CHEST Online Supplement

Barriers to Optimal Palliative Care of Lung Transplant Candidates

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e-Appendix 1.

Palliative Care In Lung Transplant Questionnaire

Screening Question

1. Do you provide clinical care for lung transplant patients as a member of a lung transplant program?
   - ☐ No
   - ☐ Yes (please specify the percent of your time)

Respondent Demographics and Characteristics

2. What is your role in the program?
   - ☐ Surgeon
   - ☐ Pulmonologist
   - ☐ Coordinator
   - ☐ Other (please specify)

3. How long have you been in independent practice? Please indicate the number of years.

4. Age

5. Gender
   - ☐ Female
   - ☐ Male

6. Where is your hospital located?
   - Country
   - Zip code/postal code, if applicable

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7. How many lung transplants has your program performed yearly, on average, over the past 3 years?
- ☐ 1 to 9
- ☐ 10 to 19
- ☐ 20 to 29
- ☐ 30 to 39
- ☐ 40 to 49
- ☐ 50 or more

8. At what stage are you involved in the care of lung transplant patients? Please check all that apply.
- ☐ Patients referred for lung transplantation
- ☐ Patients listed for lung transplantation
- ☐ Lung transplant surgery
- ☐ Lung transplant recipients immediately after surgery
- ☐ Outpatient/long term follow-up of lung transplant recipients
- ☐ None of the above

9. Please indicate other clinical activities constituting more than 10% of your practice. Please check all that apply.
- ☐ Critical care
- ☐ Palliative/hospice care
- ☐ Care of patients with end-stage lung disease who are not transplant candidates

Patient Factors

10. Various factors have been identified as possible barriers to the optimal care of patients dying while they are listed for lung transplantation. This section is intended to elicit your views about the extent to which patient factors serve as barriers to the optimal care of these patients dying in your lung transplant program.

Options for all items:
1. Not a barrier at all
2. Minimal barrier
3. Moderate barrier
4. Large barrier
5. Huge barrier

- Patient reluctance to use opiates or sedatives for symptom management because of concern about side effects
- Patient reluctance to use opiates or sedatives for symptom management because of concern about addiction
- Unrealistic patient expectations about prognosis or likelihood of survival until transplantation
- Unrealistic patient expectations about prognosis or survival after transplantation
- Unwillingness or inability of patients to plan end-of-life care
- Disagreements between patients and the transplant team about care goals
- Refusals by patients to forgo life-sustaining treatments for religious reasons
- Lack of appropriate support people
- Concern by patients that they will not receive appropriate medical care once they are enrolled in hospice or a palliative care program
- Concern by patients that they will be abandoned by the lung transplant team if enrolled in hospice or a palliative care program

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Family Factors

11. Please consider the following family factors as possible barriers to the optimal care of patients listed for lung transplantation dying in your lung transplant program.

Options for all items:
1. Not a barrier at all
2. Minimal barrier
3. Moderate barrier
4. Large barrier
5. Huge barrier

- Unrealistic family expectations about a patient's prognosis or likelihood of survival until transplantation
- Unrealistic family expectations about prognosis or survival after transplantation
- Unwillingness or inability of families to plan end-of-life care
- Disagreements within families about care goals
- Disagreements between families and the transplant team about care goals
- Refusals by families to forgo life-sustaining treatments for religious reasons

Institutional/Transplant Program/Lung Allocation System Factors

12. Please consider the following institutional, transplant program, and lung allocation system factors as possible barriers to the optimal care of patients listed for lung transplantation dying in your lung transplant program.

