



# The Palliative Care Needs of Lung Transplant Candidates

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# Relevant Financial Relationship Disclosure Statement

Palliative Care Needs of Lung Transplant Candidates

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I will not discuss off label use and/or investigational use of any drugs/devices.

None of the contributing authors have any relevant financial relationship to disclose.



# Patients on the Waitlist

Older and  
sicker

25%  
Hospitalized

14%  
Intensive  
Care

Tripled  
# of candidates on  
waitlist > 65 years

8% ECMO or  
mechanical  
ventilation

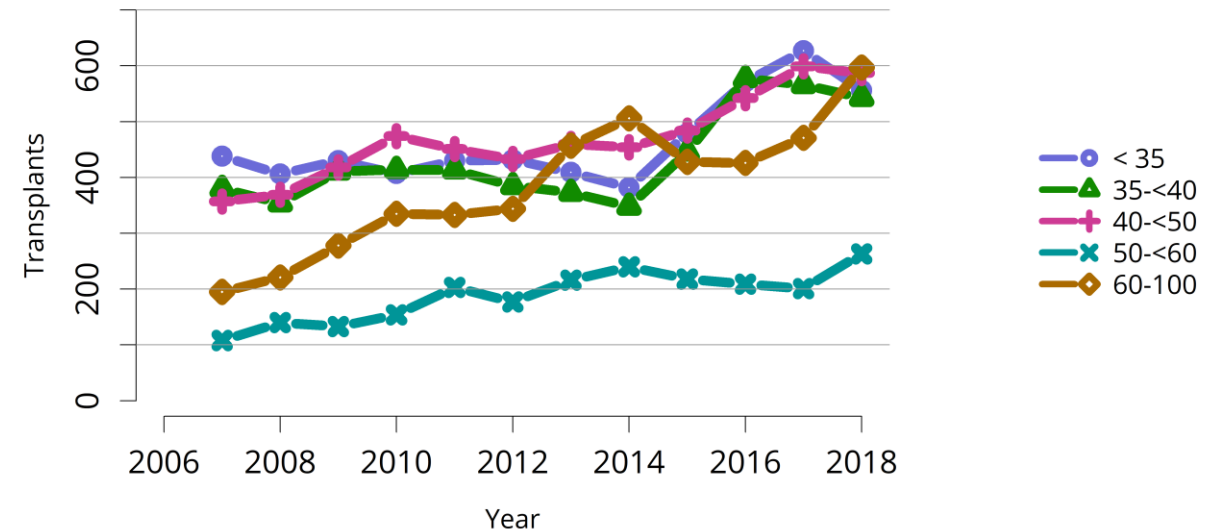


# Background

- Patients waiting for a lung transplant are older and medically complex
- They experience physical, psychological, and emotional challenges
- Palliative care has benefitted other serious illness populations (oncology, heart failure)
- Palliative care is not fully integrated into management of lung transplant patients

Valapour M, Lehr CJ, Skeans MA, et al. OPTN/SRTR 2018 annual data report: Lung. *Am J Transplant*. 2020;20 Suppl s1:427-508.

Figure LU 51. Total lung transplants by LAS



OPTN/SRTR 2018 Annual Data Report

# Aim and Methods

- **Aim:** To describe the self-reported palliative care needs of patients who are awaiting lung transplantation
- **Study Design:** Prospective cross-sectional study; single center, adult lung transplant program (Hospital of the University of Pennsylvania)
- **Data collection:** (February-October 2019)
  - Recruitment: In person or via electronic patient messaging system
  - Response rates (80.0%)
  - Survey administered using REDCap in person on tablets, via email link, or hard copy



# Framework: National Consensus Project Quality Palliative Care Guidelines 4<sup>th</sup> edition

## 8 Domains of Palliative Care:

- 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) Ethical and legal aspects of care
- 8) Care of the patient nearing the end-of-life

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



# The Needs Near the End-of-Life Screening Tool (NEST)

- Measure: Adapted version of Needs Near the End-of-Life Screening Tool (NEST) (Emanuel et al, 2001)
  - Designed for use in patients with a variety of life limiting illnesses
  - Addressed 7/8 NCP palliative care domains (3 questions added for cultural aspects of care)
  - 46 questions total
  - Based on 10-point scale (higher number = more need)
  - 1 open-ended question about additional needs added

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.

