
EXPLORING THE ROLE OF PALLIATIVE CARE IN LUNG TRANSPLANTATION,
FACTORS INFLUENCING INTEGRATION, AND PATIENTS' AND CAREGIVERS'
PALLIATIVE CARE NEEDS

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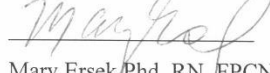
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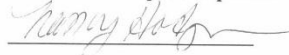
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Dedication

This work is dedicated to my husband- Eric, our three children- Emma, Caroline, and Matthew, and the many family members, colleagues, and friends who supported me throughout this period of growth. Thank you!

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ABSTRACT

EXPLORING THE ROLE OF PALLIATIVE CARE IN LUNG TRANSPLANTATION, FACTORS INFLUENCING INTEGRATION, AND PATIENTS' AND CAREGIVERS' PALLIATIVE CARE NEEDS

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Statement of Problem: Palliative care is patient- and family-centered and addresses the physical, psychosocial, and spiritual needs of patients living with serious illness. Lung transplant patients experience many physical and psychosocial challenges. However, integration of palliative care for these patients is rare and there is little research in this area. This dissertation addresses the following aims: 1) synthesize the literature describing the palliative care needs, current role, and factors influencing integration 2) describe the palliative care needs of lung transplant candidates and 3) describe the supportive care needs of family caregivers.

Methods: For the first aim, I reviewed the literature to better understand the current role of palliative care in lung transplant patient management. To address the second and third aims, I conducted cross-sectional surveys of lung transplant candidates and their caregivers. I used an adapted version of the Needs Near the End-of-Life Screening Tool (NEST) to elicit the patients' needs and the Carer Support Needs Assessment Tool (CSNAT) to describe the caregivers needs.

Results: In the seven reviewed papers, palliative care was consulted in a minority of patients and typically late in the process. The reasons for a consult were most commonly physical symptoms. Barriers such as misperception of palliative care, communication

challenges, and unrealistic patient/ family expectations impacted integration. No studies directly ascertained patients' and families' palliative care needs. For aim 2 and 3, both samples were recruited from the University of Pennsylvania Health System and included 111 patients and 78 caregivers. Patients reported physical symptoms including shortness of breath (97.3%) and tiredness (91.9%) that affect their physical activity (99.1%). Participants also had concerns related to the distress of end-of-life (81.1%) and preparing their families for losing them (75.7%). Caregivers needed more information about what to expect in the future (73.1%) and who to contact with patient concerns (57.7%). They also needed support for financial, legal, and work issues (55.1%) and their own fears and worries (51.3%).

Conclusion: Important palliative care needs were identified by both lung transplant candidates and their caregivers. Future research is needed that examines strategies to provide for these needs and associated outcomes.

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CHAPTER 1: INTRODUCTION

Background and Significance

The number of people in the U.S. who are either waiting for a lung transplant or who have received a lung transplant has grown steadily in the last decade.¹ The number of patients who are listed for lung transplant increased 42.2% over the last decade.¹ The demand for donated lungs still exceeds the supply. At the end of 2018 over 1300 candidates remained on the list and 365 either died without receiving a transplant or were removed from the list because they became too sick for transplant.¹

The acuity of lung transplant candidates also is increasing. With the introduction of the lung allocation score (LAS) in 2005, a system to prioritize lung transplant candidates based on waitlist urgency and expected post-transplant survival,² lung transplant candidates are now older, sicker, and more likely to have fibrotic lung disease.³ Furthermore, more candidates are surviving to transplant through aggressive medical treatments such as Extracorporeal Membrane Oxygenation (ECMO). Approximately 8% of patients receive mechanical ventilation or ECMO prior to transplant.¹ One quarter of the patients waiting for availability of donated lungs are hospitalized and of these 13.6% are waiting in the intensive care unit (ICU).¹ The percentage of patients on the waitlist who are 65 or older has almost tripled in the last decade (11.2% in 2007 to 32.0% in 2018).¹ While patients on the waitlist maintain the goal of transplantation and cure, the reality is that these patients are living with progressive Advanced Lung Disease (ALD).

Lung transplant patients have a myriad of physical, psychological, and emotional symptoms that impact their quality of life (QOL).^{4,6} Before transplant, patients often experience dyspnea, associated fatigue, social isolation, and the mixed emotions of the hope for transplant and the fear that they will not live until an organ becomes available.^{4,6,7} Post-transplant patients typically experience a temporary improvement in their physical symptoms, yet they still suffer from increased incidence of anxiety and depression in the first post-transplant year.⁷ Post-transplant patients also encounter new challenges including the fear of organ rejection, dependency on the health care team, and side effects from the immunosuppressants, such as tremors, muscle weakness, and hirsutism.^{4,7,8}

The physical and psychosocial burdens of their underlying ALD along with the challenges of frequent interactions with the healthcare system and uncertainties related to the transplant process require a comprehensive, interdisciplinary approach. Palliative care can provide that extra layer of support. It is patient- and family-centered care that provides for the physical, psychological, and spiritual needs related to serious illness. Its goal is to provide people living with serious illness relief from their symptoms and the stress of their illness and improve QOL for the patient and family.^{9,10} Specialist palliative care often is delivered by an interdisciplinary team of health care providers with advanced training and expertise. In a growing number of healthcare systems, palliative care is delivered in both inpatient and outpatient settings. In contrast, primary palliative care refers to care that is delivered by non-specialists who have some background or training in palliative care. For this research, palliative care refers to specialty palliative

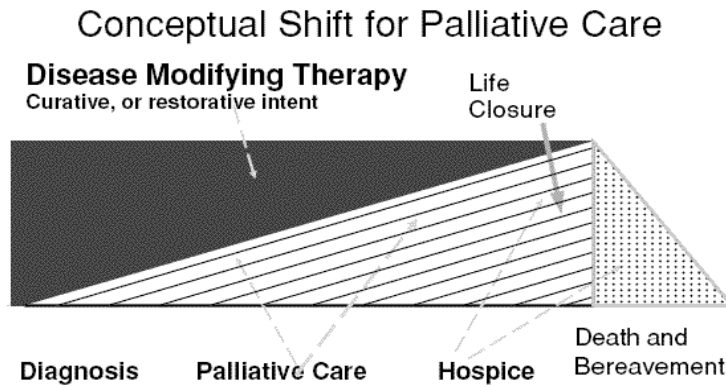


Figure 1. National Consensus Project for Quality Palliative Care, 2004

care unless otherwise specified. Palliative care is also distinct from hospice services, which focuses on terminal care for patients with a prognosis of 6 months or

less. As a condition of enrolling in the hospice benefit, Medicare and many private insurance programs require that patients forgo all curative therapies; thus, patients on a transplant list may not be eligible for hospice. In contrast, palliative care can be offered throughout the illness trajectory. As displayed in Figure 1, palliative care can be offered alongside disease modifying, curative treatment.¹⁰ For this proposal, I am focused on palliative care rather than hospice care.

Palliative care is associated with improved QOL, increased patient and caregiver satisfaction, decreased symptom burden and depression, decreased health care utilization, and even increased survival in certain disease populations.¹¹⁻¹³ Concurrent palliative care, or palliative care that is offered alongside curative treatments, is becoming the standard for advanced oncology and heart failure.^{14,15} Both the American Thoracic Society and the American College of Chest Experts recommend early integration of palliative care in the management of patients with respiratory diseases.^{16,17} Despite these recommendations, palliative care is not routinely incorporated into the management of lung transplant patients.

The literature describing palliative care integration in lung transplantation is sparse. Little is known about the current role of palliative care in lung transplantation, the palliative care needs of lung transplant patients and their caregivers, or factors influencing integration. Through this dissertation research, I will address these gaps in an effort to impact clinical practice providing for the supportive care needs of lung transplant patients.

Study Purpose and Specific Aims:

The purpose of this research was to increase the knowledge and understanding of: 1) the current role of PC in lung transplant as described in the literature, 2) the self-identified palliative care needs of lung transplant candidates and their caregivers, and 3) factors influencing these needs as outlined in the following aims:

Aim 1: Synthesize the literature describing the palliative care needs, the current role, and factors influencing integration of palliative care in lung transplantation. (See Chapter 2: Paper 1)- accepted for Publication: *Progress in Transplantation*: June 2020

Aim 2: Describe the palliative care needs of adult lung transplant candidates from the patient's perspective using an adapted version of the Needs Near the End-of-Life Care Screening Tool [NEST 13].¹⁸ (See Chapter 3: Paper 2)

Aim 2a: Explore associations between demographic and clinical variables and palliative care needs.

Aim 3: Describe the supportive care needs of lung transplant candidates' caregivers using the Carer Support Needs Assessment Tool [CSNAT].¹⁹ (See Chapter 4: Paper 3)

Aim 3a: Explore associations between caregiver demographic variables, caregiver responsibilities, patient clinical variables and caregivers' supportive care needs.

I will describe each of the three specific aims and the methods to meet these aims in the following sections. Each aim will be the focus of three separate papers that have been or will be submitted for publication in peer-reviewed journals.

APPROACH

Framework

To achieve these aims, I used the National Consensus Project (NCP) for Quality Palliative Care Practice Guidelines 4th ed as a framework.⁹ This guideline includes eight domains: 1) Structure and process of care 2) Physical aspects of care 3) Psychological aspects of care 4) Social aspects of care 5) Spiritual aspects of care 6) Cultural aspects of care 7) Care of the patient at the end-of-life 8) Legal and ethical aspects of care. These specific domains provided the framework for defining palliative care and the assessment of palliative care needs in this research. See Table 1 for definitions of the domains and recommended practice to provide for the needs in these domains according to the NCP guidelines.⁹ (Table 1).

Methods Overview

I addressed Aim 1 through an integrative review that synthesized the literature describing the palliative care needs, the current role, and factors influencing the integration of palliative care in the care of lung transplant patients from the patient's and family's perspective. Through a librarian assisted search of four databases, Embase,

Pubmed, CINAHL, and Scopus, I identified seven studies that were English language, primary studies, focused on palliative care in adult lung transplantation. I then synthesized the literature by identifying seven themes including: 1) palliative care referral rates and timing 2) Palliative care needs 3) Decision-making about consulting palliative care 4) Factors associated with palliative care referral 5) Palliative care setting and interventions 6) Palliative care outcomes and 7) Barriers to integrating palliative care into lung transplant care.

For aim 2, I completed a cross-sectional survey of lung transplant candidates at the University of Pennsylvania Health System (UPHS) using an adapted version of the Needs at the End-of-life Screening Tool (NEST- 13).¹⁸ Lung transplant candidates came from one of three groups: 1) outpatients who were being evaluated for transplant 2) inpatients who were being evaluated for lung transplant listing; and 3) outpatients who already were waitlisted. The surveys were completed either in person on a tablet, a hard copy, or through an electronic link to the survey. I also collected patient demographic and clinical variables for descriptive purposes and to follow-up our exploratory aim 2a. Multivariable models were created to explore associations between patient's demographic and clinical variables and palliative care need.

For aim 3 I conducted a cross-sectional survey of family caregivers of lung transplant candidates at the UPHS. For patients to meet criteria for lung transplant listing they must have adequate social support including a designated caregiver (s). I used the Carer Support Needs Assessment Tool (CSNAT)¹⁹ to describe the supportive care needs of family caregivers of lung transplant candidates. I also collected, demographic

information, information on caregiving responsibilities, and patient clinical information for descriptive purposes and to complete exploratory aim 3a. Multivariable models were created to explore associations with caregivers' supportive care needs.

SUMMARY

Integration of palliative care in the management of lung transplant patients has been slow. There is limited research regarding palliative care and lung transplantation. Significant gaps remain in our understanding of the palliative care needs and factors influencing the integration of palliative care in lung transplant patient management. For successful implementation of a change in practice in this area, we must address some foundational steps that are missing; namely, the systematic assessment of the current literature and a comprehensive description of the lung transplant patient's and caregiver's perspective on their palliative care needs. A thorough assessment can better inform future integration of palliative care in this complex patient population. The studies described in this dissertation begin to address these gaps.

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Table 1-1 National Consensus Project Guidelines - Palliative Care Domains and Recommendations*

<p>Domain 1- Structure and Processes of Care</p> <p>The composition of an interdisciplinary team is outlined, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Also defines the elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care.</p> <p>Recommendations for Practice:</p> <ul style="list-style-type: none"> • Comprehensive interdisciplinary assessment of patient and family • Access to palliative and hospice care 24 hours a day, 7 days a week • Care plan that addresses identified and expressed needs of patient and family • Interdisciplinary team consistent with plan of care • Education and training • Emotional impact of work • Team has relationship with hospices • Physical environment meets needs of patient and family
<p>Domain 2- Physical Aspects of Care</p> <p>The palliative care assessment, care planning, and treatment of physical symptoms are described, emphasizing patient- and family-directed holistic care.</p> <p>Recommendations for Practice:</p> <ul style="list-style-type: none"> • Assess and manage symptoms and side effects in a timely, safe and effective manner to a level of acceptability to patient and family • Measure and document pain, dyspnea, constipation, and other symptoms using standardized scales • Team documents and communicates treatment alternatives permitting patient/ family to make informed choices • Family is educated and supported to provide safe/appropriate comfort measures to patient
<p>Domain 3- Psychological and Psychiatric Aspects of Care</p> <p>Focuses on the processes for systematically assessing and addressing the psychological and psychiatric aspects of care in the context of serious illness.</p> <p>Recommendations for Practice:</p> <ul style="list-style-type: none"> • Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales • Manage psychological and psychiatric issues in a timely, safe, and effective manner to a level acceptable to patient and family • Team employs pharmacologic, nonpharmacologic, and complementary therapies as appropriate • Develop and offer a grief and bereavement program to patients and families prior to and for at least 13 months after the death of the patient

Domain 4- Social Aspects of Care

Outlines the palliative care approach to assessing and addressing patient and family social support needs.

Recommendations for Practice:

- Conduct regular patient and family care conferences with interdisciplinary team
- Interdisciplinary social assessment
- Develop and implement a comprehensive social care plan which addresses relationships, communication, work and school settings, finances, caregiver ability/ stress, and access to medicines and equipment
- Referral to appropriate services

Domain 5- Spiritual, Religious, and Existential Aspects of Care

The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs.

Recommendations for Practice:

- Develop and document a plan based on assessment of religious, spiritual, and existential concerns
- Provide information and availability of spiritual care services
- Recognize and respect religious beliefs- provides religious support
- Makes connections with community and spiritual/religious groups or individuals as desired by patient/family

Domain 6- Cultural Aspects of Care

Outlines the ways in which culture influences both palliative care delivery and the experience of that care by the patient and family, from the time of diagnosis through death and bereavement.

Recommendations for Practice:

- Incorporate cultural assessment as part of comprehensive assessment including preferences regarding disclosure of information, dietary preferences, language, family communication, desire for palliative therapies and complementary medicines, perspectives on death, suffering, and grieving.
- Assesses and aims to meet the culture-specific needs of patients and families
- Respects and accommodates range of language, dietary, habitual, and ritual practices of patients and families
- Provides professional interpreter and culturally sensitive materials
- Recruitment and hiring practices reflect cultural diversity of community

Domain 7- Care of Patient Nearing the End-of-life

Focuses on the symptoms and situations that are common in the final days and weeks of life.

Recommendations for Practice:

- Routine discussion and documentation of patient and family wishes
- Signs and symptoms of impending death are recognized and communicated
- As patients decline, team introduces or reintroduces hospice
- Provide adequate dosing of analgesics as appropriate
- Facilitate effective grieving

Domain 8- Ethical and Legal Aspects of Care

Includes advance care planning, surrogate decision-making, regulatory and legal considerations, and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy

Recommendations for Practice:

- Decision maker is documented in accordance with state law
- Document the patient's/ decision maker's goals, preferences, and choices
- Team is aware of and addresses complex ethical issues and has access to ethical committees/ consultants as needed
- Team is knowledgeable about relevant federal and state statutes and regulations

* Adapted from: National Coalition for Hospice and Palliative Care. National consensus project for quality palliative care: Clinical practice guidelines for quality palliative care. 2018;4th ed.

Chapter 2 An Integrative Review of the Role of Palliative Care in Lung Transplantation
(Publication Pending- *Progress in Transplantation*; June 2020).

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Abstract

Background: Lung transplant patients experience significant physical symptoms and psychological stress that affect their quality of life. Palliative care (PC) is an interdisciplinary specialty associated with improved symptom management and enhanced QOL. Little, however, is known about the PC needs of lung transplant patients and the role PC plays in their care.

Aim: The aim of this integrative review was to synthesize the literature describing the PC needs, current role of PC, and factors influencing integration of PC in the care of lung transplant patients.

