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## Lung transplant pulmonologists' views of specialty palliative care for lung transplant recipients

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# Lung Transplant Pulmonologists' Views of Specialty Palliative Care for Lung Transplant Recipients

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## Abstract

**Background:** Lung transplant recipients with serious illness may benefit from but rarely receive specialty palliative care (SPC) services. Transplant pulmonologists' views of SPC may be key to understanding SPC utilization but have not been well characterized.

**Objectives:** (1) To understand how transplant pulmonologists view SPC and decide to refer transplant recipients and (2) to identify unique aspects of lung transplantation that may influence referral decisions.

**Design:** We conducted semistructured interviews with transplant pulmonologists at nine geographically diverse high-volume North American transplant centers with SPC services. A multidisciplinary team analyzed interview transcripts using constant comparative methods to inductively develop and refine a coding framework related to SPC views and referral decisions.

**Results:** We interviewed 38 transplant pulmonologists; most (36/38) had referred lung transplant recipients to SPC. Participants described SPC as a medical specialty that aims to improve quality of life and distinguished SPC from hospice care, which was considered end-of-life care. Participants who viewed transplant as a temporary solution ( $n=17/38$ , 45%) described earlier utilization of SPC alongside disease-directed therapies, whereas those who viewed transplant as survival-focused ( $n=21/38$ , 55%) described utilization of SPC after disease-directed therapies were exhausted. Concerns about one-year survival metrics and use of addicting medications for symptom palliation were barriers to referral.

**Conclusions:** Transplant pulmonologists' SPC referral practices may be related to their views of lung transplantation. Optimizing use of SPC in lung transplantation will require improving communication between transplant pulmonology and SPC to ensure a collaborative effort toward patient-centered goals while addressing unique barriers to SPC referral.

**Keywords:** lung transplantation; palliative care; solid organ transplantation

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## Introduction

LUNG TRANSPLANTATION is an increasingly common therapy for patients with end-stage lung disease.<sup>1</sup> Lung transplant recipients frequently experience declines in quality of life because of transplant-related complications, especially chronic allograft rejection and face foreshortened survival.<sup>2–7</sup> Transplant recipients with serious illness may benefit from specialty palliative care (SPC), but evidence suggests SPC is rarely received.<sup>2,8,9</sup> Barriers to SPC referral for lung transplant recipients are poorly understood.<sup>8,9</sup>

How transplant pulmonologists view SPC may be key to understanding SPC utilization. Previous work suggests that oncologists' who view SPC as end-of-life care are less likely to refer patients.<sup>10–13</sup> Little is currently known about how transplant pulmonologists view SPC. Two survey studies of lung transplant providers suggest that perceptions of palliative care as end-of-life care, precluding other treatments, or contradictory to the goals of transplant may be barriers to referral.<sup>9,14</sup> Neither study, however, assessed the reasons underlying these perceptions.

Understanding how transplant pulmonologists perceive SPC and decide to refer transplant recipients to SPC is necessary to understand post-transplant SPC utilization. In this study we sought to understand how transplant pulmonologists view SPC and decide to refer transplant recipients to SPC, focusing on unique aspects of transplantation that may influence SPC utilization. Because little is known about this topic, we chose a qualitative approach suited to addressing issues of what, how, and why.<sup>15</sup> Our goal was to provide a framework for understanding post-transplant SPC utilization and enable further work to improve provision of SPC services in lung transplantation.

## Methods

### Study design

We conducted qualitative, in-depth semistructured interviews to allow flexibility in exploring transplant pulmonologists' views of SPC and decisions to refer lung transplant recipients to SPC.

### Sample and recruitment

Participants were transplant pulmonologists at high-volume centers performing >40 lung transplants a year. We used purposive sampling to recruit participants from geographically diverse centers with inpatient and outpatient SPC consult services: University of Toronto, University of Washington, University of Pittsburgh Medical Center, Duke University, University of California at San Francisco, University of Loyola, University of Pennsylvania, Brigham and Women's Hospital, and Washington University in St. Louis. Eligible participants were attending transplant pulmonologists who care for transplant recipients. Potential participants were identified with the assistance of local colleagues and initially contacted by email. Follow-up to schedule interviews was conducted through a combination of email and direct contact by local colleagues. Participants provided informed consent either in person or electronically. The University of Pittsburgh Institutional Review Board approved this study.

## Data collection

All participants completed a semistructured in-depth interview followed by a brief demographic survey. Interviews were conducted either in-person or through telephone between October 2017 and March 2018 by an investigator trained in using standard semistructured, in depth interviewing techniques (E.P.N.). The in-depth interview guide focused on three domains: understanding of SPC, deciding to refer transplant recipients to SPC, and unique aspects of transplantation affecting referral. Participants were asked to define SPC (Can you define SPC for me?) and explain the relationship between SPC and hospice care (In your mind, what is the relationship between SPC and hospice?). Questions were open-ended and nonleading, with follow-up probes used to elicit description of individual experiences and encourage participants to reflect on their own patients. Participants were also asked to discuss hypothetical patients presented in brief vignettes because sometimes asking participants to reflect on their own patients is sensitive and relevant issues can be better explored using a hypothetical patient.<sup>16,17</sup> The full interview guide is available in Supplementary Data. Interviews were audio recorded, transcribed verbatim, and conducted until thematic saturation was reached, meaning no new themes emerged from additional interviews.