Options for all items:
1. Not a barrier at all
2. Minimal barrier
3. Moderate barrier
4. Large barrier
5. Huge barrier

- Lack of a palliative care service which can evaluate and treat a dying patient
- Patients on transplant waiting list ineligible for hospice or palliative care
- Limited reimbursement for care of patient once they are in hospice or palliative care program
- High organ allocation priority for patients supported by mechanical ventilation
- Insufficient recognition by colleagues or institutional leadership of the importance of optimal end-of-life care
- Lack of consultants with special expertise in management of symptoms that are distressing to lung transplant candidates
- Insufficient involvement of a patient's referring physician after the lung transplant listing
- Insufficient continuity of care within the lung transplant program due to staffing patterns
- Insufficient continuity of care during transition from outpatient to inpatient service
- Insufficient continuity of care within the lung transplant program due to nursing staffing patterns
- Patients required by program to relocate closer to transplant center
- Patients required by transplant program to lose or gain weight
- Patients required by transplant program to participate in a structured exercise program

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Clinician Factors

13. Please consider the following clinician factors as possible barriers to the optimal care of patients listed for lung transplantation dying in your lung transplant program.

Options for all items:
1. Not a barrier at all
2. Minimal barrier
3. Moderate barrier
4. Large barrier
5. Huge barrier

- Insufficient clinician training in communication about end-of-life care issues
- Insufficient clinician training in techniques for forgoing life-sustaining treatment without patient suffering
- Competing demands for clinicians' time
- Limited reimbursement for time spent providing end-of-life care
- Inadequate communication between the transplant team and patient/families about appropriate goals of care
- Inadequate communication between the transplant team and other clinicians about appropriate care goals
- Inadequate communication within the transplant team about appropriate goals of care
- Fear of legal liability for forgoing life-sustaining treatments
- Fear of legal liability for administering opioids or sedatives to patients
- Unrealistic expectations by clinicians about patient prognosis for survival to receive a transplant
- Unrealistic expectations by clinicians about prognosis or survival after transplantation
- Limited state of the science in treatment of dyspnea
- Clinicians' reluctance to use opioids or sedatives because of concern about side effects
- Clinicians' reluctance to use opioids or sedatives because of concern about addiction
- Psychological or emotional stresses on transplant clinicians of providing care to dying patients
- Insufficient attention to diverse cultural norms and customs with respect to dying, death, and grief
- Insufficient transplant clinician training in the management of symptoms that are distressing to terminally ill patients
- Clinicians' difficulty reconciling seemingly contradictory goals of transplantation and palliative care
- Belief that patient must have a DNR order to be eligible for hospice or palliative care
- Belief that death of a patient is a professional failure for transplant clinicians
- Fear that hospice or palliative care destroys a patient's hope
- Belief that hospice or palliative care is for the imminently dying

Strategies to Improve End-of-Life Care in the Lung Transplant Program

14. Various practices, policies, and resources have been suggested as methods to improve the care of patients dying while listed for lung transplantation. This section is intended to elicit your experience with some of them, as well as your opinion of their value.

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* For each of the following items, please indicate whether it is available in (or to) your lung transplant program

Availability options for all items:
1. Yes
2. No
3. Don't know

* For each item you answer "Yes," please indicate the extent to which you believe it has been helpful in meeting the needs of staff, patients, and/or families in end-of-life care in the transplant program.
* For each item you answer "No" or "Don't know," please indicate the extent to which you believe it would be helpful in meeting these needs.

Helpfulness options for all items:
1. Available, but have not used
2. Not helpful
3. Somewhat helpful
4. Very helpful

Please select one choice from the column on the left (availability) AND one choice from the column on the right (helpfulness).

- End-of-life care quality monitoring
- Bereavement program or service
- Regular meetings of a transplant physician and nurse with patients and their families
- Training of lung transplant clinicians in end-of-life communication skills
- Role modeling and supervision of transplant clinician-trainees by clinicians experienced in end-of-life care
- Formal mechanism for emotional support of staff caring for dying patients
- Access to palliative care consultants
- Training of transplant clinicians in symptom management
- Formal system for scaled assessment and charting of patients' symptoms
- Method to help resolve differences about appropriate care goals
- Resources to accommodate diversity among families and patients at the end of life
- Access to clinical ethics consultants
- Regular pastoral care visits to the transplant clinic
- Routine advance care planning assistance for all patients listed for transplant
- Regular communication between the transplant program and referring physician
- Strategies to promote communication between patients and geographically remote support people

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