Design/ Data Sources: We searched PubMed, Scopus, CINAHL, and Embase to identify English-language, primary studies focused on PC in adult lung transplantation. Study quality was evaluated using STROBE and COREQ criteria.

Results: Seven articles were included in the review. Most were single-center, descriptive studies. Two studies used qualitative and six used quantitative methodology.

Collectively, these studies suggest that PC is typically consulted for physical and psychological symptom management, although PC consultation is uncommon and often occurs late in the lung transplant process. We found no studies that systematically assessed PC needs. Misperceptions about PC, communication challenges, and unrealistic patient/family expectations are identified barriers to the integration of PC. While limited, evidence suggests that PC can be successfully integrated into lung transplant patient management.

Conclusions: Empirical literature about PC in lung transplantation is sparse. Further research is needed to define the PC needs and opportunities for integration of PC into the care of these patients.

Keywords: Lung Transplant, Palliative care, Integrative Review

INTRODUCTION

While lung transplantation is often the final curative treatment option for patients with advanced lung disease, patients pursuing transplant face significant challenges both before and after transplant. Before transplant, patients suffer from significant physical and psychological symptoms including the distress of increasing dyspnea and the mixed emotions of the hope for transplant and the fear that they will not live until an organ becomes available.¹⁻³ Patients and families must prepare for the worst while hoping for the best. Given the progressive nature of advanced lung disease, transplant candidates often experience declining quality of life (QOL) as they wait for transplant.¹⁻³

Post-transplant patients typically experience a temporary improvement in their physical symptoms and overall QOL,^{2,4,5} yet their psychological health remains below the population norm, including increased incidence of anxiety and depression in the first post-transplant year.² Post-transplant patients also encounter new challenges such as the fear of organ rejection, dependency on the health care team, and the experience of immunosuppressant side effects, such as tremors, muscle weakness, and hirsutism.^{2,4,5}

Given the many challenges encountered before and after lung transplantation, patients may benefit from the integration of palliative care in their ongoing care. Palliative care is an interdisciplinary approach for addressing the needs of patients with life-limiting illnesses. Specialty palliative care teams often include physicians, nurses, social workers, advanced practice providers, chaplains, and therapists who have specialized skills and knowledge to assist in assessing and managing the supportive care

needs of patients with serious illnesses. Depending on the health care system, this service is available in both the inpatient and outpatient settings. While palliative care typically includes hospice, the terms are not synonymous. Palliative care is broader, and encompasses services for patients throughout the illness continuum, which can be offered alongside curative treatments.⁶ In contrast, hospice care typically focuses on comfort goals during the final weeks to months of life. In this review we will be discussing the broader term, palliative care.

There is a growing body of evidence demonstrating the benefits of palliative care for patients with serious illness.⁷⁻⁹ Early integration is associated with improved QOL and symptom burden, decreased depression symptoms, and increased survival in other populations with life limiting illnesses such as cancer or heart failure.⁷⁻⁹ Concurrent palliative care offered alongside curative treatments is the standard in some populations such as oncology.¹⁰ Moreover, several professional organizations recommend the early integration of palliative care into the care of patients with lung disease.^{11,12} Despite these benefits and recommendations, it seems palliative care is rarely integrated in the management of lung transplant patients unless all other treatment options have been exhausted. Patients with lung disease awaiting transplant are more likely to die in the ICU, intubated, with decisions about resuscitation addressed only in the last days of life if at all.^{13,14}

A deeper understanding of the current literature on palliative care in the context of lung transplant can inform future efforts to successfully integrate palliative care into the management of this patient population. Therefore, the aim of this integrative review was to explore and synthesize the current literature about palliative care in the management of

lung transplant patients, both candidates and recipients, and its effect on patients and families. Specifically, we focused on descriptions of the palliative care needs of lung transplant patients and the current role of palliative care in lung transplantation from the patients' and families' perspective.

METHODS

Search Strategy and Eligibility

We completed a librarian-assisted search in PubMed, Embase, CINAHL, and Scopus from inception to June 1, 2019. Search terms included: lung transplantation, hospice, palliative care, palliative nursing, hospice and palliative nursing, palliative therapy, terminal care, and pre-transplantation. We limited the searches to adult populations (ie over the age of 18), English-language, and primary studies that examined palliative care in the context of lung transplantation (**Table 2-1**). Both qualitative and quantitative studies were included.

After removing duplicates, two authors reviewed the titles and abstracts of the remaining articles independently and collaboratively screened for the *a priori*-defined inclusion criteria. The authors reviewed the full-text articles independently and collaboratively to determine the final sample. The process is presented in **Figure 2-1**.

Data Extraction and Quality Assessment

The final studies were organized into a table of evidence (**Table 2-2**) to facilitate iterative comparison and identification of relationships in the data. The authors reviewed the final studies independently and collaboratively established themes. Study quality was evaluated and summarized using the STROBE checklist for observational studies and the COREQ checklist for qualitative studies. As reflected in these checklists, quality was

evaluated based on the scientific methodology, the transparent reporting, and the match between the study aim and methodology.

RESULTS

The initial search yielded 406 unique studies. The titles and abstracts of these articles were reviewed by two authors, and 29 studies were selected for full text review. These 29 articles were similarly reviewed, and 7 articles were included in the final sample.¹⁵⁻²¹

Study Designs

Study designs included 5 quantitative¹⁵⁻¹⁹ and 2 qualitative studies.^{20,21} Four of the quantitative studies were retrospective cohort studies.^{15-17, 19} and 1 was a cross-sectional survey.¹⁸ One qualitative study involved interviews with individuals, and the other used a mix of individual interviews and focus group methodology.^{20, 21} All except 1 of the studies¹⁸ were conducted at a single clinical site. Three of the single-center studies were at the same institution in Toronto, Canada, but comprised unique samples from different time periods or points in the transplant process.¹⁵⁻¹⁷

Samples

The samples included lung transplant candidates, recipients, and family members. Sample sizes ranged from 10 family members of recipients²⁰ to 597 recipients.¹⁹ Of the 5 patient samples, 3 were pre-transplant^{16,17,21} and 2 were post- transplant groups.^{15,19} One qualitative study focused specifically on patients with cystic fibrosis awaiting transplant,²¹ while 2 pre-transplant studies reported a predominance of interstitial lung disease (50-65% of the samples).^{16, 17} Of the 5 studies describing patient populations, 4 reported average ages of 50- 60 years^{15-17,19} with about equal distribution of male/female

gender. Braithwaite et al (2011) looked specifically at patients with cystic fibrosis; thus, the average age is younger at 35 years.²¹

The two studies that incorporated family members' perspectives,^{20, 21} provided scant information about their characteristics. Braithwaite et al reported that family participants were middle-aged (mean= 45 years), 50% female, and included parents (60%), spouses or partners (30%), and siblings (10%).²¹

The studies were conducted in the United States, Canada, and Australia.¹⁵⁻²¹ Race and ethnicity of the samples were not described in any of the studies.

Themes

The research team identified 7 themes across the 8 studies: 1) Palliative care referral rates and timing; 2) Palliative care needs; 3) Decision-making about consulting palliative care; 4) Factors associated with palliative care referral; 5) Palliative care setting and interventions; 6) Palliative care outcomes; and 7) Barriers to integrating palliative care into lung transplant care.

Palliative Care Referral Rates and Timing: Palliative care referral rates and timing of consultation varied, but overall, few lung transplant patients received palliative care and often not until they were close to death. Four studies examined referral rates^{15,16,18,19} from 2007- 2019, one in pre-transplant patients¹⁶ and three in post-transplant patients.^{15,18,19} Among pre-transplant patients, Colman et al (2015) reported a 20.7% referral rate.¹⁶ In a recent study by Nolley et al post-transplant patient referral rates were similar at one year (27%) but increased to 42% at 5 years post-transplant.¹⁹ Song et al (2009) found that 95% of participating US lung transplant centers referred 5 or fewer recipients to palliative care annually.¹⁸

Four studies reported on the timing of palliative care referral, one pre-transplant and 3 post-transplant samples.^{15,16,18,19} Referral generally occurred late in the transplant process, close to transplant, delisting, or death. In pre-transplant patients, Colman et al reported that referral occurred a median of 32 days from transplant, delisting or death.¹⁶ In post-transplant samples, referral ranged from a median of 14 days¹⁵ to 248 days from death.¹⁹ The most recent study, Nolley et al, from 2019 reported earlier palliative care referral.¹⁹

Palliative Care Needs: No studies prospectively examined palliative care needs; rather, they described symptoms and other unmet needs generally or reported the reasons for referral, which can be viewed as a proxy for palliative care needs. For example, Braithwaite et al explored unmet needs of pre-transplant cystic fibrosis patients, their families, and the healthcare team caring for them. The authors identified a lack of knowledge about palliative care and the need for open communication about end-of-life.²¹ As one patient commented, “Palliative care only becomes relevant after a transplant has failed and a second is unlikely.”^{21(p. 255)} Another patient commented, “I need to ask more questions but sometimes I don’t even know what to ask.”^{21 (p255)}

Five retrospective studies, 2 pre-transplant^{16,17} and 3 post-transplant^{15,18,19} described the documented reasons for palliative care referral. The indications for referral were similar in the 5 studies, yet the frequency of the reasons varied. For instance, in the pre-transplant studies, dyspnea was the most common reason for referral, ranging from 29% - 90%.^{16,17} The next most common reasons were cough, pain, and psychological symptoms, such as anxiety and depression. Similarly, uncontrolled symptoms were the most common reasons for referral in post-transplant patients^{15,18,19} In 2 studies that

reported referral to palliative care later in the patient's course of illness^{15,18}, end-of-life planning was a predominant reason for referral (42- 57%). In contrast, goals of care and hospice referrals were infrequent reasons for palliative care consultation (2-9%) in Nolley et al's study of post- transplant patients who were referred to palliative care an average of 248 days before death.¹⁹

Decision to consult Palliative Care: The decision to consult palliative care in the management of lung transplant patients was complex without clear guidelines for the decision-making process or criteria. Song et al (2009) found that 44% of centers reported that decisions about consulting palliative care were made at transplant team meetings.¹⁸ Both Song et al (2009) and Colman (2015) discussed that there were no formal criteria regarding the timing of and process for referral.^{16,18} Instead patients with deteriorating clinical status and high, worsening symptom burden prompted decisions to refer to palliative care.

Factors Associated with Receiving Palliative Care: Nolley et al (2019) was the only study to examine characteristics associated with referral.¹⁹ They found 3 factors associated with post- transplant palliative care utilization: 1) Pre- transplant palliative care referral, 2) Year of transplant (more recent associated with increased referral rates), and 3) Double lung transplant.¹⁹

Palliative Care Consultation and Interventions: Four retrospective, observational studies described palliative care interventions that were delivered to transplant patients, which included symptom management, psychological and emotional support, and advance care planning.^{15-17,19} For post- transplant patients, most consults occurred in the inpatient setting,^{17,21} whereas outpatient palliative care was more common

for patients prior to transplant. The aim of Freeman et al (2016) was to examine palliative care in an outpatient clinic, therefore their pre- transplant sample was 100% outpatient¹⁷ and about half (53%) of the pre- transplant patients in Colman et al (2015) also received outpatient consults.¹⁶

Three studies, all conducted at the same institution, described specific therapies for symptoms in the pre- transplant^{16,17} and post- transplant¹⁵ setting. The most common pharmacologic intervention reported was opioids for dyspnea, pain, or both in > 92% of patients.¹⁵⁻¹⁷ No significant adverse outcomes related to the opioids were reported.¹⁵⁻¹⁷ Other commonly prescribed medications were benzodiazepines or hypnotics for insomnia and/ or dyspnea, laxatives, nonprescription analgesics, anti-emetics, and anti-depressants.¹⁷

Nonpharmacologic interventions for physical and psychological symptoms generally were not described. Two studies documented that palliative care consultation commonly resulted in referral to psychiatric specialists- 39% in pre- transplant and 46% in the post- transplant patients.^{15,16} Referrals to spiritual care also occurred frequently; Coleman et al reported that following palliative care consultation, over 40% of both pre- and post-transplant patients were referred to spiritual care services.^{15,16}

Although goals of care discussions and advance care planning frequently were listed as reasons for palliative care referral, little information was provided on the actual interventions. One pre- transplant study indicated 74% of patients referred for palliative care engaged in a discussion of advance directives but there was limited description of the information covered in these discussions.¹⁷

Outcomes of Palliative Care: Three studies, two pre- transplant^{16,17} and one post- transplant,¹⁵ reported on patient outcomes related to symptom management and advance care planning delivered by palliative care clinicians.

Two studies^{16,17} examined changes in symptoms over time. Freeman et al found statistically significant improvements in sleep and cough following palliative care consultation.¹⁷ Colman et al reported a 39% improvement in dyspnea in pre- transplant patients following initiation of opioids as well as a trend towards improvement in exercise tolerance.¹⁶

One pre-transplant¹⁶ and one post- transplant¹⁵ study reported outcomes of advance care planning interventions delivered by the palliative care team: place of death and documentation of patient preferences regarding cardiopulmonary resuscitation. Both studies reported that despite palliative care consultation, most pre-transplant (90%) and post-transplant patients (88%) died in the acute care setting.^{15,16} However, consultation was late, < 32 days from transplant, delisting, or death.¹⁶ In contrast, one small study (N=24) found that consultation increased the percentage of post-transplant patients with documented resuscitation orders, including higher rates of “do not resuscitate” orders.^{15,16} In another small (N=31), single-site study, Colman et al found that 94% of pre-transplant patients had documented resuscitation preferences at the time of referral; following palliative care consultation, 19% changed their resuscitation preferences to “do not resuscitate.”¹⁶

Barriers to Palliative Care:

Patients’ and Families’ View: Two studies explored patients’ and families’ perspectives on related barriers to palliative care referral.^{20,21} Song et al, (2010)

interviewed family caregivers of post-transplant patients.²⁰ Braithwaite et al, (2011) interviewed 12 pre-transplant patients with cystic fibrosis (CF) and 10 family members of patients with CF who had died pre-transplant.²¹ Both studies reported similar issues, including limited understanding of palliative care and end-of-life care. These studies also found that patients saw transplantation as the cure for their disease and therefore felt it unnecessary to consider palliative care. Families expressed a reluctance to stop extraordinary treatment until there was no hope of transplant.^{20,21}

Both patients and families reported wanting more information about end-of-life care, yet several barriers affected this communication.²¹ Views about whose responsibility it was to initiate these discussions varied. Patients preferred that the providers initiate these discussions,²¹ whereas clinicians in Song et al (2010) indicated they let patients drive the conversations.²⁰ Lastly, patients reported that they feared abandonment by the transplant team if palliative care was consulted.²¹

DISCUSSION

We examined the literature about the palliative care needs of lung transplant patients, current role of palliative care in the management of these patients, and factors affecting palliative care integration. Despite casting a wide net in our searches, we found only 7 relevant studies. Overall the studies demonstrate that both pre- and post-transplant patients experience significant symptom burden and psychospiritual distress, yet palliative care consultation occurs late if at all.^{15,16,18} Although early palliative care is associated with improved outcomes in patients with serious illness, issues such as a lack of clearly defined palliative care needs; inadequate guidelines on when and how to incorporate palliative care in clinical management; and patient and family identified

barriers prevent palliative care integration in the care of lung transplant patients. Despite these challenges, 4 studies described palliative care integration for 20% to 42% of these patients, which was associated with improved symptom management and increased documentation of resuscitation orders.^{15-17,19}

Although palliative care needs have been described in patients with chronic obstructive pulmonary disease, cystic fibrosis, and idiopathic pulmonary fibrosis,²²⁻²⁶ we found limited research examining palliative care needs in advanced lung disease patients who are referred for transplant. The significant physical and psychological symptoms described in these patients appear to continue into the transplant process, and there is evidence that the transplant process introduces new challenges.³ For example, transplant patients face complex emotional challenges related to balancing the hope for transplant and normalcy with the fear that they will not survive until transplant. They also experience guilt that the organ donor must die for them to live. Furthermore, goals of care conversations between patients and providers may be influenced by a concept called the organ transplant imperative, described as the unwritten expectation that patients and health care providers will proceed toward the goal of transplant even when the patient experiences changes in their clinical status.²⁷ Finally, some patients perceive that the transplant negates the need for palliative care or end-of-life planning.²³ More information is needed to understand how the complexity of the transplant experience affects the palliative care needs of lung transplant patients and how best to tailor palliative care to meet these unique needs.

