



Barriers to Optimal Palliative Care of Lung Transplant Candidates

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Background: The provision of effective palliative care is of great importance to patients awaiting lung transplantation. Although the prospect of lung transplantation provides hope to patients and their families, these patients are usually very symptomatic from their underlying disease.

Methods: An e-mail questionnaire was sent to members of the American College of Chest Physicians' Transplant NetWork and the Pulmonary Council of the International Society for Heart and Lung Transplantation (ISHLT). The survey included questions about barriers to providing palliative care, the availability of palliative care services, and recommended strategies to improve palliative care for lung transplant candidates.

Results: The 158 respondents represented approximately 65% of transplant programs in the ISHLT registry. Respondents were in practice a mean of 11.3 (\pm 9) years, 70% were pulmonologists, 17% were surgeons, and 13% were other care providers. Barriers were classified into domains including patient factors, family factors, physician factors, and institutional/transplant program/lung allocation system factors. Significant patient/family barriers included unrealistic patient/family expectations about survival, unwillingness to plan end-of-life care, concerns about abandonment or inappropriate care after enrollment in a palliative care program, and family disagreements about care goals. For institutional/program/allocation system barriers, only the requirement for weight loss or gain to meet program-specific BMI requirements was identified. Significant physician barriers included competing time demands and the seemingly contradictory goals of transplant vs palliative care. Strategies recommended to improve palliative care included routine advance care planning for patients awaiting transplantation, access to palliative care specialists, training of transplant physicians in symptom management, and regular meetings among transplant physicians, nurses, patients, and families.

Conclusions: Physicians providing care to lung transplant candidates reported considerable barriers to the delivery and acceptance of palliative care and identified specific strategies to improve palliative care for lung transplant candidates. *CHEST* 2013; 143(3):736-743

Abbreviations: ACCP = American College of Chest Physicians; ISHLT = International Society for Heart and Lung Transplantation

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing problems associated with serious illnesses. It is applicable "early in the course of illness, in conjunction with other therapies that are intended to prolong life."¹ Ideally, palliative care is offered in parallel with active treatment of a patient's underlying disease, regardless of the prognosis. Unlike end-of-life or hospice care, palliative care is not limited to the terminal phase of illness.

The provision of palliative care is an essential element of the management of patients with advanced lung disease. The American College of Chest Physicians (ACCP) and the American Thoracic Society both published statements emphasizing the importance of palliative care for such patients.^{2,3} Although the prospect of lung transplantation provides hope to patients and their families, these patients are usually very symptomatic from their underlying disease.³ Often, the severity of their symptom distress is an important factor driving the decision to list them for

lung transplant. These patients are facing the possibility of death and need assurance that their medical, emotional, and spiritual needs will be met. In the United States, 16.8% of patients die waiting for a transplant or posttransplant within 1 year of lung transplant listing.⁴ Requirements imposed on patients by lung transplant programs, such as relocation to the vicinity of the lung transplant center, stringent BMI measurements, or supervised exercise program participation, may at times be at odds with palliative care principles. For example, relocation to a transplant center may remove patients from loved ones, weight loss requirements may deprive patients of foods they enjoy, weight gain requirements may involve unpleasant dietary supplementation or the placement of feeding tubes, and required exercise may provoke dyspnea. This study was conducted to better understand the barriers to the delivery of palliative care to lung transplant candidates and to identify helpful strategies to improve such care, from the perspective of physicians who provide care to patients awaiting lung transplantation.

MATERIALS AND METHODS

Between December 2009 and March 2010, using the online survey tool surveymonkey.com, an anonymized e-mail questionnaire was sent from the ACCP to all members of the ACCP Transplant NetWork and of the Pulmonary Scientific Council of the International Society for Heart and Lung Transplantation (ISHLT).

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To avoid duplicate mailings to individuals who were members of both organizations, membership lists were compiled into a single database of unique individuals. Reminder e-mails were sent to nonresponders at 1-month intervals for an additional 3 months.