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

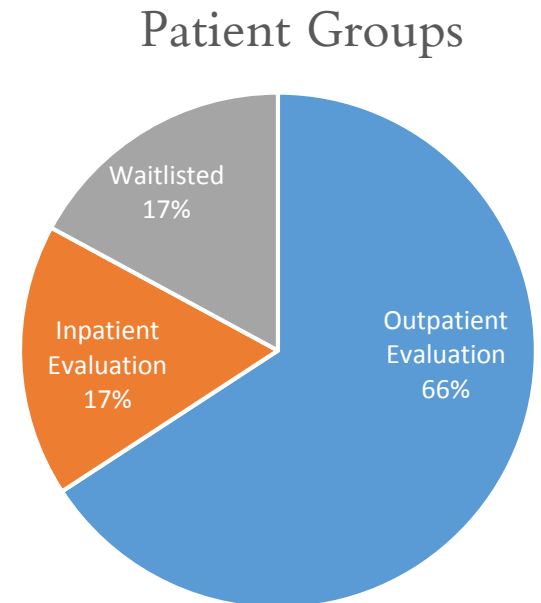
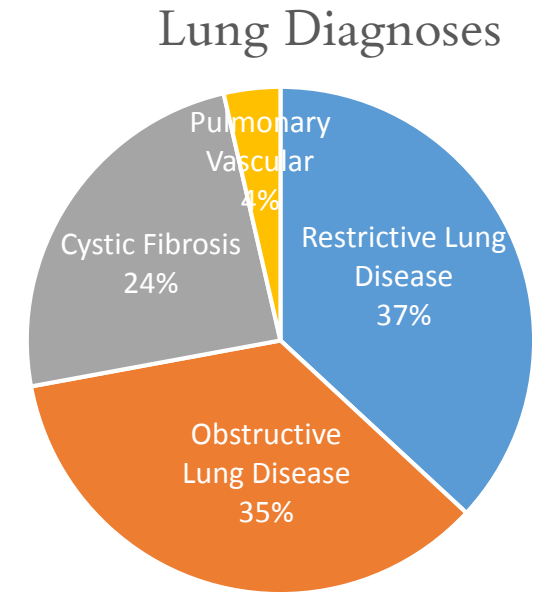
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# Sample: Lung Transplant Candidates

N = 111

- 83.5% Caucasian
- 80% not working (50% disabled; 30% retired)
- 65.8% outpatient evaluations
- 60% female
- 60.2% married, partnered
- Average age: 56.4 (SD 13.1)
- Mean Lung Allocation Score: 41.5 (SD 14.1)





