcomes was mixed. Finally, there is no clear association between palliative care interventions and survival.

In summary, evidence for the ability of palliative interventions to improve quality of life is both established and growing. How do these potential benefits of palliative care apply to lung transplantation? We must consider how potential palliative care needs evolve from pre to post-transplantation.

What are potential palliative care needs across the transplant trajectory?

We will consider potential palliative care needs while awaiting transplant, in the early post-transplant period, and further out from transplantation. Three sources of literature provide insight: (I) the palliative care needs of patients with end stage lung disease have been studied outside of the transplant context, (II) quality of life in lung transplantation has been studied extensively, and (III) there are a few studies of palliative care utilization pre and post-transplant. We begin with the potential needs of transplant candidates.

Patients with end stage lung diseases experience poor quality of life due to physical symptoms, psychological symptoms (especially anxiety and depression), treatment burdens, and existential distress (35-47). Consistent with these studies, transplant candidates co-managed with Palliative Care at the University of Toronto all experienced moderate to severe symptoms including dyspnea, cough, insomnia, anxiety, depression, and pain (48,49). Other palliative care needs may be prevalent and under-recognized. Patients with advanced cystic fibrosis have unmet palliative care needs including existential distress, emotional support, advanced care planning, assistance with decision making, and caregiver support (50-52). Similarly the palliative care needs of patients with idiopathic pulmonary fibrosis (IPF)

and chronic obstructive pulmonary disease (COPD) include illness understanding, assistance with coping, and emotional distress (53-61).

Additional stressors likely unique to transplant include the decision to pursue transplant, anxiety from the transplant evaluation, worry about being selected as and remaining a candidate, and surviving to receive a transplant (62-64). Anxiety, depression, and distress increase with time on the waiting list (65-67). Importantly, patients with maladaptive coping strategies experience lower quality of life while waiting (68-70). Transplant candidates thus experience reduced quality of life due to significant symptoms and need assistance with emotional support and coping while awaiting transplantation.

The early post-transplant period is a critical time that affects the long-term quality of life trajectory. Critically, a stressful perioperative transplant experience and early poor quality of life is linked to persistently lower quality of life (71-75). This association is notable given trends in the lung allocation score era of transplanting sicker, older, and frailer patients, longer ICU stays, longer hospitalizations, and more early post-transplant complications (76-79). Further, while most patients experience lasting improvements in quality life, quality of life does not improve for some individuals and declines for others (2,80-82). In one recent study, nearly 20 percent experienced a decline in mental quality of life in the first post-transplant year (82). A decline in mental quality of life is notable as that psychiatric co-morbidity is common after transplant. Depression particularly is worrisome as it impacts up to a third of transplant recipients and is associated with both mortality and chronic allograft dysfunction (75,83-90). Persistent or new frailty and cognitive dysfunction early after transplant are also linked to persistent decrements in quality of life (81,91-93).

At the University of Pittsburgh, we found that nearly a third of transplant recipients received palliative care in the first post-transplant year (11). The vast majority of palliative care encounters occurred in the inpatient setting, including a third during the transplant hospitalization primarily for symptom management and support. While potential palliative care needs deserve further study, they may include new symptoms related to multiple organ systems, medication side effects, changes in social relationships, and worry about post-transplant complications, allograft function, and long-term outcomes (37,71,94-96).

Further out from transplant, complications such as chronic lung allograft dysfunction (CLAD), chronic non-

pulmonary organ failure, and malignancy can impact quality of life. The impact of CLAD is particularly significant as after CLAD onset, patients experience decrements in general, physical, and mental quality of life (97-104). Transplant recipients followed longitudinally have a decline in mobility and energy, increased dyspnea, perform fewer activities of daily living, and experience more anxiety and depression (100,101). Moreover, transplant recipients and their caregivers perceive a diagnosis of CLAD as returning to a pre-transplant state (105).