The survey questionnaire (available in e-Appendix 1) included demographic and practice-related questions, as well as questions about barriers to palliative care for lung transplant candidates and the usefulness of existing or proposed strategies to improve palliative care. This instrument was modified, with permission, from a validated and previously published survey of ICU physicians that assessed barriers to palliative care in patients with critical illness receiving ICU treatment.⁵ Items from that questionnaire were adapted to make them specifically relevant to lung transplantation. Additional items were solicited from members of a dedicated ACCP multidisciplinary working group and members of the ACCP Transplant NetWork steering committee. A pilot version of the questionnaire was circulated to 23 members of the steering committees of the ACCP Interstitial Lung Disease and Palliative and End-of-Life Care Networks, because they have an interest in the subject matter and would not be included in the final survey. Pilot testers also completed a "clinical sensibility questionnaire" to assess the face validity, content validity, clarity, and usefulness of the survey, using a 1 to 5 scale from least to most sensible for each component of sensibility. An open-ended question elicited additional comments about the survey. Reviewers rated the clinical sensibility of the survey high, similar to the ratings for the ICU survey⁵ (mean [SD]: face validity, 4.3 [0.5]; content validity, 4.3 [0.8]; clarity, 4.4 [0.5]; and usefulness, 4.0 [0.6]).

A defined list of items was framed as "possible barriers to optimal care of patients dying while listed for lung transplantation" and these items were classified into domains including patient factors, family factors, physician factors, and institutional/transplant program/lung allocation system factors. Respondents were asked to rank each proposed barrier on a five-point scale (1, not a barrier at all; 2, minimal barrier; 3, moderate barrier; 4, large barrier; and 5, huge barrier).

Respondents were then asked to assess the usefulness of a defined list of strategies to improve palliative care. When the strategy was available at a respondent's center, answers were based on experiences with the resources. If they had never used a resource despite its availability, they were asked to indicate so. When the resources were unavailable, or availability was unknown, responses were based on how helpful a strategy would be, if available. Respondents were asked to rate the degree of helpfulness of strategies by classifying them as not helpful, somewhat helpful, or very helpful.

Analysis of Data

We used respondent postal codes, where provided, to classify respondents by transplant program and country. Eligibility depended on an affirmative response to a screening item at the beginning of the questionnaire asking whether the respondent provided clinical care to lung transplant patients. We excluded those who answered "no" to this screening item. We calculated frequencies and percentages for responses to each item from all eligible respondents. Barriers rated as moderate, large, or huge were classified as significant. Strategies that were deemed "very helpful" by >50% of respondents were deemed significant.

For each domain of barriers (patient factors, family factors, physician factors, and institutional/program factors), we added respondents' scores for all items in that domain to obtain a domain score. Scores for all four domains were summed to generate a total score. We used Student *t* tests, one-way analyses of variance, or nonparametric tests for trend as appropriate to examine for bivariate associations between barrier scores and respondent characteristics grouped into categories including practice location, years

in practice, number of transplants per year for the respondent's program, and role in the program. Stata 11 (StataCorp) was used for statistical analyses.

This study was approved by the University Health Network Research Ethics Board, Toronto, Canada (REB No. 09-0869-BE). Consent was assumed by completion of the survey.

RESULTS

E-mail invitations were sent to 1,602 potential participants, including 589 members of the ISHLT. Responses from 75 individuals were excluded because these respondents reported that they did not provide care for lung transplant candidates. Six additional respondents failed to complete any item in the survey and thus were also excluded from the analyses. Completed surveys were received from 158 individuals from at least 90 different programs in 21 countries. According to the ISHLT registry, 138 programs reported performing lung transplants between January 2009 and June 2010, the time interval in which the survey was distributed (L. Bennett-Edwards, PhD, personal communication, March 2011). Therefore, responses to our survey were representative of approximately 65% of active lung transplant programs.

Detailed characteristics of the respondents and of the transplant programs with which they were affiliated are provided in Table 1. Respondents had been in practice a mean of 11.3 (± 9) years; 70% were pulmonologists (111 of 158); 17% were surgeons ($n = 27$); and 13% were other care providers, including nurse practitioners, program coordinators, intensivists, and allied health professionals ($n = 20$).