Early palliative care was associated with improved QOL, increased patient and family satisfaction, decreased hospitalizations, and decreased mortality in some groups of

patients.^{9,28-30} We found that when palliative care was consulted, it often occurred late in the process- days before death, transplant, or delisting and only after transplant or re-transplant options have been exhausted. Consistent guidelines or standardized processes regarding when and how to integrate palliative care in the management of transplant patients were not identified. Some authors have suggested that the point in the disease trajectory when providers are discussing lung transplant is an ideal time to also discuss palliative care integration.^{31,32} Standards have been established in other groups of seriously ill patients who are referred for life-sustaining or curative therapies; for example, patients receiving ventricular assist devices for heart failure must be managed by a multi-disciplinary team that includes a palliative care specialist.³³ Recent clinical practice guidelines by the American Society of Clinical Oncology also recommend that palliative care be provided concurrently with curative treatments for oncology patients.¹⁰ The most recent study in this review, Nolley et al reported progress, with a 42% palliative care referral rate post- transplant at their institution;¹⁹ however, this high referral rate may be unique to their center.

Also missing from the literature is a description of a successful model that includes palliative care in both the pre- and post- transplant phase and considers factors such as availability of specialty palliative care, cost of utilization, and a risk/ benefit analysis. More work is needed to provide, understand, and measure the impact of early palliative care on lung transplant patient management and define a standard that offers early palliative care access for these patients.

Some of the studies reviewed identified barriers to integrating palliative care into regular transplant patient management. Many of these barriers have been described in

other patient groups.³⁴⁻³⁶ For successful integration of palliative care to occur in lung transplant, key stakeholders need to be involved and strategies to directly address these barriers need to be developed. Education of transplant patients and families is needed to dispel the misperception that palliative care is only about end-of-life care. Routine discussion and identification of triggers for integration of palliative care (such as the pre-transplant evaluation) in the transplant process are other ways to address these barriers.

Although we used a systematic, comprehensive approach to our review, we only included studies that focused on both palliative care and lung transplantation; thus, it is possible that we missed relevant articles. For example, there were several studies that focused on patients with advanced lung disease, a portion of whom were listed for transplant; we excluded these studies because findings were not reported separately for transplant patients. We made this decision to provide data that clearly relates to palliative care and lung transplant; however, it is possible that we excluded studies with relevant information. As defined in our aim, we chose to include only studies related to the patient's and family's perspective. This decision enabled a clear presentation of the limited knowledge from this view, however it is important to consider the provider's perspective in future research as well. The studies reviewed also have limitations- they were predominantly single- center, heterogeneous studies that lack replication and comparative samples. Also, the inclusion of 3 studies from the same institution may have heavily reflected the palliative care process at this center. These limitations were considered in the interpretation of the findings.

CONCLUSION

This is the first integrative review to examine the literature describing the palliative care needs, the role of palliative care, and patient and family identified barriers to palliative care in the lung transplant setting. Although the literature is limited, it provided a foundation for informing clinical practice and future research. The most significant finding was the lack of a systematic assessment of palliative care needs from the patient's and family caregiver's perspective. To deliver patient-centered care, we need to understand how patients and families identify their needs. We also found that referral to palliative care often occurs late, suggesting that processes to elicit and document needs early in the pre-transplant phase are needed. Successful models for delivering palliative care to these patients and their families must address the myriad patient/family concerns and barriers.

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Table 2-1 Search Criteria

Inclusion Criteria:
<ul style="list-style-type: none"> *Examined palliative care in context of lung transplantation (Must include both: palliative care & lung transplantation) *Primary research- data generating *English language *Adult population *Patient and Family Perspective
Exclusion Criteria:
<ul style="list-style-type: none"> *Does not look at palliative care and lung transplantation *Review or opinion piece *Not available in English *Not a full text article (for example, abstract or poster presentation) *Population: not adults (< 18 years of age) *Focused on providers' perspective *Focused on patients with advanced lung disease, some of whom are awaiting lung transplant, but no data specific to the transplant sub- population provided *Multi-organ transplant

Figure 2-1
Figure 1: Literature Search Diagram

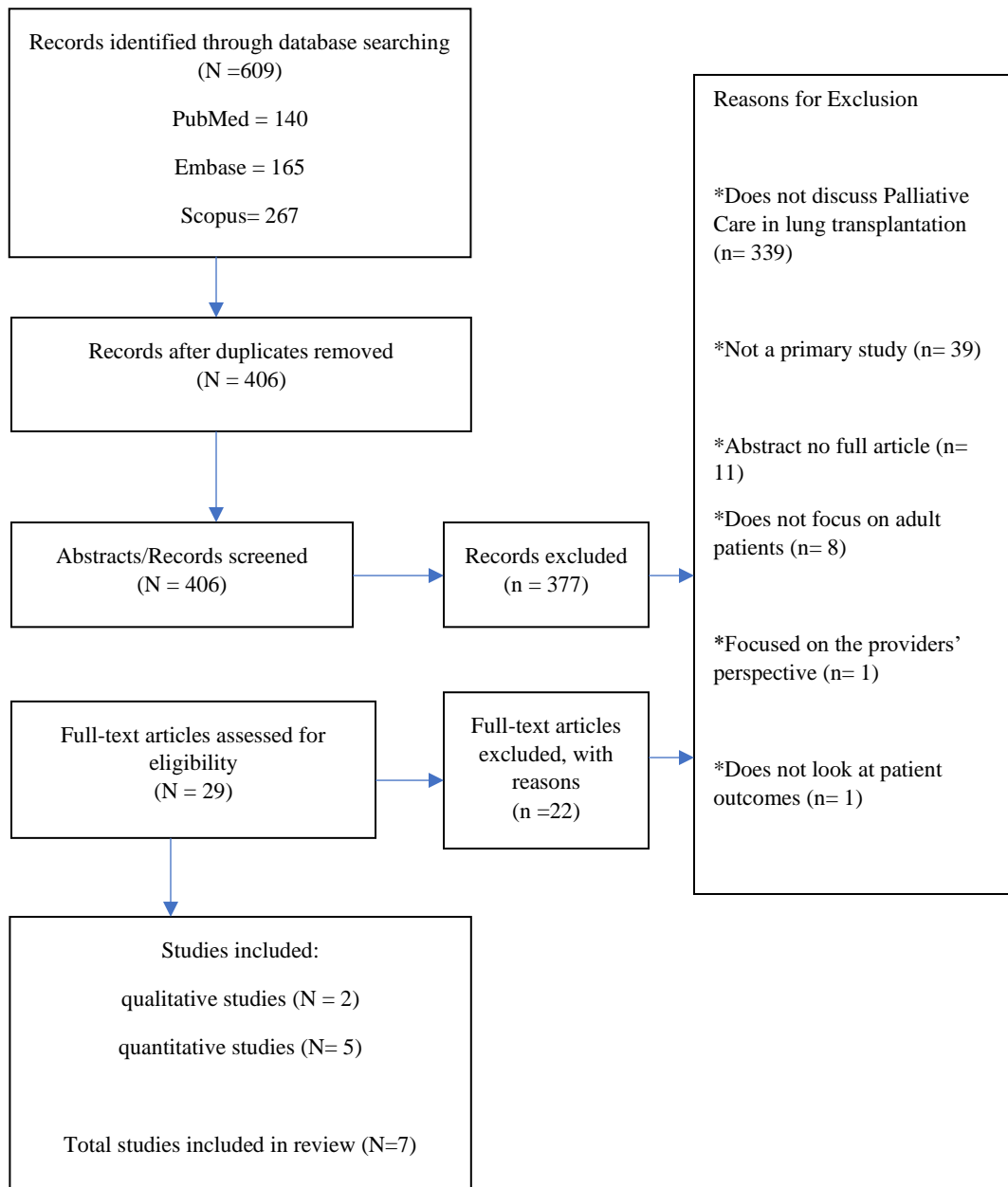


Table 2-2 Table of Evidence

Table 2. Table of Evidence				
Study	Design/ Aim	Sample/ Setting	Key Findings	Quality Scores
Braithwaite et al., 2011	Qualitative Aim: explore unmet needs for Cystic Fibrosis pts on waitlist and families	12 patients with cystic fibrosis 10 family members Single center, Australia	6 Themes: 1) Lack of knowledge about palliative care; 2) Positive mindset about transplant is barrier to palliative care; 3) Fear that palliative care referral is patient abandonment; 4) Close relationship with treating team 5) Clear communication- Clear honest discussions are valued 6) Unmet needs- The balance of the burden of caring for dying patients and balancing hope against death	COREQ 30/32
Colman et al., 2015a	Retrospective cohort study Aim: Describe characteristics of patients referred for PC and determine if they safely received opioids	64 patients referred to a Single center, Canada	20.7% of patients referred to palliative care Referral made median of 65 days from listing and 32 days from transplant, delisting or death 92% of referred pts prescribed opioids for dyspnea; No episodes of opioid-related respiratory depression Trend toward increased exercise tolerance in pts on opioids	STROBE: 21/22

<p>Colman et al., 2015b</p>	<p>Retrospective cohort study</p> <p>Aim: Describe characteristics, interventions and outcomes of recipients referred for palliative care</p>	<p>24 patients; Single center, Canada</p>	<p>67% referred for tiredness, shortness of breath, drowsiness</p> <p>75% patients were inpatient</p> <p>Median time between transplant and PC = 3 years Median time between palliative care and death = 14 days</p> <p>92% receiving opioids</p>	<p>STROBE: 19/22</p>
<p>Freeman et al., 2016</p>	<p>Retrospective cohort study</p> <p>Aim: Evaluate effectiveness of outpatient palliative care clinic</p>	<p>115 LT candidates referred to outpatient palliative care; Single center, Canada</p>	<p>Most common reasons for referral: dyspnea and/or cough</p> <p>No significant change in overall ESAS between baseline and follow-up</p> <p>Statistically significant improvements in sleep and cough</p> <p>Trend toward improvement in pain</p>	<p>STROBE: 19/22</p>
<p>Nolley et al., 2019</p>	<p>Retrospective cohort study</p> <p>Aim: Describe location, timing, and reason for specialty palliative care referral</p>	<p>597 recipients; Single US center</p>	<p>Cumulative incidence of PC encounters at 1 year = 27%; 5 years = 43%</p> <p>> 60% palliative care encounters occurred in first year after transplant</p> <p>> 90% of PC encounters were inpatient</p> <p>76% referred for symptom management</p>	<p>STROBE: 21/22</p>

			Pre-transplant palliative care and double LT associated with greater use post- transplant	
Song et al., 2009	Cross sectional-survey Aim: Assess pattern of palliative care services for lung recipients	18 US centers	Low number of palliative care referrals across centers (< 5/ year / center) Chronic rejection most likely reason for referral (94%) Average survival after palliative care referral = < 30 days. Most frequent reasons for referral:1) end-of-life planning; 2) pain/symptom management; 3) functional decline; 4) family support; 5) psychological support; 6) frequent hospitalizations; 7) patient request	STROBE: 19/22
Song et al., 2010	Qualitative Aim: Explore families' perceptions of chronic rejection and impact on management and caregiving.	10 family caregivers Single US center,	Family caregivers: Chronic rejection is inevitable, irreversible, unpredictable; Possibility of re-transplant instilled hope Palliative care referral indicated poor prognosis, & palliative care equals end-of-life care	COREQ:27/32

Abbreviations: Consolidated Criteria for Reporting Qualitative Research (COREQ), Edmonton Symptom Assessment Scale (ESAS), Strengthening the Report of Observational studies in Epidemiology (STROBE).

Chapter 3: The Palliative Care Needs of Lung Transplant Candidates

Abstract

Background: Palliative care has been shown to improve outcomes for patients living with serious illness but has not been fully integrated into the care of lung transplant patients. Patients awaiting lung transplantation are medically complex and live with significant physical symptoms and psychosocial issues. However, little is known about the palliative care needs of these patients.

Objective: The aim of this paper was to describe the palliative care needs of patients with advanced lung disease who are being evaluated for or awaiting lung transplantation.

Methods: A cross-sectional survey of lung transplant candidates using an adapted version of the Needs at the End-of-life Screening Tool (NEST-13).

Results: One hundred and eleven lung transplant candidates from a single center institution participated. The sample was mostly Caucasian (83.5%), females (60.0%), and had either restrictive lung disease (36.4%) or obstructive lung disease (35.6%). The highest rated palliative care needs, based on a 10-point scale, were difficulty being physically active (mean = 7.9; SD= 2.6), physical symptoms (mean = 7.4; SD= 2.6), missing work due to their illness (mean= 6.2; SD= 4.0), and concerns that life might end (mean = 5.1; SD= 3.6). Participants reported that religious beliefs or spiritual life contribute to their sense of purpose (mean = 4.1; SD 3.9) but reported few unmet support needs in this area (mean= 0.9; SD= 2.0). Only 6.4% reported seeing a palliative care specialist and many (48.2%) were unsure what a palliative care specialist is.

Conclusion: Lung transplant candidates have important palliative care needs. More information is needed to determine the resources and clinical strategies to best meet these needs.

Key words: Lung transplantation, palliative care, supportive care

INTRODUCTION

The number of patients on the US lung transplant waitlist has grown steadily with a 42.2% increase in the number of candidates added to the waitlist over the last decade.¹ Despite an increase in transplants, the demand for organs still exceeds the supply. At the end of 2018, over 1300 people remained on the list and 365 patients either died or were too sick for transplant during that year.¹

Lung transplant candidates are older and sicker than they have been in the past.¹ In 2018, almost one-third of lung transplant candidates were 65 years and older.¹ Recent trends in Lung Allocation Scores (LAS), a system to prioritize candidates for transplant based on clinical characteristics, hemodynamics, expected mortality on the waitlist and survival post-transplant, demonstrated increasing proportion (17.1%) of patients in the highest (sickest) range (50-100). Furthermore, 8% of candidates were bridged to transplant with the use of Extracorporeal Membrane Oxygenation (ECMO) or mechanical ventilation.¹ One quarter of the patients were hospitalized prior to transplant and 13.6% of them required a stay in the intensive care unit (ICU).^{1,2}

With the increasing acuity of patients on the lung transplant waitlist, it is not surprising that these patients experience a myriad of physical, psychological, and emotional issues. Although lung transplant patients have various pulmonary diagnoses that lead to their advanced disease, all have irreversible organ failure and significant symptom burden such as breathlessness, cough, and fatigue.^{3,4} These patients also experience diminishing functional status, social isolation, decreased quality of life (QOL), and increased incidence of anxiety.³⁻⁶ Moreover, once listed the transplant

process adds unique stressors such as the potential need for relocation to be closer to the transplant center, and candidates face the mixed emotions of the hope for transplant and the fear that they will not live until an organ becomes available.⁵ Given these physical, psychosocial and financial challenges, healthcare teams must be prepared to help patients and their families navigate through the transplant process and address a broad range of issues.

Palliative care is one evidence-based approach to meeting the complex needs of patients with serious illness and their families. It is interdisciplinary, patient- and family-centered care that addresses physical and psychological symptoms, and spiritual distress that is based on patients' values and goals of care. There is strong evidence supporting the benefits of early palliative care integration in the management of patients with life limiting illnesses.⁷⁻⁹ Concurrent palliative care, offered alongside curative treatments, is quickly becoming the standard of care in some patient populations, such as oncology and heart failure.^{10,11} Despite this progress, palliative care is rarely integrated into the care of patients with advanced lung disease (ALD) awaiting lung transplant. Moreover, little is known about the palliative care needs of this group.¹²

Our group conducted an integrative review of palliative care in the context of lung transplantation and we were unable to identify any research that specifically described the palliative care needs of these patients.¹² Two studies looked retrospectively at lung transplant candidates receiving palliative care and reported reasons for palliative care referral which provides some information about the needs of those referred.^{13,14} One qualitative study described the experiences of patients on the waitlist and identified some

needs related to end-of-life and palliative care.¹⁵ However there was no systematic assessment of the palliative care needs of these patients. The aim of this analysis was to describe the palliative care needs of patients with ALD who are being evaluated for or awaiting lung transplantation. Additionally, we explored associations between demographic and clinical variables and palliative care needs.

METHODS

Design

We used a quantitative, cross-sectional design to describe the palliative care needs of adult lung transplant candidates. All research procedures were approved by the University of Pennsylvania IRB.

Sample and Setting

We recruited participants from the adult lung transplant program at the University of Pennsylvania Health System (UPHS). The sample included lung transplant candidates who were in one of three groups: 1) outpatients who were being evaluated for transplant; 2) inpatients who were being evaluated for lung transplant listing; and 3) outpatients who already were waitlisted. Inclusion criteria included: 18 years and older; able to read and write English; physically and cognitively able to complete the survey alone or with the aid of caregiver. We excluded multi-organ transplant candidates and patients being considered for re-transplant.