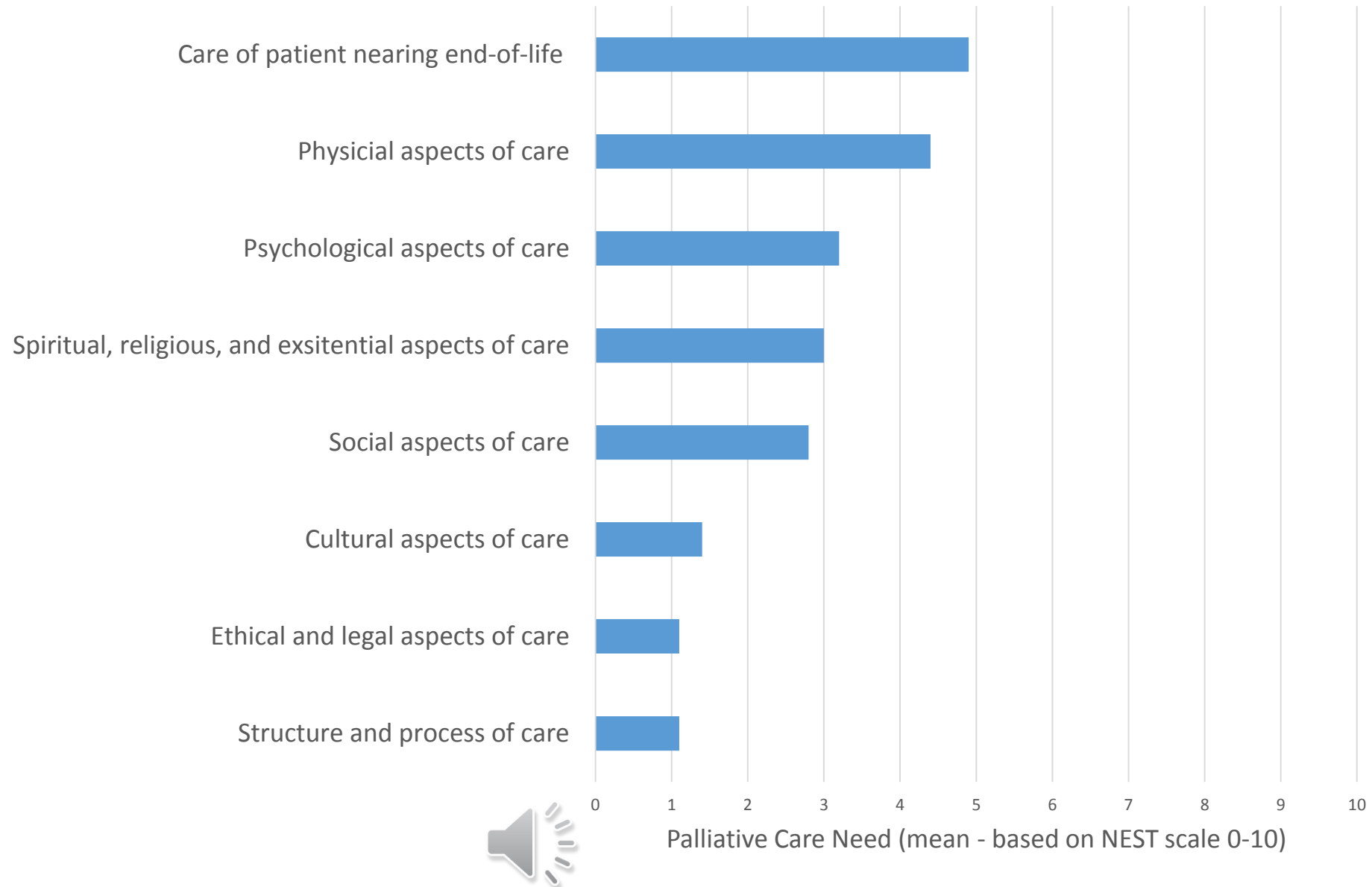
# Results: Top 10 Patients' Palliative Care Need by Item

Need	Mean	SD	Median	IQR	*Some Need Count (Percent)
Difficulty being as physically active as you would like	7.9	2.6	9.0	4.0	110(99.1)
Suffer from physical symptoms	7.4	2.6	8.0	4.0	85(76.6)
Must miss work due to your illness	6.2	4.0	8.0	7.0	76(68.5)
Shortness of Breath	5.9	2.8	6.0	4.0	108(97.3)
Feel Tranquil or Serene	5.5	3.0	5.0	5.0	89(80.2)
Distressed by the thought your life might end	5.1	3.6	5.0	6.5	90(81.1)
Tiredness	5.2	2.8	5.0	4.0	102(91.9)
Experience financial hardship r/t your illness	4.9	3.4	5.0	5.0	91(82.0)
Difficulty trying to prepare family and friends for possibility of losing you	4.8	3.7	5.0	7.0	84(75.7)
Help with homemaking such as making meals or keeping house	4.7	3.5	5.0	6.0	90(81.1)

Blue= physical needs; Red = end-of-life needs; Black = social needs



# Results: Patients' Palliative Care Need by 8 Domains



# Findings

- Greatest areas of need
  - End-of-life concerns
  - Physical aspects of care
- 50% haven't discussed their beliefs on death and dying with their health care team
- Only 7% reported seeing a palliative care specialist; most were unfamiliar with the term
- Those that were inpatients had greater palliative care needs.



# Limitations

- Single Center Study
- Measure limitations
  - Not tested in lung transplant population
  - No validated questions on cultural aspects of care related to palliative care needs



# Conclusion: Clinical Implications

- Strategic integration of palliative care to meet the needs of lung transplant candidates
  - Target inpatient evaluations
- Communication strategies needed to address end-of-life concerns identified
  - Example- Serious Illness Conversation Program, Vital Talk





## For Questions Contact:

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