Barriers to Palliative Care

Barriers to palliative care were identified across all domains (Table 2), with the greatest number of barriers identified in the patient domain and the family factor domain. Within these domains, respondents highlighted unrealistic expectations about survival until transplant (rated as a significant barrier in patients and in families by 67% and 76% of respondents, respectively) and after transplant (64% in patients, 71% in families) and unwillingness to plan end-of-life care (67% in patients, 75% in families). In addition, 62% of responding physicians identified patients' concern that medical care would be inadequate after palliative or hospice care was initiated as a significant barrier to palliative care. Fifty-seven percent of physicians rated patient fear of abandonment after referral to palliative care as a significant barrier to palliative care, whereas 61% felt that family disagreements about goals of care were an important barrier. The only institutional/program/system factor identified by at least 50% of respondents was the requirement to gain or lose weight to meet program-

Table 1—Baseline Characteristics of Survey Respondents and Transplant Centers

Variable	Respondents
Role	
Pulmonologist	111 (70)
Surgeon	27 (17)
Other	20 (13)
Sex	
Male	112 (71)
Female	46 (29)
Age, mean (SD), y	45.1 (8.6)
Years in practice, mean (SD), y	11.3 (9)
Transplants/y at center	
1-9	27 (17.2)
10-19	40 (25.2)
20-29	17 (10.8)
30-39	22 (14.0)
40-49	17 (10.8)
> 50	34 (21.7)
Practice location	
United States	99 (62.7)
Non-United States	59 (37.3)
Africa	1 (0.6)
Asia	6 (3.8)
Australia	5 (3.2)
Canada	13 (8.2)
Europe	34 (21.5)
Stage of care	
Patients referred for lung transplant	141 (89.2)
Patients listed for lung transplant	139 (88.0)
Lung transplant surgery	48 (30.4)
Lung transplant recipients immediately after surgery	138 (87.3)
Outpatient/long-term follow-up of lung transplant recipients	130 (82.3)
None of the above	3 (1.9)
Other clinical activities constituting > 10% of practice	
Critical care	83 (52.5)
Palliative/hospice care	9 (5.7)
End-stage lung disease (not transplant candidates)	74 (46.8)

Data are presented as No. (%) unless indicated otherwise. $n < 158$ for items not answered by all transplant physicians in our respondent group. Percentages exceed 100% for items with multiple nonexclusive response options.

specific BMI requirements for transplant (52%). Physician factors included competing demands for a physician's time (62%) as well as difficulty in reconciling the seemingly contradictory goals of transplant and of palliative care (51%).

Scores for the patient and program domains of barriers, and total scores across all domains of barriers, were higher for respondents working in transplant programs in other countries as compared with those providing transplant care in the United States. Mean differences were two units ($P = .01$) for the patient domain, six ($P = .0001$) for the program domain, and 14 ($P = .02$) for the total barrier score. Other characteristics, including years in practice, role in the program, and program volume, were not associated with differences in domain or total barriers scores.