The lung transplant team notified the research team of weekly outpatient and inpatient evaluations. Two members of the research team reviewed the list of patients

already in the process of evaluation and those on the waitlist and identified any additional potential participants. We recruited patients using several strategies. For most outpatient evaluations, we were scheduled to see the patients in the clinic with other consultants and researchers from the transplant team. For inpatient evaluations, after checking with the nurse or transplant team regarding whether the patient was medically stable and appropriate for participation in the study, we approached the patient in person in the hospital. If a patient was unsuitable for participation for medical reasons, we followed their progress through weekly team meetings to re-evaluate their ability to participate. We also contacted 119 potential participants who were already waitlisted or awaiting additional work-up through a secure patient messaging system. We sent a message explaining the study and providing the first author's contact information.

We consented participants in person whenever possible. If the patient was not coming in for a clinic visit, we consented by phone, using a phone script discussing the voluntary nature of the study, the purpose, the procedures etc., documenting verbal consent, and sending the patient a copy for their records. The adapted NEST survey and all collected data were stored in the secure website, REDCap[®]. Most participants completed the survey on a tablet using a REDCap[®] interface with a member of the research team available for questions. A few patients requested to complete the survey on a hard copy and then a member of the research team entered their responses into REDCap[®]. Some participants, particularly those who were already waitlisted, were emailed a link to the survey, which they completed independently online. We designed

the electronic version of the NEST to minimize missing data by requiring participants to respond to each item before proceeding to the next question.

Measures

We used an adapted version of the Needs at the End-of-Life Screening Tool (NEST-13) to describe palliative care needs. This instrument was constructed from a validated framework¹⁶ and designed to screen for end-of-life needs for persons experiencing a variety of life limiting illnesses. The NEST screens for palliative care needs in four dimensions: 1) Social Needs 2) Existential matters 3) Symptoms (physical and psychological and 4) Therapeutic matters (NEST).¹⁷ It is comprised of thirteen screening questions and 51 potential follow-up questions if the response to the screening question was above a designated threshold. Responses to NEST questions regarding needs are based on a 10-point scale with anchors at each end such as “none” or “a great deal” guiding patient’s responses. In general, a higher score indicates more need. The NEST-13 has undergone initial psychometric testing and there is some limited evidence that the tool is feasible for clinical use and sensitive to change.¹⁷

Nine of the follow-up questions included in the NEST are from the Edmonton Symptom Assessment Scale (ESAS), a well-tested, widely used, patient rated symptom assessment scale.¹⁸ The ESAS was developed for and tested in cancer patients with palliative care needs and asks about symptoms such as pain, shortness of breath, anxiety, depression, etc..^{18,19} If a patient reports physical or psychological symptoms above the established threshold on the NEST screening questions, they are instructed to complete

the ESAS questions in follow-up. The ESAS is also scored on a 10-point scale similar to the NEST.

Several studies have reported using the NEST in a variety of populations and healthcare settings including the emergency department, the intensive care unit (ICU), patients with ovarian cancer, cancer patients in the ICU, and older palliative care patients.²⁰⁻²⁵ Most commonly the studies used either the screening NEST-13(just the 13 questions) or a modified version of the measure.

We modified the NEST and the process for administering it to meet the aims of this study. For example, the NEST's 13 screening questions address 7 of the 8 domains of palliative care defined in the National Consensus Project (NCP) for Quality Palliative Care: Clinical Practice Guidelines.²⁶ There are no questions asking directly about cultural aspects of care, therefore we added 3 questions to address this domain and align the NEST with the current NCP guidelines: 1) How much do you feel your cultural preferences (such as: communication and language issues, dietary preferences, medical decision making, complementary health treatment options, and beliefs about life and death) are respected by your health care team? 2) How much does your health care team respect your interest in alternative or complementary medicine? 3) How much does your team respect your beliefs on dying and death? In addition to the questions added regarding cultural aspects of care, we added one open-ended question to capture any additional supportive care needs: Are there any other concerns that you have regarding your supportive care needs?

In the original NEST the additional follow-up questions are asked only if respondents screen “positive” based on thresholds established for each of the screening questions. We decided to include ALL questions regardless of responses on the screening questions to obtain a fuller description of palliative care needs. Additionally, four members of the research team with expertise in palliative care and lung transplantation reviewed the survey and revised it to clarify questions and streamline the final survey. The final revised measure included 46 questions, 9 of which were Edmonton Symptom Assessment Scale (ESAS) questions.

We pilot-tested the adapted NEST with five patients to make sure that participants understood and could respond to the new and revised questions. We also examined internal consistency reliability of the NEST items organized by NCP palliative care domains (Table 3-1). Each domain had between 2 and 11 items. Cronbach alphas for each of the eight groupings ranged from 0.65 to 0.86.

We also collected demographic information such as age, and education level as well as clinical variables. The first author or a trained research assistant collected the following information from the electronic medical record:

Frailty Index (Short Physical Performance Battery - SPPB): SPPB is a group of tests including gait analysis, repeated chair stands, and balance tests used to monitor functional outcomes. The SPPB is based on a 12-point scale with lower scores indicating greater frailty. Low performance on the SPPB is associated with increased unplanned hospitalizations and increased mortality in lung transplant patients.^{27,28}

Lung Allocation Score (LAS): the LAS is a standard clinical measure that uses several patient characteristics and clinical data to prioritize patients on the lung transplant waitlist in the U.S., Germany, and Denmark.^{29,30} The LAS ranges from 0-100 with higher scores representing patients in greater need for transplant.³¹

Pulmonary Diagnoses Category: Diagnoses were grouped into the four categories that are used in the LAS: 1) obstructive lung diseases such as COPD; 2) pulmonary vascular diseases, e.g. pulmonary hypertension; 3) cystic fibrosis; and 4) restrictive lung diseases, e.g. pulmonary fibrosis.³¹

Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT) is a comprehensive assessment of the psychosocial factors that affect transplant.³² Areas measured include knowledge of medical illness and the transplant process, willingness to undergo transplant, treatment compliance, lifestyle factors, social support system, and psychological stability. SIPAT scores range from 0 to 115, with higher scores indicating greater psychosocial readiness for transplant.³²

Statistical Analyses

We used descriptive statistics to summarize the characteristics and palliative care needs of the sample. We calculated means, medians, and interquartile ranges for the 46 NEST items, including the ESAS questions, and for the eight palliative care domains. We calculated total scores only for surveys with at least 80% valid responses, defined as a non-missing response that was not “prefer not to answer” or “not applicable”. We calculated a total NEST score as the mean of all domains combined that met criteria. Two

of the cultural domain items had between 42.3 and 50.5% “not applicable” responses and therefore we included them for descriptive purposes but excluded this domain data from the total NEST score.

We explored factors associated with palliative care needs by creating multivariable models to predict total NEST Scores using backward elimination techniques. We chose this technique because it aligns with our exploratory aims and its ease of use.³³ We included four variables, ethnicity (collapsed to Caucasian/non-Caucasian), patient group (i.e., outpatient evaluation, inpatient evaluation, and waitlisted), Lung Allocation Score, and Frailty Index that were significantly associated ($p < 0.05$) with Total Nest Scores in the bivariate analyses. We also included patient age given the increasing number of lung transplant candidates over the age of 65.¹ We used a significance level of 0.1 for the backward elimination process. All statistical analyses were carried out using SAS 9.4 statistical software.

RESULTS

Description of Sample

Of the 224 patients approached either in person or through the secure messaging system, 139 consented and 111 submitted complete surveys. We omitted data from one survey which had 18 item responses that either were left blank or answered, “prefer not to answer.” (Figure 3-1)

The sample was mostly patients undergoing outpatient evaluations (65.8%), Caucasian (83.5%), and female (60.0%). The average age was 56.4 years (SD = 13.1) and most were married or in a relationship with a significant other (60.2%).

Approximately 50% were disabled and another 30% retired. Most patients had restrictive lung disease- 36.4%, followed closely by obstructive lung disease- 35.6%, cystic fibrosis- 24.6% and pulmonary vascular diseases- 3.6%. The mean LAS was 41.5 (SD = 14.1) and the participants lived an average of 2 hours (SD = 2.7) from the transplant center. (Table 3-2)

Palliative Care Needs

Table 3-3 presents the descriptive statistics for all NEST and ESAS items, organized from highest (more need) to lowest mean scores. Mean item scores ranged from 0.8 (SD:1.5) - 7.9 (SD:2.6) on general NEST questions and 0.5 (SD:1.4) – 5.9 (SD:2.8) on ESAS items. Highest item scores reflected physical challenges related with the illness (e.g., “Difficulty being as physically active as you would like”). Symptom severity was further reflected in two ESAS items: shortness of breath (mean= 5.9; SD =2.8) and tiredness (mean= 5.2; SD =2.8). Participants also reported that their illness often caused them to miss work or cut back on work (mean=6.2; SD = 4.0). The ESAS item regarding well-being was rated as the greatest psychological need. (mean= 4.7; SD=2.4) Lowest items means were reported for nausea (mean= 0.5; SD= 1.4), trusting your healthcare team (mean= 0.7; SD= 1.5), and feeling your healthcare team listens to you (mean= 0.8; SD= 1.5).

Participants also rated needs related to end-of-life such as “distress that your life might end” and “difficulty trying to prepare family and friends for the possibility of losing you” as important needs (means 4.8 – 5.1). Although patients reported religious beliefs and spiritual life as an important source of purpose for them (mean= 4.1; SD=

3.9), they indicated very little need in obtaining religious and spiritual support (mean= 0.9; SD = 2.0). They also had low needs in relation to their health care team, reporting that the team “listens”: (mean = 0.8; SD = 1.5) and that they trusted their health care team (mean = 0.7; SD =1.5).

Domain means reflected the item findings (Table 3-4); in other words, the physical aspects of care domain had a mean score of 4.4 (SD = 1.6). The domain with the highest mean score, however, concerned end-of-life issues (mean = 4.9; SD =3.1). This domain included two items that reflected concerns or distress around the possibility of death. (Table 3-1) Needs related to the structure and processes of care, such as how much you trust your healthcare team, and those reflecting Ethical and Legal Aspects (e.g. How much do you feel you are able to participate in decisions about your health care?) had the lowest mean scores.

Twenty-eight patients (25.2%) provided additional free text comments about their supportive care needs. The needs described in these comments were similar to those described in the NEST and can be broadly grouped as: 1) psychological/ emotional needs 2) informational needs/ what to expect 3) connectedness to the health care team, 4) financial needs/ costs of medicines, 5) spirituality, and 6) management of symptoms/comorbidities. Table 3-5 provides examples of these comments.

Results from the multivariable analyses showed that two factors were significantly associated with overall NEST scores. Patient ethnicity (Caucasian/Non-Caucasian; $\beta=0.55$; $p = 0.09$) and patient group (Inpatient evaluation/Outpatient

evaluation/waitlist; Outpatient: $\beta = -0.8$; $p = 0.01$; waitlist: $\beta = -1.2$; $p = 0.003$), were significantly associated with palliative care needs.

DISCUSSION

This study describes the palliative care needs of 111 lung transplant candidates from a large, single center lung transplant program. The sample is similar to other lung transplant candidates' data with most being Caucasian with either restrictive or obstructive lung disease.^{1,31} Participants reported physical issues such as difficulty being physically active, shortness of breath, and tiredness as their highest needs. Interestingly, needs around end-of-life issues also were quite high. Regression analysis demonstrated two factors, patient group and ethnicity, were predictive of palliative care need.

Our findings regarding the significant physical needs of these patients is consistent with earlier research.^{13,14} Other studies using the NEST also found physical needs and symptom management were high among patients with ovarian cancer, and those admitted to intensive care units and emergency departments.^{23,24} Previous studies looking at the reasons lung transplant patients were referred to palliative care consistently reported physical symptoms such as dyspnea, cough, and fatigue as needs requiring palliative care referral.³⁴⁻³⁶

The finding that end-of-life care is a highly rated need for lung transplant patients is important because end-of-life care has not traditionally been prioritized in these patients. One influencing factor was described by Santivasi in 2017, a concept called the “organ transplant imperative”, a perceived obligation for providers and patients to proceed to transplant and not engage in goals of care discussions regardless of changes in

clinical status.³⁷ Additionally, a survey of lung transplant providers identified patients' and families' lack of readiness to discuss end-of-life as one of several barriers to end-of-life care or palliative care.³⁸ Another contributing factor identified by Braithwaite et al (2011) was a lack of clarity on whether providers or patients should initiate conversations about these issues.¹⁵ These factors contribute to lung transplant patients being more likely to die in the ICU, on a ventilator, with late resuscitation orders compared to samples of patients with ALD not listed for transplant.^{39,40} Although participants in this study rated needs due to distress that their life might end and the need to prepare loved ones for the possibility of losing them as important, almost 50% indicated they haven't discussed their beliefs on death and dying with their providers. These issues regarding end-of-life are not unique to lung transplant patients, but clearly it is an unmet need that requires strategic interventions.

Given the research describing the many psychological and emotional challenges lung transplant patients experience,²⁻⁵ we were surprised that patients did not rate items related to psychological aspects of care higher. One possible explanation for this finding relates to previous evidence that the ESAS Depression and Anxiety items have limited screening ability. Patients with cancer indicated the terms "anxiety" and "depression" were unspecific.¹⁹ Another possible reason for this finding is that these symptoms are well managed. Lastly, patients being evaluated for transplant may be reluctant to report these symptoms and needs, fearing they could jeopardize their chance of being listed.^{5,42}

Two factors, patient group and patient ethnicity, were associated with increased palliative care needs. Of the three groups (outpatient evaluations, inpatient evaluations,

and waitlisted), patients undergoing inpatient evaluation were more likely to rate their palliative care needs higher. Given that physical symptoms were among the highest reported needs, this finding is not surprising. Similarly, patient ethnicity was associated with increased palliative care needs. The reason for this finding is unclear but may be related to greater disease severity among non-Caucasian lung transplant candidates.⁴³ More research is needed to explore these and other factors influencing palliative care needs.

This study had limitations that should be considered. One limitation was the relatively small sample from a single institution. These factors affect the generalizability of the findings; however, the characteristics of the sample were comparable to national lung transplant waitlist data. The aims of the study were primarily descriptive, but a larger sample size would enable more rigorous regression analysis of predictors of palliative care needs. Another limitation was that our sample included patients receiving inpatient care, creating a sample that had different needs. Another factor that limited our analysis was the high “not applicable” response rate on the cultural domain questions. These questions provided useful descriptive information in this area but could not be included in the regression analysis. More research is needed to better define cultural dimensions and screening questions that are important to the lung transplant population. Lastly, recruitment in the electronic messaging system presented some challenges and resulted in a lower yield compared to in person recruitment [35.3% (42/119) via electronic messaging system vs. 96.2% (101/105) in person approach].

CONCLUSION

Lung transplant candidates have important palliative care needs identified in this study. Yet, despite these needs, only 7% reported seeing a palliative care specialist and most indicated they didn't know what a palliative care specialist is. Early palliative care integration has been beneficial in other populations of patients with life limiting illnesses.^{7,9} The unmet needs identified by these patients such as shortness of breath, tiredness, limited physical activity, missing work due to their illness, and distress over the thought their life might end are examples of needs that could be addressed by palliative care specialists, but more information is needed to determine the best timing and methods to meet the needs of lung transplant patients. Additional training of lung transplant providers in goals of care discussions and setting standards to build frequent end-of-life discussions into patient and family care may be beneficial. More research is needed to better understand ethnic and racial differences in lung transplant referrals and the impact of culture on the needs of patients with ALD being evaluated for or awaiting lung transplantation.

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Appendix A: Adapted NEST

Patient Needs Assessment

Thank you for agreeing to participate in this important research. You are being invited to participate because you are either being evaluated for a lung transplant or are currently listed for a lung transplant. The purpose of this study is to better understand lung transplant patients' supportive care needs (supportive care needs are considered the services required to meet your physical, emotional, social, psychological, spiritual, cultural, and informational needs). The survey should take about 15- 20 minutes to complete. All information you provide will remain confidential. If there is a question you are not comfortable answering, select the option- "Prefer not to answer". If you have any questions, please ask the member of the research team administering the survey. Thank you so much for your participation.

1. How much of a financial hardship is your illness for you or your family?

Not at all									A great deal	Prefer not to answer	
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

1a. How much of a problem have you had getting your health insurance plan to cover your treatment?

Not at all									A great deal	Prefer not to answer	
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

1b. How much do you have to miss work or cut back on work due to your illness?

Not at all									A great deal	Prefer not to answer	
0	1	2	3	4	5	6	7	8	9	10	

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

- Not currently working

1c. How much do others have to miss work or cut back on work to care for you?