Caregivers of transplant candidates and transplant recipients likely have unmet palliative care needs as well. They may feel unprepared for the caregiving experience and face worries about the recipients health, finances, and their own well-being (106-109). Caregivers can experience lower quality of life, high caregiving burdens, fatigue and depression (110,111). Importantly, caregiver strain has been associated with worse post-transplant outcomes (111,112).

Finally, we must also consider the limitations of existing studies. No studies have cross sectionally or longitudinally assessed palliative needs of candidates, recipients, or their caregivers with validated instruments. Further, commonly used quality of life instruments have not been validated in transplant populations and many not capture transplant specific quality of life including (2). A recently validated instrument, the Lung Transplant Quality of Life (LT-QOL) survey, that assesses novel quality of life domains in lung transplant recipients will hopefully provide further insight (113).

In summary, there is a substantial evidence that our patients and their caregivers have needs that fall under the auspices of palliative care. These needs are likely prevalent, underappreciated, and impact patient centered outcomes. While further study of patient and caregiver needs and palliative care interventions are necessary, we think the existing evidence argues strongly there is a clear role for palliative care in lung transplantation. How then can we optimally use palliative care across the transplant trajectory?

How can we integrate palliative care in lung transplantation?

There are several models for providing palliative care (114,115). A key distinction is between primary palliative care and specialist palliative care. Whereas specialist palliative care is delivered by a provider that has completed training in palliative care medicine, primary palliative care is delivered by providers without such training (115).

In the transplant context, members of the transplant team may provide primary palliative care by treating symptoms and discussing prognosis and treatment goals. In contrast specialist palliative care delivered by palliative care providers, as described prior, excels at assessment and management of difficult symptoms and addressing multiple sources of distress and suffering. Specialist palliative care can either be delivered by referral to a palliative care specialist or by embedding a palliative care specialist in the transplant team.

We, like others, think an embedded or integrated model is preferable (116). Transplant providers frequently provide primary palliative care in managing symptoms and guiding decision making. Transplant providers, however, are not trained to manage complex symptoms, address existential distress, assist with coping, or other domains addressed by palliative care specialists. Embedding or integrating a palliative care specialist in the transplant team provides access, enables longitudinal patient relationships, builds familiarity and trust, and helps transplant and palliative care providers work through other barriers to palliative care (12,117). Some providers may prefer to refer patients with psychological, coping needs, or spiritual distress to psychiatry, psychology, or other specialists. We agree there is a role for those specialists who may be more accessible than palliative care at some programs. In our experience, a benefit of referring to palliative care is the ability of a single additional provider to address multiple sources of distress and refer to additional specialists such as psychiatry or pain management if needed.

One model for integrated palliative care would be to include palliative care starting in the transplant evaluation to aid in identifying patients and caregiver's symptom and support needs while awaiting transplant. During the peri-operative phase, integration of palliative care would enable assessment of symptom and support needs during this critical time. The association between a stressful perioperative transplant experience and persistently lower quality of life has similarities to the experience of patients undergoing bone marrow transplantation. That integrated palliative care during bone marrow transplantation longitudinally reduces psychological symptom burdens and improves quality suggests that the peri-transplant period is a particularly critical time for palliative care involvement. After transplant, as quality of life improves, patients could be seen less frequently or discharged from palliative care depending on their trajectories. Then as either acute complications such as acute rejection or infections requiring

hospitalization or chronic complications like CLAD arise, palliative care could be re-engaged to again assist with support and symptom management.

Conclusions

We think there is a clear role for palliative care in lung transplantation. Transplant candidates, recipients, and their caregivers experience significant symptoms and multiple sources of distress with uncertain long-term outcomes. There is growing evidence that palliative care improves quality of life by identifying and addressing symptoms and other sources of distress and enabling better coping. Integrating palliative care specialists into the transplant team stands to benefit our patients and their caregivers and improve critical patient centered outcomes.

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