Table 2—Barriers to Palliative Care

Survey Question	Not a Barrier at All	Minimal Barrier	Moderate Barrier	Large Barrier	Huge Barrier
Patient factors					
Patient reluctance to use opiates or sedatives for symptom management because of concern about side effects (n = 140)	20	53.6	20.7	5.7	0.0
Patient reluctance to use opiates or sedatives for symptom management because of concern about addiction (n = 141)	20.6	49.6	24.8	5.0	0.0
Unrealistic patient expectations about prognosis or likelihood of survival until transplant* (n = 141)	4.3	29.1	37.6	27.0	2.1
Unrealistic patient expectations about prognosis or survival after transplant* (n = 140)	7.1	29.3	45.0	15.7	2.9
Unwillingness or inability of patients to plan end-of-life care* (n = 141)	2.1	31.2	39.0	19.9	7.8
Disagreements between patients and the transplant team about care goals (n = 139)	10.8	48.2	32.4	7.9	0.7
Refusals by patients to forgo life-sustaining treatments for religious reasons (n = 141)	32.6	58.9	6.4	1.4	0.7
Lack of appropriate support people (n = 141)	16.3	37.6	29.1	14.9	2.1
Concern by patients that they would not receive appropriate medical care once they were enrolled in hospice or palliative care program* (n = 140)	8.6	29.3	37.9	19.3	5.0
Concern by patients that they would be abandoned by the lung transplant team if enrolled in hospice or palliative care program* (n = 140)	11.4	31.4	29.3	22.9	5.0
Family factors					
Unrealistic family expectations about patient's prognosis or likelihood of survival until transplant* (n = 138)	2.9	21.0	44.2	26.1	5.8
Unrealistic family expectations about prognosis or survival after transplant* (n = 137)	5.8	23.4	46.0	19.7	5.1
Unwillingness or inability of families to plan end-of-life care* (n = 137)	3.6	21.2	45.3	26.3	3.6
Disagreements within families about care goals* (n = 136)	4.4	34.6	43.4	16.2	1.5
Disagreements between families and the transplant team about care goals (n = 134)	6.7	44.8	38.8	8.2	1.5
Refusals by families to forgo life-sustaining treatments for religious reasons (n = 137)	32.1	54.7	9.5	2.9	0.7
Institutional, transplant program, and lung allocation system factors					
Lack of a palliative care service that could evaluate and treat a dying patient (n = 135)	45.2	25.9	15.6	7.4	5.9
Patients on transplant waiting list ineligible for hospice or palliative care (n = 134)	35.8	32.8	20.1	10.4	0.7
Limited reimbursement for care of patient once he/she is in hospice or palliative care program (n = 132)	53.0	29.5	12.9	3.8	0.8
High organ allocation priority for patients supported by mechanical ventilation (n = 130)	30.8	39.2	14.6	13.8	1.5
Insufficient recognition by colleagues or institutional leadership of the importance of optimal end-of-life care (n = 134)	28.4	32.8	23.9	11.9	3.0
Lack of consultants with special expertise in management of symptoms distressing to lung transplant candidates (n = 134)	39.6	26.9	19.4	9.0	5.2
Insufficient involvement of patient's referring physician after lung transplant listing (n = 133)	23.3	39.1	27.1	7.5	3.0
Insufficient continuity of care within lung transplant program due to staffing patterns (n = 134)	38.1	39.6	14.9	6.0	1.5
Insufficient continuity of care during transition from outpatient to inpatient service (n = 132)	37.9	43.9	15.2	1.5	1.5
Insufficient continuity of care within lung transplant program due to nursing staffing patterns (n = 133)	39.1	39.1	15.8	4.5	1.5
Requirement by transplant program for patient to relocate closer to transplant center (n = 135)	28.1	40.0	24.4	4.4	3.0
Requirement by transplant program for patient to lose or gain weight* (n = 134)	17.2	30.6	32.8	14.9	4.5
Requirement by transplant program for patient to participate in structured exercise program (n = 132)	23.5	37.9	28.0	9.1	1.5

(Continued)

Table 2—Continued

Survey Question	Not a Barrier at All	Minimal Barrier	Moderate Barrier	Large Barrier	Huge Barrier
Physician factors					
Insufficient physician training in communication about end-of-life care issues (n = 129)	14.0	45.0	28.7	10.9	1.6
Insufficient physician training in techniques for forgoing life-sustaining treatment without patient suffering (n = 129)	15.5	48.1	24.8	8.5	3.1
Competing demands for physician time ^a (n = 128)	8.6	29.7	37.5	21.1	3.1
Limited reimbursement for time spent providing end-of-life care (n = 126)	32.5	39.7	18.3	7.1	2.4
Inadequate communication between transplant team and patient/families about appropriate goals of care (n = 129)	17.1	41.1	31.0	9.3	1.6
Inadequate communication between transplant team and other physicians about appropriate goals of care (n = 129)	19.4	38.0	31.8	8.5	2.3
Inadequate communication within transplant team about appropriate goals of care (n = 128)	32.8	40.6	20.3	5.5	0.8
Fear of legal liability for forgoing life-sustaining treatments (n = 128)	44.5	42.2	9.4	1.6	2.3
Fear of legal liability for administering opioids or sedatives to patients (n = 128)	53.9	39.1	3.9	2.3	0.8
Unrealistic expectations by physicians about patient prognosis for survival to receive transplant (n = 127)	22.0	44.1	22.0	7.9	3.9
Unrealistic expectations by physicians about prognosis or survival after transplant (n = 128)	25.0	39.8	26.6	6.3	2.3
Limited state of the science in treatment of dyspnea (n = 127)	18.1	40.9	26.0	11.0	3.9
Physician reluctance to use opioids or sedatives because of concern about side effects (n = 128)	30.5	38.3	20.3	8.6	2.3
Physician reluctance to use opioids or sedatives because of concern about addiction (n = 128)	39.8	38.3	13.3	6.3	2.3
Psychologic or emotional stresses on transplant physicians as a result of providing care to dying patients (n = 128)	20.3	44.5	25.8	8.6	0.8
Insufficient attention to diverse cultural norms and customs with respect to dying, death, and grief (n = 128)	16.4	50.8	27.3	5.5	0.0
Insufficient transplant physician training in management of symptoms distressing to terminally ill patients (n = 129)	18.6	41.9	24.8	13.2	1.6
Physician difficulty in reconciling seemingly contradictory goals of transplant and palliative care ^a (n = 127)	13.4	35.4	28.3	17.3	5.5
Belief that patient must have do-not-resuscitate order to be eligible for hospice or palliative care (n = 126)	31.7	34.9	23.0	5.6	4.8
Belief that death of patient is a professional failure for transplant physicians (n = 125)	33.6	41.6	15.2	8.0	1.6
Fear that hospice or palliative care destroys patient's hope (n = 127)	26.0	32.3	22.0	15.7	3.9
Belief that hospice or palliative care is for the imminently dying (n = 127)	29.2	30.7	25.2	13.4	5.5