Not at all											A great deal		Prefer not to answer
0	1	2	3	4	5	6	7	8	9	10			
✦	✦	✦	✦	✦	✦	✦	✦	✦	✦	✦		✦	

1d. How much do others have to increase their work hours or number of jobs to help pay for your medical care?

Not at all											A great deal		Prefer not to answer
0	1	2	3	4	5	6	7	8	9	10			
✦	✦	✦	✦	✦	✦	✦	✦	✦	✦	✦		✦	

1e. How much do you face costs related to your illness or treatment that cause you or another person to work more, sell property, take out a loan or mortgage, or withdraw money from your savings?

Not at all											A great deal		Prefer not to answer
0	1	2	3	4	5	6	7	8	9	10			
✦	✦	✦	✦	✦	✦	✦	✦	✦	✦	✦		✦	

2. How much trouble do you have getting the medical care you need?

Not at all											A great deal		Prefer not to answer
0	1	2	3	4	5	6	7	8	9	10			
✦	✦	✦	✦	✦	✦	✦	✦	✦	✦	✦		✦	

3. How much help do you need with things like making meals or getting to the doctor?

Not at all									A great deal	Prefer not to answer	
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

3a. How much help do you need with homemaking, such as preparing meals or keeping house?

Not at all									A great deal	Prefer not to answer	
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

3b. How much help do you need with taking medications for example- pills, nebulizers, or intravenous?

Not at all									A great deal	Prefer not to answer	
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

3c. How much help do you need with personal care, such as bathing or feeding?

Not at all									A great deal	Prefer not to answer	
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

3d. How much difficulty do you have being as physically active as you would like?

Not at all									A great deal	Prefer not to answer
------------	--	--	--	--	--	--	--	--	--------------	----------------------

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

4. How much does your illness seem senseless and meaningless?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

4a. How much are you distressed by the thought that your life might end?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

4b. How much do you feel frightened?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

4c. How much do you feel anger or bitterness?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

4d. How much do you feel tranquil and serene?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

5. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

6. How much do you feel confused, anxious or depressed?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

7. How much difficulty do you have finding someone to confide in?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

7a. How much difficulty do you have finding someone to share your most private fears or worries?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

8. How much do religious beliefs or your spiritual life contribute to your sense of purpose?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

8a. How difficult is it for you to get the religious or spiritual support you need?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

9. How much do you feel unsettled in your relationships with the people close to you?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

9a. How much difficulty do you have trying to prepare family and friends for the possibility of losing you?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

10. How much do you feel your health care team (doctors, nurse practitioners, nurses, social worker, chaplain, therapists, etc.) respects you as an individual?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

10a. How much do you feel that you are able to participate in decisions about your care?

Not at all A great deal Prefer not to answer
0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

10b. How much do you trust your health care team?

Not at all A great deal Prefer not to answer
0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

10c. How much do you feel that your health care team listens to what you have to say about your illness or medical treatment?

Not at all A great deal Prefer not to answer
0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

10d. How much do you feel that your health care team tells you bad news in a sensitive and caring manner?

Not at all A great deal Prefer not to answer
0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

11. How much difficulty do you have understanding the information from your health care team?

Not at all A great deal Prefer not to answer
0 1 2 3 4 5 6 7 8 9 10

✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

11a. How much do you feel that your health care team has given you a clear explanation of your treatment alternatives?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

11b. How much do you feel that your health care team has given you clear information about the risks and side effects of your treatment?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

12. How much do you feel that the health care you are getting fits with your goals?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

13. How much do you feel your cultural preferences (such as communication and language issues, dietary preferences, medical decision making, complementary health treatment options, and perspective on dying and death) are respected by your health care team?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

13a. How much does your health care team respect your interest in alternative or complementary medicine?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

○ N/A

13b. How much does your health care team respect your belief on dying and death?

Not at all A great deal Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

○ N/A- Haven't discussed with health care team

Please rate how you are feeling right now:

Pain

No pain Worst possible pain Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

Tiredness (Lack of Energy)

No Tiredness Worst possible tiredness Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

Nausea

No nausea Worst possible nausea Prefer not to answer

0 1 2 3 4 5 6 7 8 9 10
 ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦ ✦

Depression (feeling sad)

No depression		Worst possible depression	Prefer not to answer								
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

Anxiety (feeling nervous)

No anxiety		Worst possible anxiety	Prefer not to answer								
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

Drowsiness (feeling sleepy)

No drowsiness		Worst possible drowsiness	Prefer not to answer								
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

Appetite

No lack of appetite		Worst possible appetite	Prefer not to answer								
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

Well-being (how you feel overall)

Best possible well-being		Worst possible well-being	Prefer not to answer								
0	1	2	3	4	5	6	7	8	9	10	
+	+	+	+	+	+	+	+	+	+	+	+

Shortness of Breath

No shortness of breath		Worst possible shortness of breath	Prefer not to answer
------------------------	--	------------------------------------	----------------------

0 1 2 3 4 5 6 7 8 9 10
+ + + + + + + + + + +

15. Are there any other concerns that you have regarding your supportive care needs (supportive care needs are considered the services required to meet your physical, emotional, social, psychological, spiritual, cultural and informational needs)?

Background:

What is your age? _____

How do you identify your race/ethnicity?

- American Indian/ Alaska Native
- Black or African America
- Native Hawaiian or other Pacific Islander
- Asian
- Hispanic/ Latino
- White or Caucasian
- Other

How do you identify your gender?

- Male
- Female
- Transgender
- Gender non-conforming
- Prefer not to answer

What is your current marital status?

- Married or Domestic partnership
- Widowed
- Divorced
- Separated
- Single/Never married
- Prefer not to answer

What is the highest level of education you have completed?

- Less than high school
- High school or equivalent (for example: GED)
- Some college, no degree
- Associate's degree
- College/Bachelor's degree
- Post-College degree

What is your current employment status?

- Employed, working 40+ hours per week
- Employed, working < 40 hours per week
- Not employed, not disabled
- Retired
- Disabled, not able to work

How many times have you been hospitalized in the last year?

Have you ever seen a palliative care specialist?

- Yes
- No
- I am unsure what a palliative care specialist is
- Prefer not to answer

When was the last time you saw your primary health care provider?

- In the past 3 months
- 3-6 months ago
- 6-9 months ago
- 9-12 months ago
- More than 12 months ago
- Prefer not to answer

Table 3-1

| Adapted NEST13 According to National Consensus Project Palliative Care Domains |
|---|
| <p>Structure and Processes of Care:
 The composition of an interdisciplinary team is outlined, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Also defines the elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care.</p> |
| <ul style="list-style-type: none"> a. How much do you feel your health care team (doctors, nurse practitioners, nurses, social worker, chaplain, therapists, etc.) respects you as an individual? b. How much do you trust your health care team? c. How much do you feel that your health care team listens to what you have to say about your illness or medical treatment? d. How much do you feel that your health care team tells you bad news in a sensitive and caring manner? e. How much difficulty do you have understanding the information from your health care team? |
| <p>Physical Aspects of Care:
 The palliative care assessment, care planning, and treatment of physical symptoms are described, emphasizing patient- and family-directed holistic care.</p> |
| <ul style="list-style-type: none"> a. How much difficulty do you have being as physically active as you would like? b. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems? c. Please rate how you are feeling right now: Pain* d. Please rate how you are feeling: Tiredness- lack of energy* e. Please rate how you are feeling: Nausea* f. Please rate how you are feeling: Drowsiness- feeling sleepy* g. Please rate how you are feeling: Appetite* h. Please rate how you are feeling: Shortness of breath* |
| <p>Psychological and Psychiatric Aspects of Care:
 Focuses on the processes for systematically assessing and addressing the psychological and psychiatric aspects of care in the context of serious illness.</p> |
| <ul style="list-style-type: none"> a. How much do you feel confused, anxious or depressed? b. Please rate how you are feeling: Depression- feeling sad c. Please rate how you are feeling: Anxiety- feeling nervous d. Please rate how you are feeling: Well- being- how you feel overall |
| <p>Social Aspects of Care:</p> |

| |
|--|
| <p>Outlines the palliative care approach to assessing and addressing patient and family social support needs.</p> |
| <ul style="list-style-type: none"> a. How much trouble do you have getting the medical care you need? b. How much of a financial hardship is your illness for you or your family? c. How much do you have to miss work or cut back on work due to your illness? d. How much do others have to miss work or cut back on work to care for you? e. How much do others have to increase their work hours or number of jobs to help pay for your medical care? f. How much do you face costs related to your illness or treatment that cause you or another person to work more, sell property, take out a loan or mortgage, or withdraw money from your savings? g. How much help do you need with things like making meals or getting to the doctor? h. How much help do you need with homemaking, such as preparing meals or keeping house? i. How much help do you need with taking medications for example- pills, nebulizers, or intravenous? j. How much help do you need with personal care, such as bathing or feeding? k. How much of a problem have you had getting your health insurance plan to cover your treatment? |
| <p>Spiritual, Religious, & Existential Aspects of Care:
The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs.</p> |
| <ul style="list-style-type: none"> a. How much does your illness seem senseless and meaningless? b. How much do you feel frightened? c. How much do you feel anger or bitterness? d. How much do you feel tranquil and serene? e. How much do religious beliefs or your spiritual life contribute to your sense of purpose? f. How difficult is it for you to get the religious or spiritual support you need? g. How much difficulty do you have finding someone to confide in? h. How much difficulty do you have finding someone to share your most private fears or worries? i. How much do you feel unsettled in your relationships with the people close to you? |
| <p>Cultural Aspects of Care:</p> |

| |
|---|
| <p>Outlines the ways in which culture influences both palliative care delivery and the experience of that care by the patient and family, from the time of diagnosis through death and bereavement.</p> |
| <ul style="list-style-type: none"> a. How much do you feel your cultural preferences (such as communication and language issues, dietary preferences, medical decision making, complementary health treatment options, and perspective on dying and death) are respected by your health care team? b. How much does your health care team respect your interest in alternative or complementary medicine? c. How much does your health care team respect your belief on dying and death? |
| <p>Care of Patient Nearing the End-of-life:
Focuses on the symptoms and situations that are common in the final days and weeks of life.</p> |
| <ul style="list-style-type: none"> a. How much are you distressed by the thought that your life might end? b. How much difficulty do you have trying to prepare family and friends for the possibility of losing you? |
| <p>Ethical and Legal Aspects of Care:
Includes advance care planning, surrogate decision-making, regulatory and legal considerations, and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy.</p> |
| <ul style="list-style-type: none"> a. How much do you feel that your health care team has given you a clear explanation of your treatment alternatives? b. How much do you feel that your health care team has given you clear information about the risks and side effects of your treatment? c. How much do you feel that the health care you are getting fits with your goals? d. How much do you feel that you are able to participate in decisions about your care? |

*= ESAS items; measured on a scale of “0, No pain, depression etc to 10, Worst possible pain, depression etc”; Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The edmonton symptom assessment system (ESAS): A simple method for the assessment of palliative care patients. *Journal of palliative care*. 1991;7(2):6-9.

NEST questions adapted from: Emanuel LL, Alpert HR, Emanuel EE. Concise screening questions for clinical assessments of terminal care: The needs near the end-of-life care screening tool. *J Palliat Med*. 2001;4(4):465-474.

Domain and descriptions adapted from: National Coalition for Hospice and Palliative Care. National consensus project for quality palliative care: Clinical practice guidelines for quality palliative care. 2018;4th ed.

Figure 3-1: Recruitment

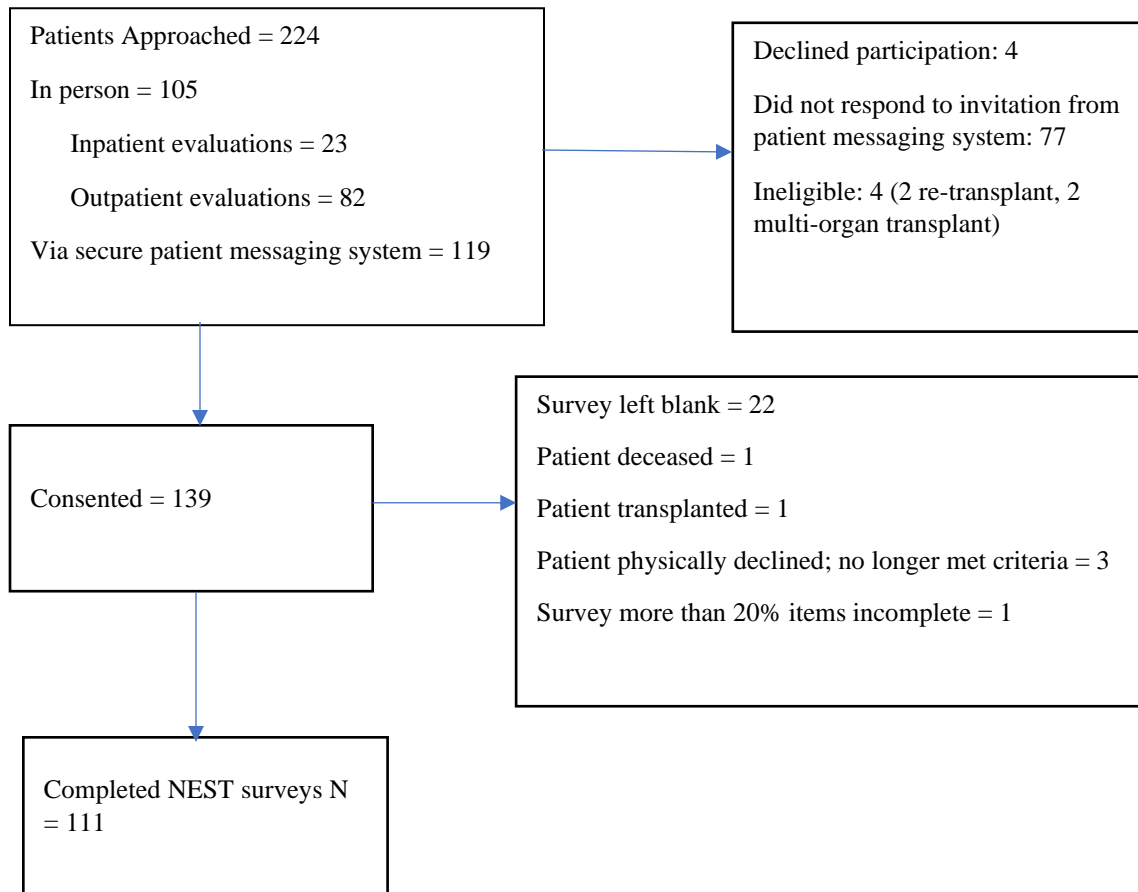


Table 3-2: Patient Characteristics

| Gender | Number | Percentage |
|--|--------|------------|
| Female | 66 | 60.0 |
| Male | 43 | 39.1 |
| Other/Prefer not to answer | 2 | 1.8 |
| Race | | |
| American Indian/ Alaskan Native | 0 | 0 |
| Black/African American | 9 | 8.3 |
| Native Hawaiian/ Pacific Islander | 0 | 0 |
| White/Caucasian | 91 | 83.5 |
| Hispanic/Latino | 4 | 3.7 |
| Asian | 4 | 3.7 |
| Other/ Prefer not to answer | 3 | 2.7 |
| Marital Status | | |
| Married/ Partnered | 65 | 60.2 |
| Divorced/ Separated | 22 | 20.4 |
| Widowed | 6 | 5.6 |
| Single | 15 | 13.9 |
| Prefer not to answer | 3 | 2.7 |
| Level of Education | | |
| Less than High School | 2 | 1.8 |
| High School or equivalent | 34 | 31.2 |
| Some College (includes Associate degree) | 35 | 32.1 |
| Bachelors degree | 18 | 16.5 |
| Graduate/ Professional school (post graduate degree) | 20 | 18.4 |

| | | |
|---|----|------|
| Prefer not to answer | 2 | 1.8 |
| Employment Status | | |
| Employed Full time (40+hours/week) | 10 | 9.0 |
| Employed Part Time (<40 hours/week) | 12 | 10.8 |
| Not employed/ Retired | 34 | 30.6 |
| Disabled- not able to work | 55 | 49.6 |
| Prefer not to answer | 0 | 0 |
| Ever seen a PC Specialist | | |
| Yes | 7 | 6.4 |
| No | 50 | 45.5 |
| Unsure what a PC specialist is | 53 | 48.2 |
| Prefer not to answer | 1 | 0.9 |
| Last time saw Primary Provider | | |
| In past 3 months | 81 | 74.3 |
| 3-6 months | 17 | 15.6 |
| 6-9 months | 1 | 0.9 |
| 9-12 months | 7 | 6.4 |
| More than 12 months | 3 | 2.8 |
| Prefer not to answer | 2 | 1.8 |
| Lung Diagnosis Code Category: Count (percentage) | | |
| A: Obstructive Lung Disease | 39 | 35.5 |
| B: Pulmonary Vascular Disease | 4 | 3.6 |
| C: Cystic Fibrosis | 27 | 24.6 |
| D: Restrictive Lung Diseases | 40 | 36.4 |
| Patient Group | | |

| | | |
|--|------------|------|
| Outpatient Evaluation | 73 | 65.8 |
| Inpatient Evaluation | 19 | 17.1 |
| Waitlist | 19 | 17.1 |
| Age: mean (standard deviation) | 56.4(13.1) | |
| SIPAT: mean (standard deviation)
*Higher score= more psychosocial risks | 11.3(7.7) | |
| Frailty Index (SPPB): mean (standard deviation)
Range: 0-12 * Lower score = frailer | 10.8 (2.1) | |
| Lung Allocation Score (LAS): mean (standard deviation) Range: 0-100 | 41.5(14.1) | |
| Travel time (hours) to transplant center: mean (standard deviation) | 2.0(2.7) | |
| Number of hospitalizations in past year: mean (standard deviation) | 1.53(1.76) | |