Data are presented as %.

^aBarriers that were considered significant.

Strategies to Improve Palliative Care

Several strategies for facilitating palliative care were identified (Table 3). Routine advance care planning for listed patients (54%) and access to palliative care consultants (62%) were considered important by most respondents. In addition, regular meetings between transplant physicians, nurses, patients, and families (78%) and routine communication among the transplant program and referring physician (52%) were considered helpful. Respondents indicated that training of transplant physicians in symptom management (54%) and end-of-life communications skills (52%), and role modeling and supervision of transplant physician-trainees by physicians experienced in end-of-life care (51%), were helpful in improving palliative care for patients awaiting lung transplantation.

DISCUSSION

The American Thoracic Society's Clinical Policy Statement regarding palliative care recommends that "palliative care should begin when a patient becomes symptomatic and is usually concurrent with restorative and life-prolonging care."² The ACCP Position Statement affirms that "palliative care in this broad sense is not restricted to those who are dying or those

enrolled in hospice programs."³ Accordingly, palliative care services should be integrated and concurrent with other medical care for patients with advanced lung disease, including those who are referred for lung transplant. However, these recommendations may not be fully implemented at many lung transplant centers. This study examines physician-perceived barriers to palliative care in patients who are listed for lung transplantation.

Studies that have examined barriers to palliative care in other patient populations such as patients with cancer and with end-stage, nonmalignant diagnoses have suggested various explanations for delayed referral or inadequate palliative care, including lack of knowledge about palliative care among health-care providers; unpredictable prognosis, particularly in patients who do not have cancer; palliative care referrals being viewed as "giving up" on a patient; and lack of referral criteria for palliative care.⁶⁻¹¹ In our study, lack of physician knowledge about palliative care was not viewed as an important barrier. This may be because most lung transplant physicians are experienced in dealing with patients with advanced lung disease, among whom symptom distress is common. However, concerns about abandonment and about inadequate medical care after initiation of palliative or hospice care, which the respondents attributed to

Table 3—Strategies to Improve Palliative Care

Potential/Existing Strategy	Available but Have Not Used	Not Helpful	Somewhat Helpful	Very Helpful
End-of-life care quality monitoring (n = 123)	8.1	8.1	48.5	35.4
Bereavement program or service (n = 124)	9.0	2.0	47.0	42.0
Regular meetings of transplant physician and nurse with patients and their families (n = 123)	0.0	0.9	21.2	77.9 ^a
Training of lung transplant physicians in end-of-life communication skills (n = 123)	2.0	2.0	43.9	52.0 ^a
Role modeling and supervision of transplant physician trainees by physicians experienced in end-of-life care (n = 123)	1.0	8.2	39.8	51.0 ^a
Formal mechanism for emotional support of staff caring for dying patients (n = 123)	7.2	6.2	48.5	38.1
Access to palliative care consultants (n = 123)	5.4	2.7	29.7	62.2 ^a
Training of transplant physicians in symptom management (n = 99)	1.9	2.9	41.0	54.3 ^a
Formal system for scaled assessment and charting of patients' symptoms (n = 100)	4.0	13.0	61.0	22.0
Method to help resolve differences about appropriate care goals (n = 113)	3.0	7.0	53.0	37.0
Resources to accommodate diversity among families and patients at end of life (n = 98)	2.1	6.2	57.7	34.0
Access to clinical ethics consultants (n = 98)	14.0	31.8	40.2	14.0
Regular pastoral care visits to transplant clinic (n = 97)	6.9	16.7	40.2	36.3
Routine advance care planning assistance for all patients listed for transplant (n = 97)	1.0	5.9	39.6	53.5 ^a
Regular communication between transplant program and referring physician (n = 111)	1.9	6.5	39.8	51.9 ^a
Strategies to promote communication between patients and geographically remote support people (n = 105)	2.1	4.2	55.2	38.5

Data are presented as %.