Table 3-3: Palliative Care Needs by Item

| Need | Prefer not to answer/
Not applicable responses | Mean | SD | Median | IQR | *Some Need Count (Percent) |
|---|---|-------------|-----------|---------------|------------|-----------------------------------|
| Difficulty being as physically active as you would like | 0 | 7.9 | 2.6 | 9.0 | 4.0 | 110(99.1) |
| Suffer from physical symptoms | 0 | 7.4 | 2.6 | 8.0 | 4.0 | 85(76.6) |
| Must miss work due to your illness | 1 prefer not to answer
55 N/A | 6.2 | 4.0 | 8.0 | 7.0 | 76(68.5) |
| Shortness of Breath | 0 | 5.9 | 2.8 | 6.0 | 4.0 | 108(97.3) |
| **Feel Tranquil or Serene | 0 | 5.5 | 3.0 | 5.0 | 5.0 | 89(80.2) |
| Distressed by the thought your life might end | 3 prefer not to answer | 5.1 | 3.6 | 5.0 | 6.5 | 90(81.1) |
| Tiredness | 0 | 5.2 | 2.8 | 5.0 | 4.0 | 102(91.9) |
| Experience financial hardship r/t your illness | 4 prefer not to answer | 4.9 | 3.4 | 5.0 | 5.0 | 91(82.0) |
| Difficulty trying to prepare family and friends for possibility of losing you | 7 prefer not to answer | 4.8 | 3.7 | 5.0 | 7.0 | 84(75.7) |

| | | | | | | |
|---|-------------------------|-----|-----|-----|-----|-----------|
| Help with homemaking such as making meals or keeping house | 0 | 4.7 | 3.5 | 5.0 | 6.0 | 90(81.1) |
| Well Being | 0 | 4.7 | 2.4 | 5.0 | 4.0 | 108(97.3) |
| Illness seems senseless and meaningless | 20 prefer not to answer | 4.3 | 3.9 | 5.0 | 8.0 | 63(56.8) |
| Feel frightened | 0 | 4.2 | 3.2 | 4.0 | 6.0 | 91(82.0) |
| **Religious beliefs or spiritual life contribute to sense of purpose | 4 prefer not to answer | 4.1 | 3.9 | 4.0 | 8.0 | 89(80.2) |
| Need help with making meals and getting to the doctors | 2 prefer not to answer | 3.6 | 3.6 | 3.0 | 6.0 | 73(65.8) |
| Feel confused, anxious or depressed | 1 prefer not to answer | 3.4 | 2.9 | 3.0 | 4.0 | 85(76.6) |
| Others have to miss work or cut back on work r/t your illness | 3 prefer not to answer | 3.3 | 3.2 | 3.0 | 5.0 | 76(68.5) |
| Drowsiness | 0 | 3.2 | 3.0 | 3.0 | 5.0 | 80(72.1) |
| Anxiety | 2 prefer not to answer | 3.0 | 3.0 | 2.0 | 5.0 | 75(67.6) |
| Face costs related to your illness or treatment that cause you or another person to work more, sell property, etc | 6 prefer not to answer | 2.6 | 3.3 | 1.0 | 5.0 | 57(51.4) |

| | | | | | | |
|--|---------------------------------|-----|-----|-----|-----|----------|
| Appetite | 2 prefer not to answer | 2.6 | 3.0 | 1.0 | 5.0 | 59(52.3) |
| Feel anger or bitterness | 2 prefer not to answer | 2.5 | 3.0 | 1.0 | 4.0 | 67(60.4) |
| Difficulty finding someone to share most private fears and worries | 2 prefer not to answer | 2.4 | 3.6 | 0.0 | 3.0 | 47(42.3) |
| **Health care team respects your interest in alternative or complementary medicine | 7 prefer not to answer; 47 N/A; | 2.3 | 2.7 | 2.0 | 3.5 | 21(18.9) |
| Difficulty understanding information you receive from your health care team | 3 prefer not to answer | 2.3 | 2.9 | 1.0 | 4.0 | 69(62.1) |
| Problem getting health insurance to cover your treatment | 1 prefer not to answer | 2.2 | 2.8 | 1.0 | 4.0 | 56(50.5) |
| Difficulty finding someone to confide in | 1 prefer not to answer | 2.1 | 3.2 | 0.0 | 3.0 | 45(40.6) |
| Pain | 0 | 2.0 | 2.6 | 0.0 | 4.0 | 55(49.6) |
| Depression | 0 | 1.8 | 2.4 | 0.0 | 3.0 | 54(48.7) |
| Feel unsettled in your relationships | 1 prefer not to answer | 1.7 | 2.6 | 0.0 | 3.0 | 47(42.3) |

| | | | | | | |
|---|-------------------------|-----|-----|-----|-----|----------|
| **Feel health care team has given you a clear explanation of treatment alternatives | 3 prefer not to answer | 1.6 | 2.6 | 0.0 | 2.5 | 48(43.2) |
| Need help with personal care (eg. feeding or bathing) | 0 | 1.4 | 2.6 | 0.0 | 2.0 | 40(36.0) |
| Others have to increase work to help pay for your medical care | 9 prefer not to answer | 1.3 | 2.4 | 0.0 | 2.0 | 28(25.2) |
| Trouble getting the medical care you need | 1 prefer not to answer | 1.2 | 2.1 | 0.0 | 2.0 | 44(39.6) |
| **Feel health care team has given you clear information about risks and side effects of your treatment? | 2 prefer not to answer | 1.2 | 2.2 | 0.0 | 1.0 | 69(62.2) |
| Need help with taking medications | 3 prefer not to answer | 1.2 | 2.3 | 0.0 | 2.0 | 38(34.2) |
| Feel health care you are getting fits with your goals | 8 prefer not to answer | 1.1 | 1.6 | 0.0 | 2.0 | 47(42.3) |
| **Feel your cultural preferences are respected by your health care team | 10 prefer not to answer | 1.0 | 1.9 | 0.0 | 1.0 | 39(35.1) |

| | | | | | | |
|--|--------------------------------|-----|------|-----|-----|----------|
| Health care team respects your beliefs on dying and death | 3 prefer not to answer; 56 N/A | 1.0 | 1.63 | 0.0 | 2.0 | 12(10.8) |
| **Health care team tells you bad news in a sensitive and caring manner | 3 prefer not to answer | 1.0 | 1.6 | 0.0 | 2.0 | 42(37.8) |
| **Feel that you are able to participate in decisions about your care | 1 prefer not to answer | 0.9 | 1.9 | 0.0 | 1.0 | 32(28.8) |
| **Feel health care team respects you as an individual | 5 prefer not to answer | 0.9 | 1.7 | 0.0 | 1.0 | 38(34.2) |
| Difficulty getting religious or spiritual support you need | 8 prefer not to answer | 0.9 | 2.0 | 0.0 | 1.0 | 27(24.3) |
| **Feel health care team listens to you | 2 prefer not to answer | 0.8 | 1.5 | 0.0 | 1.0 | 39(35.1) |
| **Trust health care team | 1 prefer not to answer | 0.7 | 1.5 | 0.0 | 1.0 | 30(27.0) |
| Nausea | 0 | 0.5 | 1.4 | 0.0 | 0.0 | 19(17.1) |

*Some Need = any numerical answer other than 0 (for example 1-10)

**Reverse Coded

Table 3-4: Palliative Care Need by Domain

| Domain Name | N= | # (%) Missing-
includes blank,
prefer not to
answer, and N/A
responses | Mean € | SD | Median | Interquartile
range |
|--|-----------|---|---------------|-----------|---------------|--------------------------------|
| Care of patient
nearing the
end-of-life | 102 | 9(8) | 4.9 | 3.1 | 5.0 | 5.0 |
| Physical
aspects of care | 111 | 0(0) | 4.4 | 1.6 | 4.3 | 2.4 |
| Psychological
aspects of care | 110 | 1(1) | 3.2 | 2.2 | 2.5 | 3.3 |
| Spiritual,
religious, and
existential
aspects of care | 100 | 11(10) | 3.0 | 1.9 | 2.7 | 2.8 |
| Social aspects
of Care | 106 | 5(5) | 2.8 | 1.8 | 2.4 | 2.5 |
| *Cultural
aspects of care | 18 | 93(84) | 1.4 | 1.7 | 0.8 | 2.3 |
| Ethical and
legal aspects of
care | 101 | 10(9) | 1.1 | 1.6 | 0.5 | 1.5 |
| Structure and
process of care | 109 | 2(2) | 1.1 | 1.2 | 0.8 | 1.6 |
| Total | 111 | 0(0) | 2.9 | 1.2 | 2.7 | 1.7 |

*Cultural Domain excluded from Total due to large # of N/A

€ Possible range: 0 – 10

Table 3-5: Free Text Responses

| Theme | # of Comments | Examples |
|--|---------------|--|
| Psychological/
emotional needs | 7 comments | <p>“The problem with this disease is waiting for a lung. I do have some anxiety that by the time I get one my health will be much worse than it already is.”</p> <p>“Sometimes need something for anxiety”</p> <p>“I am concerned with the possibility of not receiving a transplant.”</p> |
| Financial needs/ costs of
medicines | 6 comments | <p>“Not knowing the financial implications that are awaiting me and my family. I don’t want to pass in a few years and leave my wife penniless.”</p> <p>“My only concern is meeting the financial needs for post-transplant medications annually for the rest of my life.”</p> |
| Informational needs/
what to expect | 5 comments | <p>“...Things happened so fast and I don’t remember of anyone explaining to me that I had options. I was feeling that surgery was my option.”</p> <p>“Optimal care would be services that assist with offering communication in other languages such as mandarin to help explain things to family, but that is a stretch.”</p> |
| Spirituality | 4 comments | <p>“No one has asked me yet if I want to visit with a chaplain.”</p> <p>“I guess because of my strong beliefs and the amazing support of</p> |

| | | |
|---------------------------------------|------------|---|
| | | my husband I know I can do anything... I can not imagine how anyone goes through what I have my whole life without the help of God.” |
| Connectedness to the health care team | 3 comments | <p>“I feel like my doctors...are not accessible enough for me. They are lovely when I see them, but I can’t get directly in touch with them after my appointments. [The transplant center] is far from where I live, so I can’t make an appointment every time I want to speak with them.”</p> <p>“I have pamphlets to read but as far as any actual discussions with my team I feel lost in a lot of ways.</p> |
| Management of symptoms/comorbidities | 2 comments | “... I still experience very significant arthritis pain on a regular basis.” |

Chapter 4: The Supportive Care Needs of Lung Transplant Candidates' Caregivers

Abstract

Background: Research has shown that providing care for persons with advanced illness has an impact on caregivers' physical, psychological, and emotional health. Patients being evaluated for lung transplantation or those on the transplant waitlist are required to have an identified caregiver. However, little is known about the specific supportive care needs of family caregivers of persons with advanced lung disease (ALD) awaiting lung transplantation.

Objective: The aim of this study was to describe the supportive care needs of family caregivers of patients with ALD who are being evaluated for or awaiting lung transplantation.

Methods: A cross sectional survey of the caregivers of lung transplant candidates using the Carers' Support Needs Assessment Tool (CSNAT).

Results: The sample included 78 designated caregivers from a single-center institution. Participants were predominantly Caucasian and female, with a mean age of 58 years (SD: 13). Most were the patient's spouse or partner. Most participants reported needs in the following areas: what to expect in the future; who to call with healthcare concerns; financial, legal and work issues; and caregivers' feelings and worries (51.3- 73.1%). When asked if they need more support in these areas, 25-33% indicated they needed "quite a bit more" or "very much more" support, demonstrating substantial need, in what

to expect in the future, who to call with healthcare concerns, and financial, legal, or work issues.

Conclusion: Future research should focus on screening methods, such as regular use of the CSNAT with lung transplant caregivers, and follow-up interventions to provide for these supportive care needs.

Keywords: Caregiver, Lung transplantation, Palliative care

INTRODUCTION

The number of patients who are waitlisted for lung transplant in the U.S. has grown steadily with a 42.2% increase in the number of candidates added over the last decade.¹ These patients are older and more medically complex, and the number of organs needed continues to exceed the donor supply. At the end of 2018, 365 patients either died or were too sick to remain on the list.¹ These patients live with significant physical symptom burden such as dyspnea, cough, and fatigue, as well as psychological and emotional stressors.²⁻⁴ Given the complex care needed to support both lung transplant candidates and recipients, The International Society for Heart and Lung Transplant Consensus Document for Selection of Lung Transplant Candidates recommends identification of a reliable support person or family caregiver in order to be waitlisted for lung transplantation; furthermore, lack of social support may be considered an absolute contraindication to transplantation.⁵

Family members are essential team members in caring for patients living with advanced serious illnesses. In 2015, over 40 million family members and friends in the US provided an average of 24.4 hours per week to care for their family member.⁶ Family caregivers make a difference for persons receiving an organ transplant. For example, research has shown that post-transplant patients' self-care agency, or the ability to take care of themselves, was associated with the quality of the patient-caregiver relationship.⁷ In addition, survival and risk of graft failure post-transplant may be associated with the type of caregiver selected pre-transplant, such as a spouse versus an adult child.⁸

The impact of the family caregiver is clear, but the responsibilities of caregiving have consequences. The burden of caregiving has negative effects on caregivers' physical, psychological, and emotional health.⁹⁻¹¹ Myaskovsky and colleagues reported that caregivers' physical health declined in the first year post-cardiothoracic transplant.¹² Furthermore, higher caregiver burden was significantly associated with lower health-related quality of life, particularly in the physical health domains.¹² Xu et al. found that caregivers were more likely to report an overall lower mood than transplant recipients.¹³ A healthcare system that relies on these caregivers must understand and provide for their supportive care needs.

Palliative care is interdisciplinary health care that provides for the supportive care needs of both patients with serious illness and their family caregivers. Palliative care is associated with improved caregiver outcomes in persons with advanced cancer and other life-limiting illnesses.^{14,15} There is also evidence that palliative care can improve caregiver satisfaction with care, increase confidence in managing symptoms, and decrease caregiver psychological distress.¹⁴⁻¹⁸ Despite the pivotal role of the family caregiver and the important role palliative care plays in caregiver outcomes, there is a critical gap in information on the supportive care needs of these caregivers.

There is scant research describing the supportive care needs of the caregivers of lung transplant candidates. The transplant process adds unique stressors for the patient and their family including the financial strain of transplant and the cost of a lifetime of post-transplant medications, the possible need for re-location to be closer to the transplant center, and the constraints of "waiting" for an organ.^{10,11,19,20} More information is needed

to understand the needs of these caregivers. The purpose of this study was to describe the caregivers' supportive care needs as they care for their family member waiting for lung transplantation.

METHODS

Design

We used a quantitative, cross-sectional design to describe caregivers' supportive care needs. This analysis was part of a larger study to examine the supportive care needs of patients undergoing evaluation, or currently waitlisted for lung transplantation and their family caregivers. The University of Pennsylvania IRB approved the study.

Sample and Setting

Participants were recruited from the adult lung transplant program at the University of Pennsylvania Health System (UPHS). Lung transplant candidates are required to identify caregivers before listing for transplantation. Participants were caregivers identified by potential (i.e., undergoing evaluation for transplantation) or currently waitlisted lung transplant candidates. Caregivers were eligible if they were 18 years or older; able to read and write English; and physically and cognitively able to complete the survey alone or with the aid of research assistant. Caregivers of multi-organ transplant patients or re-transplant candidates were not included. In a few cases, more than one caregiver for a patient was identified, and all were invited to complete the survey.

As part of a larger study, the lung transplant team identified weekly outpatient and inpatient lung transplant evaluations. Two members of the research team also reviewed the list of patients already undergoing evaluation and those waitlisted. Caregivers were either identified directly by patients or by research staff accessing patients' social work assessment note. We used several approaches for recruitment. Patients undergoing outpatient evaluation were encouraged to bring a support person with them to meet the consultants; in these cases, research team members approached the caregivers at the time of the patient's evaluation visit. We approached caregivers of inpatients who were undergoing evaluations in person during their visits or left an information sheet and contact information with the patient. For patients in the process of outpatient evaluation work-up or those waitlisted we contacted the patient through a secure patient messaging system with our contact information if the patient or caregiver were interested in participating. Whenever possible we reviewed the study and consented in person. If the caregiver was not visiting the patient soon or accompanying the patient on a clinic visit, we reviewed a script for phone consent, documented verbal consent, and sent a copy to the caregivers for their records.

The CSNAT survey and all data were stored in the secure website, REDCap[®]. Most participants completed an electronic version of the survey using a tablet with a member of the research team available to answer questions. Three participants requested a hardcopy which they returned to a member of the research team. Some participants, particularly those who were already waitlisted, were emailed a link to the survey, which they completed independently online.

Measures

We measured family caregivers' needs using the Carer Support Needs Assessment Tool (CSNAT). The CSNAT is a 14-item instrument that assesses a broad range of caregivers' concerns, including managing the patients' needs such as symptoms, as well as the caregivers' needs, for example, dealing with one's feelings and finding time for oneself. All items are framed using the stem: "do you need more support with...." Response options are: 0) no, 1) a little bit more, 2) quite a bit more, and 3) very much more. The CSNAT was developed as a screening measure; key domains were identified through interviews with bereaved family caregivers of hospice patients in the United Kingdom.²¹ The instrument has undergone preliminary psychometric testing which demonstrated good face, content, and criterion validity and sensitivity to change that was comparable with similar measures.^{21,22}

Although the CSNAT is brief and framed in terms of "supportive care," it covers seven of the eight domains identified in the National Consensus Project Palliative Care Guidelines.²³ Only one domain, "cultural aspects of care," was not explicitly addressed in the CSNAT. For this reason, we added a question, "Do you need more support with the cultural needs of you and your family member?", yielding a total of 15 questions. We pilot-tested the new question with five caregivers to make sure that participants understood and could respond to the question. In addition to the 15 forced-choice questions, the CSNAT also included one open-ended question, "Are there any other concerns regarding the patient's or your supportive care needs?"

To describe the sample and evaluate factors that may influence caregivers' supportive care needs, we also asked participants to complete a brief investigator-developed questionnaire that elicited demographic information (e.g., age, gender, employment, relationship to patient) and basic information about their caregiving history and activities. In addition, we collected data on the patient's disease category and lung allocation score (LAS). The latter is a widely used score to prioritize waitlisted lung transplant patients based on calculations related to the urgency for their transplant and their chance of survival post-transplant.²⁴

Statistical Analyses

Descriptive statistics were used to describe the characteristics of the sample. To report caregivers' needs, we tallied the number and percentages by item for each of the response options, including "prefer not to answer," and calculated the median and interquartile range. We also determined an overall CSNAT score by calculating means for the 15 items. If a survey had more than 20% (3 of the 15 questions) of missing data, including "prefer not to answer" responses, the survey was not included in any of the analyses.

We explored factors that contribute to overall caregivers' supportive needs by constructing multivariable models to predict overall CSNAT score using backward elimination techniques. This analytic method was used due to its simplicity and appropriateness for exploratory analyses.²⁵ Because of the small sample size, we limited the models to five variables to ensure accuracy of the model.²⁶ We included several variables that have been found to be associated with caregiver burden: caregiver age,

caregiver ethnicity, and number of caregiving hours/ week. We also included patient lung allocation score (LAS) because of its significance with caregiver needs in bivariate analyses association ($\beta = 0.18$; $p = 0.02$) and patient groups (inpatient, outpatient, waitlist) because of our previous finding that this factor was significantly associated with patients' needs. (paper 2) We used a value of $p < 0.1$ as the criterion for retention in the backward elimination procedure. All statistical analyses were carried out using SAS 9.4 statistical software.

RESULTS

Description of Sample

Of the 106 caregivers approached, 101 consented and 78 submitted analyzable surveys defined as providing responses for at least 12 of the items (Figure 4-1). The sample was primarily Caucasian (86.7%) and female (63.6%) with a mean age of 58.2 (SD:13.6). Most participants reported their relationship to the patient as spouses or significant others (55.8%), followed by adult children (15.6%). Most caregivers were employed (62.8%), either full- (41.0%) or part-time (21.8%). Seventy-two percent indicated they lived with the patient. (Table 4-1).

Most caregivers (64.1%) reported participating in 2- 4 different caregiving tasks. Commonly reported tasks included taking patients to medical appointments (76.9%), meal preparation (65.4%), and housekeeping (62.8%). Less commonly, they helped with personal care (38.5%), monitoring medications (33.3%), and physically moving the patient (14.1%). They reported providing an average of 25.6 (range: 0–168) hours of caregiving per week.

Supportive Care Needs

Overall, caregivers reported low needs for supportive care, with most CSNAT item medians falling in the 0-1 (“no need” or “a little more”) range on the 0-3 scale. (Table 4-2) Although the level of need was low across the items, the frequency of caregivers having any need exceeded 50 percent for *knowing what to expect in the future*; *knowing who to contact for concerns about the patient, financial, legal or work-related issues*; and *dealing with one’s own feelings and worries* (Figure 4-2). Furthermore, approximately one-third of respondents reported that they needed “quite a bit more” or “very much more” support for *knowing what to expect in the future* (33.8%) and *who to ask regarding concerns about the patient* (29.5%). Over one quarter of the sample indicated that they needed quite a bit or very much more support for *financial, legal, and work-related issues* (25.6%) (Table 2).

Thirteen, or about 17% of caregivers provided written comments describing their needs. Most comments overlapped with issues addressed in the CSNAT and reflected needs for 1) psychological and emotional support for the patient and caregiver (6 comments); 2) informational needs about what to expect (4 comments); and 3) practical concerns such as- relocation (2 comments), financial (3 comments), and equipment (2 comments). For example, One participant summarized the needs of the caregiver regarding what to expect in the future: “There are too many unknowns: about the long-term prognosis, what to expect if she doesn’t move forward w/ the transplant; her life expectancy w/ or w/o transplant; how the disease will progress and what her final days/months might be like.” Another caregiver described their emotional needs, “...just

overwhelming at times. Upsetting when patient is upset about hospital stay or other treatments. Knowing you can't fix the problem." A few comments about the practical concerns included, "Concerns about relocation to be near enough to transplant center." and "Insurance coverage for pulmonary rehabilitation is difficult."

Factors Associated with Caregivers' Supportive Needs Only one variable was found to be significantly associated with overall CSNAT scores in the regression analysis. The Lung Allocation Score was significantly associated with caregivers' supportive needs. ($\beta = 0.18$; $p=.02$).

DISCUSSION

This study describes the supportive care needs of 78 lung transplant candidate's caregivers from an urban, tertiary academic center with a large lung transplant program. The sample was comparable with previously described lung transplant caregiver samples including mostly female, Caucasian, spouses or significant others.^{12,13} Although participants most often rated their needs as only requiring "a little more support", the majority of caregivers indicated they had marked supportive needs in dealing with their own emotions and worries; financial, legal, or work issues; knowing who to contact if the patient needed something; and knowing what to expect in the future.

Our finding that, on average caregivers expressed low level of need for supportive care is consistent with previous studies.^{21,27,28} For example Alviriza et al (2018) evaluated the CSNAT as a measure of caregiver need for patients in palliative home care programs and noted that caregivers were reluctant to accept care for themselves and therefore were more comfortable rating their needs as "a little more."²⁷ Additionally,

Harding and Higginson (2001) in a qualitative study of caregivers of patients at the end-of-life described the caregivers' view that although they recognized their stress and anxiety, they were ambivalent regarding their own needs.²⁹ These factors may contribute to how caregivers of patients with life limiting illness rate their needs.

Despite the generally low median scores, there were several items that were identified as needs by the majority; furthermore, 25.6-33.8% of respondents reported that they had substantial needs in these areas. These findings are consistent with previous studies. For example, caregiver needs around "what to expect in the future," supports research conducted with palliative homecare in the United Kingdom and Sweden, and brain cancer in Australia.^{21,27,28} Need for information about illness and treatment trajectories for lung transplant candidates caregivers may be high because communication is hindered due to identified factors such as unrealistic patient and family survival expectations, family disagreement about care goals, and providers' uncertainty about prognoses.^{30,31} Because discussion of goals of care and options for care are integral to the work of palliative care specialists, our findings underscore the importance of integrating this service in the care of lung transplant candidates. It also suggests that providing primary palliative care training for lung transplant team members is needed.

Another finding when comparing our results to previous studies using the CSNAT in different populations, is that the lung transplant candidates' caregivers were more likely to identify needing more support with financial, legal, or work issues (55.1%) compared to other populations such as brain cancer and home hospice (20-25%). These findings support the identified financial strain in the transplant process.^{10,20}

We found only one patient-related factor, the Lung Allocation Score which is a measure of patient urgency for transplant and survivability post-transplant, had a significant effect on caregiver needs. This finding was surprising in that previous research has identified several patient and caregiver characteristics, such as caregiver age, whether the caregiver lived with the patient, presence of financial strain, and hours of caregiving as associated with greater caregiver needs or decreased caregiver QOL.^{10,32} On the other hand, it does suggest that with a deteriorating patient, an increasing LAS may be an appropriate trigger to consider a specialty palliative care consult. One limitation with this finding is that the variable is continuous (0-100); that is, there is no precise cut-off when a patient is sick enough or their LAS is high enough to consider palliative care integration. More research is needed in this area.

This study has some limitations that should be considered. First, our sample was relatively small and was drawn from a single institution which limits generalizability of the findings. It also hindered our ability to examine the relationship among patient, caregiver and health system factors and caregivers' supportive care needs. Second, the use of the CSNAT may be problematic, although there is some support for its validity, the issue of high floor effects should be considered. Ewing et al (2013) reported that, despite low mean scores the CSNAT demonstrated sensitivity to change that was comparable to similar measures.²¹ In interpreting our findings, one should recognize that the CSNAT was designed as a screening tool and that caregivers may under rate their needs as discussed. Thus, clinicians and researchers should explore caregivers' responses

to understand fully the nature of each identified need to intervene appropriately and effectively.

Future research that looks at caregivers' needs longitudinally across the transplant process may be useful to determine the most appropriate time for palliative care integration. Examination of the routine use of measures, such as the CSNAT, to screen for the supportive care needs of lung transplant candidates' is needed. Interventions provided by the lung transplant or palliative care team to meet these supportive care needs and associated outcomes should also be explored.

CONCLUSION

This study describes substantial supportive care needs of caregivers of lung transplant candidates. Processes to improve communication between the health care team, the patient, and their family, particularly regarding what to expect in the future and who to contact with issues, are needed. Additionally, the finding that the majority of caregivers indicate a need for more support to address their fears and worries supports early integration of palliative care that focuses on both the patient and caregiver. Using the CSNAT as a screening measure to highlight caregivers that need more support provided by the transplant team or palliative care consultation may be useful. Triggers such as LAS to identify when palliative care is needed may also be useful, although further exploration to determine a particular score or range to trigger a palliative care consult may be needed. Caregivers are an essential part of the lung transplant team. Interventions by the lung transplant and palliative care teams to meet the identified palliative care needs should be the focus of future work.

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Figure 4-1 Recruitment flow chart

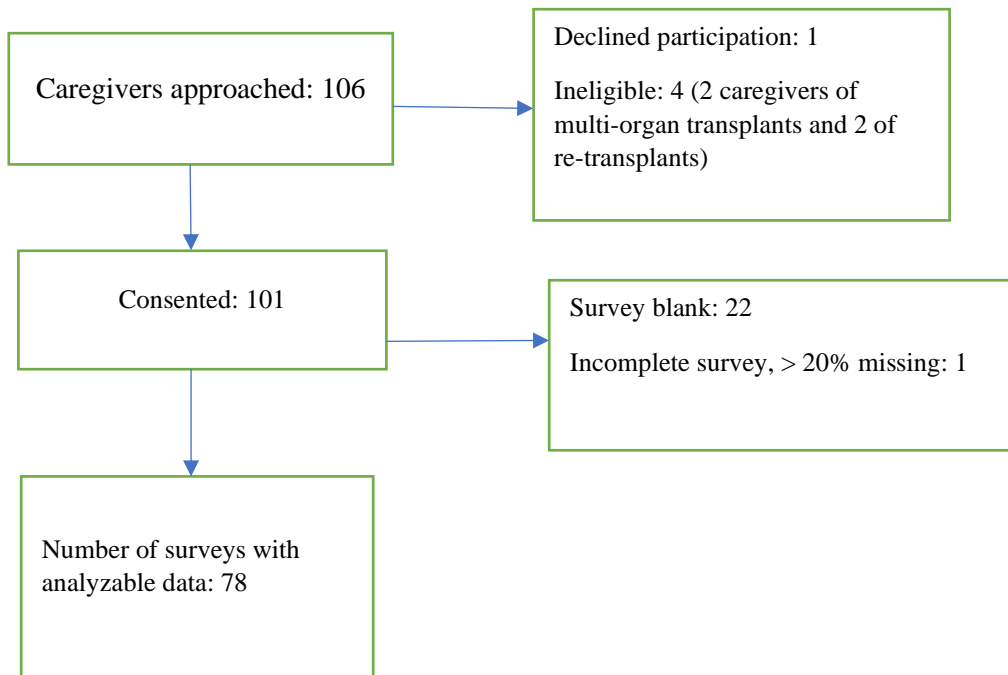


Table 4-1 Caregiver Characteristics

| | | |
|---------------------------------------|-------------|------------|
| Age: mean (standard deviation) | 58.2 (13.6) | |
| | Number | Percentage |
| Gender | | |
| Female | 49 | 63.6 |
| Male | 27 | 35.1 |
| Other | 1 | 1.3 |
| Prefer not to answer | 1 | 1.3 |
| Race | | |
| Black/African American | 3 | 4.0 |
| White/Caucasian | 65 | 86.7 |
| Hispanic/Latino | 3 | 4.0 |
| Asian | 3 | 4.0 |
| Other | 1 | 1.3 |
| Prefer not to answer | 3 | 4.0 |
| Relationship to patient | | |
| Spouse | 43 | 55.8 |
| Adult child | 12 | 15.6 |
| Sibling | 5 | 6.5 |
| Parent | 7 | 9.1 |
| Other (Niece/nephew, friend, other) | 10 | 13.0 |
| Prefer not to answer | 1 | 1.3 |
| Employment status | | |
| Employed Full Time (40+ hours) | 32 | 41.0 |
| Employed Part Time- (< 40 hours) | 17 | 21.8 |
| Not employed/ Retired (Combined) | 26 | 33.3 |
| Disabled | 3 | 3.9 |
| Prefer not to answer | 0 | 0 |
| Marital status | | |
| Married/ Partnered | 60 | 76.9 |
| Widowed | 3 | 3.9 |
| Divorced/ Separated | 7 | 9.0 |
| Single | 8 | 10.3 |
| Prefer not to answer/Missing Data | 0 | 0 |
| *Caregiver tasks | | |
| Personal care | 30 | 38.5 |
| Meal preparation | 51 | 65.4 |
| Medical appointments | 60 | 76.9 |
| Housekeeping | 49 | 62.8 |
| Physically moving patient | 11 | 14.1 |
| Monitoring meds | 26 | 33.3 |
| Prefer not to answer/Missing Data | 8 | 10.3 |
| Live with patient | | |