^aStrategies that were considered very helpful by > 50% of respondents.

patients, parallel the findings reported in nontransplant populations. Physicians in our study viewed this as a patient and family-related barrier but not as a physician-related factor. However, >40% of the respondents identified physicians' fear that hospice or palliative care destroys a patient's hope and physicians' belief that hospice or palliative care is only appropriate for the imminently dying as barriers to palliative care.

Recently, Song et al¹² surveyed physicians about barriers to palliative care referrals and consultations after lung transplant. The most common barrier was the misconception that palliative care was synonymous with end-of-life care. In addition, uncertainty about recipients' prognoses, the perception that palliative care precludes further aggressive treatment, and the challenge of discussing palliative care with lung transplant recipients and their families were all seen as barriers.

In the physician domain, respondents to our survey identified difficulty reconciling the seemingly contradictory goals of transplant and palliative care as an important barrier. The findings by Song et al¹² that physicians equate palliative care with end-of-life care may help explain this. Lung transplant candidates must also fulfill strict criteria such as an optimal BMI for surgery, which may negatively impact patients' quality of life by forcing dietary modifications, and which was, therefore, felt to be a significant barrier to palliative care by study respondents. However, the goal of palliative care, by definition, is congruent with the goals of lung transplant, namely, to improve the quality of life for patients with advanced lung disease. Lung transplant adds the additional objective of prolonging patient survival with which the goals of palliative care are fully consistent. In fact, evidence is emerging that survival with serious illness such as advanced lung cancer is longer for patients receiving palliative care together with curative or life-prolonging treatments.¹³

The results of our study reinforce the importance of communication among care providers, patients, and their families. Unrealistic patient and family expectations about prognosis and survival before and after transplantation were considered a significant barrier, as was the unwillingness or inability of patients or their families to plan for care at the end of life. From a physician perspective, competing demands for time were highlighted. If physicians had more time to discuss prognosis, to reinforce the need for advance care planning, and to answer patient and family concerns, they might integrate palliative care in more timely and appropriate ways.

Our results suggest that physicians practicing in other countries may perceive greater barriers to palliative care than do those who practice within the United States. An emerging body of literature exam-

ines the development of, and barriers to, palliative care for oncologic and nononcologic disease outside North America. A number of common themes have emerged from these studies, including (1) a lack of awareness of palliative care as a field, and inadequate understanding of palliative care needs at a public and governmental level; (2) limited financial and material resources; (3) inadequate professional training programs; and (4) problems relating to opioid availability.¹⁴⁻¹⁹

This study has limitations. First, the proportion of individuals responding to our survey was low. Because we did not screen in advance for eligibility, and some individuals returning surveys were ineligible, it is likely that some of the nonresponders were also ineligible and thus that the response rate among eligible members of the sample was higher. In addition, we obtained responses from at least 90 unique lung transplant programs, which, according to the ISHLT registry, represent approximately 65% of the programs in operation between January 2009 and June 2010 (L. Bennett-Edwards, PhD, personal communication, March 2011). Second, we did not directly survey patients and their family members. Physicians' perception of barriers to palliative care may differ from those of patients and family members. Future work should focus on validating and expanding these results by including patient and family perspectives. Finally, the definition of "palliative care" was not explicitly stated at the beginning of the study and palliative care was used interchangeably with end-of-life care at times. Therefore, the results may, in part, reflect issues involving end-of-life care, because many individuals continue to believe that palliative care is synonymous with dying. Indeed, the wording of our survey may have inadvertently served to reinforce that belief.

CONCLUSIONS

Our study demonstrates that physicians providing care to patients awaiting lung transplant perceive important barriers to the delivery and acceptance of palliative care. Strategies endorsed by the respondents, who are front-line caregivers for these patients, may help improve such care. Future research is needed to examine patient and family perspectives of palliative care and to investigate the impact of such care on the quality of life and other outcomes of patients and families.

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Additional information: The e-Appendix can be found in the "Supplemental Materials" area of the online article.

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