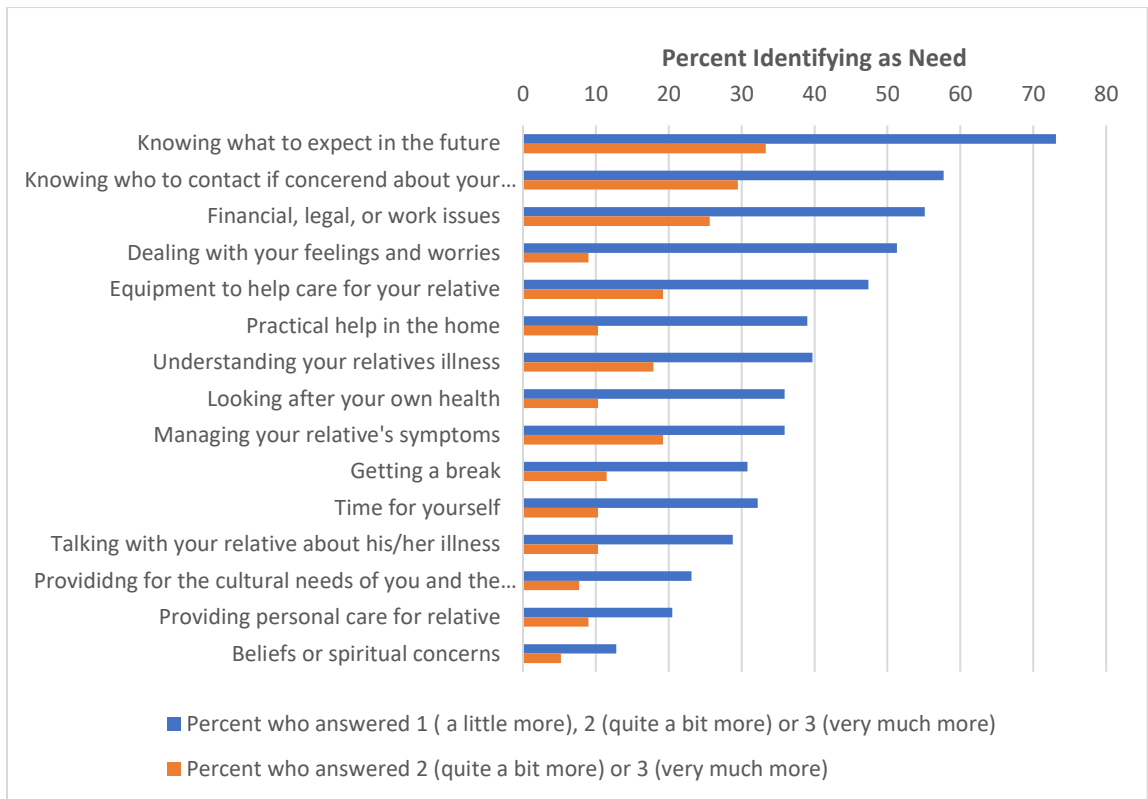
| | | |
|--|-------------|------|
| Yes | 54 | 72.0 |
| No | 21 | 28.0 |
| Prefer not to answer/Missing Data | 3 | 3.9 |
| Years of relationship with patient: mean (SD) | 31.0 (16.2) | |
| Number of years caregiving: mean (SD) | 8.9 (13.6) | |
| Hours/week caregiving: mean (SD) | 25.6 (43.8) | |

*Percentage > 100 because respondents could select more than 1

Table 4-2 Caregivers' Needs

| | Median | Interquartile range (IQR) | Amount of additional support needed | | | | |
|--|--------|---------------------------|-------------------------------------|---------------|------------------|----------------|----------------------|
| | | | None | A little more | Quite a bit more | Very much more | Prefer not to answer |
| | | | Count (Percent) | | | | |
| Understanding patient's illness | 0.0 | 1.0 | 47 (60.3) | 17(21.8) | 10 (12.8) | 4 (5.1) | 0 (0.0) |
| Time for yourself | 0.0 | 1.0 | 53 (68.0) | 17 (21.8) | 6 (7.7) | 2 (2.6) | 0 (0.0) |
| Managing patients' symptoms | 0.0 | 1.0 | 49 (62.8) | 13 (16.7) | 12 (15.4) | 4 (5.1) | 0 (0.0) |
| Financial, legal, or work issues | 1.0 | 2.0 | 34 (43.6) | 22 (28.2) | 16 (20.5) | 4 (5.1) | 0 (0.0) |
| Providing personal care | 0.0 | 0.0 | 60 (76.9) | 10 (12.8) | 4 (5.1) | 3 (3.9) | 1 (1.3) |
| Dealing with your feelings and worries | 1.0 | 1.0 | 37 (47.4) | 33 (42.3) | 6 (7.7) | 1 (1.3) | 1 (1.3) |
| Knowing who to contact if concerned about patient | 1.0 | 2.0 | 32 (41.0) | 23 (29.5) | 13 (16.7) | 10 (12.8) | 0 (0.0) |
| Looking after your own health | 0.0 | 1.0 | 49 (62.8) | 20 (25.6) | 6 (7.7) | 2 (2.6) | 1 (1.3) |
| Equipment to care for patient | 0.0 | 1.0 | 39 (50.0) | 23 (29.5) | 7 (9.0) | 8 (10.3) | 1 (1.3) |
| Beliefs or spiritual concerns | 0.0 | 0.0 | 67 (85.9) | 6 (7.7) | 2 (2.6) | 2 (2.6) | 1 (1.3) |
| Talking with the patient about his/her illness | 0.0 | 1.0 | 57(73.1) | 13 (16.7) | 5 (6.41) | 3 (3.9) | 0 (1.3) |
| Practical help in the home | 0.0 | 1.0 | 46 (59.7) | 22 (28.6) | 7 (9.1) | 1 (1.3) | 1 (1.3) |
| Knowing what to expect in the future | 1.0 | 2.0 | 20 (26.0) | 30 (39.0) | 22 (28.6) | 5 (5.2) | 1 (1.3) |
| Getting a break | 0.0 | 1.0 | 51 (65.4) | 15 (19.2) | 4 (5.1) | 5 (6.4) | 3 (3.9) |
| Providing for cultural needs of you and the patient | 0.0 | 0.0 | 59 (75.6) | 12 (15.4) | 3 (3.9) | 3 (3.9) | 1 (1.3) |

Figure 4-2 Percent Caregiver Need



Blue Bar = % who answered 1 (a little more), 2 (quite a bit more), or 3 (very much more)

Red Bar = % who answered 2 (quite a bit more) or 3 (very much more)

INTRODUCTION

Palliative care is interdisciplinary, patient- and family-centered care that can provide for the many supportive care needs of people living with serious illnesses. As described in this dissertation, lung transplant patients (both pre- and post-transplant) are medically complex, with a multitude of physical, psychological and emotional challenges.¹⁻⁴

Although lung transplant patients may likely benefit from palliative care, integration of palliative care in the management of these patients is uncommon and late in the disease process. Additionally, there is a paucity of literature on this topic. More information is needed to understand the current role of palliative care in the management of lung transplant patients and factors contributing to the late integration in the care of these seriously ill patients.

In this dissertation, I examined palliative care in the context of lung transplantation through three aims and related sub-aims:

Aim 1: Synthesize the literature describing the palliative care needs, the current role, and factors influencing integration of palliative care in lung transplantation.

Aim 2: Describe the palliative care needs of adult lung transplant candidates from the patient's perspective using an adapted version of the Needs Near the End-of-Life Care Screening Tool [NEST 13].⁵

Aim 2a: Explore associations between demographic and clinical variables and palliative care needs.

Aim 3: Describe the supportive care needs of lung transplant candidates' caregivers using the Carer Support Needs Assessment Tool [CSNAT].⁶

Aim 3a: Explore associations between caregiver demographic variables, caregiver responsibilities, patient clinical variables and caregivers' supportive care needs.

I reported the background, methods and findings for all aims in three publishable manuscripts. For the first aim, I conducted an integrative review. The paper that reports my findings is "in press" at *Progress in Transplantation*. For aims 2 and 3, I collected and analyzed primary data and drafted two additional papers that will be submitted for publication following my dissertation defense. The following section describes my synthesis of these three studies separately and collectively.

SYNTHESIS OF FINDINGS

In the integrative review, I identified only seven studies that examined palliative care in the context of lung transplantation for adult patients.⁷⁻¹³ From this review I learned that palliative care is consulted only in about a quarter of pre- and post-transplant patients.^{7,9,13} When palliative care was consulted, it was often late in the transplant process when other treatment options were exhausted.^{7,8} The reviewed studies suggested there were no formal criteria guiding referral to palliative care for these patients,^{7,11} and there were many barriers affecting integration. These barriers included the misconception that palliative care is synonymous with end-of-life care, uncertainty about prognoses, and patients' and families' limited knowledge of palliative care.¹⁰⁻¹²

One of the most important findings in the review was the lack of a systematic assessment of palliative care needs from the patients' and caregivers' perspective. I identified one qualitative study which explored unmet needs for transplant candidates with cystic fibrosis and their families.¹² The authors reported that patients and families expressed a desire for more knowledge about the end of life but were ambivalent about asking for more information in the context of pursuing a curative treatment such as transplantation. In general, patients and families had limited knowledge about palliative care, but were open to getting support from "other" team members.¹² Five studies looked retrospectively at reasons for palliative care referral and found that the most common reasons were physical symptoms such as dyspnea, cough, and fatigue, and psychological symptoms such as anxiety and depression.^{7-9,11,13} Patients were also referred for end-of-life planning, particularly if they were referred near death or delisting.^{7,8,13} In general, there was a lack of information describing the broader palliative care needs from the patients' and caregivers' perspective, a foundational step to successful palliative care integration in the management of lung transplant patients. From this integrative review, I concluded that further work in describing the palliative and support care needs of patients and caregivers is appropriate and greatly needed (Aims 2 and 3).

The second aim provided important insights about patients' perspective of their palliative care needs. Similar to earlier studies, my findings confirmed that these patients have significant physical needs related to their shortness of breath and fatigue, impacting their ability to be physically active and to work.^{1,8} Notably, I found that patients were most concerned about their own end-of-life needs and preparing their family for the

possibility of losing them. This finding contrasted with providers' beliefs that lung transplant patients and families were not ready to discuss end-of-life.¹⁴ My findings indicated these patients are, indeed, very concerned about these issues and they need more support in this area. Yet despite the need to discuss end-of-life issues, almost 50% of participants indicated they haven't discussed their beliefs on death and dying with their health care team. Moreover, only 7% of the patients received specialty palliative care, and almost 50% were unfamiliar with what is palliative care. Significant physical symptoms and end-of-life care are two areas where specialty palliative care can make a difference. After describing the needs of lung transplant patients, strategies to meet the palliative care needs of lung transplant candidates are needed.

Aim 3 showed that, although caregivers reported their needs as low, 70% of caregivers needed more support with knowing what to expect in the future, and 33% indicated they needed substantial support in this area. Transplant opens treatment possibilities for patients with organ failure, but the reality is that these patients and their caregivers need to prepare for the hope of transplant and the reality of living and dying with Advanced Lung Disease (ALD). One caregiver provided free text that clarified this issue, "There are too many unknowns: about the long term prognosis, what to expect if she doesn't move forward w/ the transplant; her life expectancy w/ or w/o transplant; how the disease will progress and what her final days/ months might be like." The caregiver respondents also reported significant needs, such as who to contact if the patient had health care concerns, challenges with finances, work, and legal issues, and their own

emotional support needs. Palliative care is patient- and family-centered and should be considered in addressing the caregivers' needs identified in this study.

An issue raised in all three papers is the challenge of the hope for transplant and the reality of end of life and the effects on communication and decision making. Findings in Papers 1, 2, and 3 indicate that lung transplant patients and their families need increased communication and support regarding what to expect and end-of-life concerns. In Paper 1, the reviewed studies observed that lung transplant patients and their families lack knowledge of palliative care and what to expect at the end of life.^{10,12} Patients and families indicated they want increased communication about these issues, but several identified barriers prevented this. In Paper 2, the participating lung transplant candidates indicated end-of-life care was an important area where they need more support. Yet, most of the patients reported they have not discussed their beliefs on death and dying with their providers. Lastly, in Paper 3, caregivers reported their need for more information on what to expect in the future, which may mean a broad range of things, one of which as indicated by caregivers' comments is what to expect at the end of life. The topic of transplant and end of life is complex and influenced by many factors; however, the findings in this research study identified needs of the patients and caregivers that should be addressed.

For both aims 2 and 3, I conducted multivariable analyses to identify factors associated with palliative care need. Two variables, patient group (i.e., inpatient or outpatient) and patient ethnicity, were associated with higher patient palliative care needs and one variable, patient Lung Allocation Score (LAS), was associated with caregiver

supportive care need. Inpatient evaluations were associated with palliative care needs and, thus, this variable may serve as a useful trigger for programs exploring how best to integrate palliative care. Patient ethnicity was another variable associated with palliative care need in the final model. Non-Caucasians were more likely to have higher palliative care needs. This finding needs to be considered both in clinical decisions and future research. Lastly, patient acuity, as identified by a higher LAS, was associated with caregivers' supportive care needs and thus could also be used as a trigger for palliative care consults.

DISCUSSION

Challenges in integrating palliative care are not unique to the lung transplant population. Issues have been identified in the broader ALD population.¹⁵⁻¹⁷ Despite evidence that patients with ALD and those with lung cancer both experience significant physical and psychological symptom burden, patients with ALD are less likely to receive timely palliative care consultation.^{18,19} Additionally, other solid organ transplant literature suggests palliative care utilization is uncommon in liver and heart transplant.^{20,21} We can learn from progress made in patient populations such as oncology and heart failure, that incorporate standards of care that include palliative care and require collaboration from palliative care experts for reimbursement.^{22,23} However the specific factors influencing integration of palliative care in the management of lung transplant patients, such as the organ transplant imperative, unpredictable disease trajectories, the distressing burden of dyspnea and its impact on daily life are unique to lung transplant patients and need to be considered in designing strategies to impact the issues identified in this research.

LIMITATIONS

There are limitations in this research to be considered. I chose to include all lung transplant candidates, inpatient evaluations, outpatient evaluations and waitlisted, even though I knew this may create a heterogeneous sample. Since the aim of this research was mainly descriptive, I felt that a more inclusive approach aligned with my aim. However, with the insight of my committee, I recognized that there may be differences among these groups. All participants had ALD and were either being evaluated for or were listed for lung transplantation. Not surprisingly, preliminary analysis suggested that the inpatient group was more acutely ill, as indicated by a higher LAS. This group also was associated with greater palliative care need. There were only 19 inpatient evaluations, so the sample size was not large enough to explore these differences further, and it was also beyond the aim of this study. However, future research to examine the differences in these groups and associations with palliative care need may be indicated.

FUTURE IMPLICATIONS

There are both clinical and research implications related to this research. Based on these findings, next steps should focus on methods to meet the palliative care needs identified in this study. Research has shown a benefit of early palliative care integration in other serious illness populations.²⁴⁻²⁶ I chose to approach these patients at the time of evaluation for this reason. The findings indicate there are significant palliative care needs, even at the time of evaluation, and, therefore, considering palliative care is appropriate. Also, Nolley et al (2019) found that palliative care was more likely to be utilized post-transplant if they were consulted pre-transplant.¹³ Thus, early integration of palliative

care may benefit patients and their families in both the pre- and post-transplant periods. Future studies are needed to examine ways to best meet the identified needs described in this research.

Strategies are needed to address the end-of-life needs identified and facilitate communication between the health care team, the patients, and their families. Proactive communication training and conversation prompts have increased goals of care discussions, prompted communication about stopping aggressive therapy, and improved emotional distress of family members in ICU and heart failure patients.^{27,28} Similar training of the lung transplant team to facilitate proactive communication and goals of care discussions may be beneficial in addressing the identified end-of-life needs.

Although this research answered important questions, it also raised questions. The adapted NEST and CSNAT provided useful information, but there were limitations. Neither measure addressed the NCP palliative care domain, cultural aspects of care. Further, I was unable to find validated questions regarding palliative care needs related to cultural factors; thus, I developed questions regarding cultural aspects of care. For two of the questions many respondents did not feel the question applied to them and they chose the N/A response. Given the scant research on cultural beliefs and its impact on palliative care, particularly in lung transplant patients, this is an important area for future research. Another question uncovered through this research related to the role of ethnicity in lung transplant patients' palliative care needs. Consistent with a previous study,²⁹ we found that the inpatient evaluations, who were more acutely ill, were more ethnically diverse.

More research is needed to understand the palliative care needs of inpatient lung transplant patients, given that many are non-Caucasian.

CONCLUSION

This research provided evidence that palliative care is rarely integrated in the management of lung transplant patients, yet the patients and their caregivers have significant needs that would likely benefit from the added layer of support from this specialty. Recognizing the limited resource of specialty palliative care and the many factors influencing integration, providers and researchers need to be strategic in patient selection and integration of these services. Future work in practice and research should address: 1) utilization of evidenced based communication strategies to promote early and frequent goals of care conversations by trained providers, 2) implementation of targeted palliative care possibly prioritizing inpatients, candidates with increasing LAS, and Non-Caucasians and 3) the influence of culture and ethnicity on palliative care needs among lung transplant patients,

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