## Data analysis

Data analysis was performed iteratively and the coding framework was developed using the constant comparative method.<sup>18,19</sup> Using this approach, four investigators with multidisciplinary backgrounds (E.N., D.K., M.A.D., and Y.A.S.) reviewed a subset of transcripts and inductively developed a codebook describing transplant pulmonologists' views of SPC and factors influencing SPC referral. Through multiple cycles of coding, comparison, and refinement codes were classified, grouped, and refined into themes. All disagreements were discussed and resolved by group consensus. An investigator trained in qualitative analysis (E.N.) applied the final coding framework to all transcripts. A second investigator (J.F.) coded 30% of transcripts with comparison to ensure full intercoder agreement between coders with disagreements resolved by consensus. As a final step we conducted member checking by sending synthesized results to a subset of participants who provided feedback on the relevance of the results to their experiences.<sup>20</sup> The qualitative data analysis software NVIVO (NVIVO 11 for Macintosh; QSR International) facilitated analysis. Demographic data were summarized using counts, percents, means, and medians.

## Results

Among 61 transplant pulmonologists contacted for participation, 38 completed interviews with participation from all 9 sites. Demographic characteristics of participants are listed in Table 1. Qualitative analysis yielded three major themes emerged related to study aims.

### Defining SPC

Transplant pulmonologists described SPC as an approach to care for patients with chronic or advanced medical disease that aims to improve quality of life (Table 2).

Nearly all participants ( $n = 34/38$ , 89%) described SPC as providing symptom management. Symptoms for which they

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANT TRANSPLANT PULMONOLOGISTS

Characteristic	N = 38
Age, years, mean ( $\pm$ SD)	43.3 ( $\pm$ 7.1)
Female sex	32% (12)
Caucasian	76% (29)
Latino	8% (3)
Years practicing transplant pulmonology, median (IQR)	8 (4–15)
Half days per week in clinic, mean ( $\pm$ SD)	2 ( $\pm$ 1)
Palliative Care Fellowship	3% (1)
Have referred a transplant recipient to SPC	95% (36)

IQR, interquartile range; SD, standard deviation; SPC, specialty palliative care.

felt SPC offered benefit for included pain, anxiety, and breathlessness. One participant described how SPC could help a range of symptoms that differ from patient to patient: “it’s patient dependent thing...(SPC could help) any symptoms associated with their underlying disease process which could include pain or anxiety or dyspnea or discomfort related to treatment.”

A third of participants ( $n = 12/38$ , 32%) described SPC as providing psychological or spiritual support. Some participants described how support provided by SPC was important for both transplant recipients and their caregivers. As one participant explained, SPC can be for the patient and “for the family or the loved ones who take care of the patient... when somebody goes for a lung transplant there’s only one patient, but everybody who is taking care of a patient basically has to have the same support.”

About half of participants ( $n = 20/38$ , 53%) described SPC as helping to identify patient preferences or discussing goals of care. One participant described SPC as a specialty that “focuses on identifying patient preferences and trying to help

patients understand how to receive treatment that is consistent with their wishes.”

Virtually all participants ( $n = 37/38$ , 97%) described SPC as providing more than hospice, which was described as end-of-life care and a component of the services that SPC provides (Table 2). For example, one participant described SPC and hospice as existing “as a continuum...symptom control in the setting of aggressive medical care all the way to the other end of the spectrum which is educating and initiating Hospice Care.”

### Views of lung transplantation

Participants expressed two differing views of lung transplantation (Table 3). Approximately half of participants ( $n = 17/38$ , 45%) described transplant as temporary solution for an incurable disease or exchange of problems with uncertain outcomes. One compared transplantation to a chronic disease, stating that “essentially we are dealing with a chronic disease...we’re exchanging one set of problems for another...getting a lung transplant doesn’t mean you are going to live forever...it’s not a perfect fix.”

Other participants ( $n = 21/38$ , 55%) described transplant as therapy focused on treatment and survival. As one participant described, “so much of the push in transplant is to treat, to beat the odds...transplant itself is salvage therapy and then when the graft starts failing you do all sorts of things for salvage therapy.” Several felt a treatment-focused mindset was shared by transplant recipients. According to one participant, “our philosophy and I think most patients’ philosophy is that once they get a transplant they’re gonna want to do everything they can to make it last as long as possible.”

Participants’ views of transplantation were associated with different SPC referral practices (Table 3). Those describing transplant as a temporary solution tended to

TABLE 2. TRANSPLANT PULMONOLOGISTS PREDOMINANT VIEWS OF SPECIALTY PALLIATIVE CARE AND HOSPICE CARE

	Comments
Defining SPC	
Symptom management 34/38 (89%)	“I would define it as providing the alleviation of suffering...aspects of suffering that patients can go through physically, emotionally, psychologically (palliative care) can help with”
Support for patients and caregivers: 12/38 (32%)	“Palliative care is an approach to managing symptoms for patients with non-curable illnesses um, at any point along their disease trajectory... it also can deal with it can deal with somatic symptoms and psychosocial symptoms and also help to support the families”
Establishing patient preferences or goals of care: 20/38 (53%)	“Palliative care is more encompassing of, of the bigger picture of goals of care, you know, not even just at end of life...how do people want things to look as they get sicker, if they have a chronic illness, or at the end of life.”
Relationship between SPC and hospice care	
Hospice is a component of SPC and is end-of-life care: 37/38 (97%)	“I think that hospice is an avenue that palliative care can use to facilitate a very comfort-focused approach to the end of life. Palliative care can obviously also include a lot of approaches at different stages of life that don’t necessarily result in dying...Hospice would be a tool in the palliative care armory” “I do view hospice as kind of equivalent with end of life...For patients that aren’t end of life and wouldn’t be considered for hospice there would still be a role for palliative care. So like in a Venn Diagram there’d be some overlap for the end of life, but not necessarily for everybody”

TABLE 3. TRANSPLANT PULMONOLOGISTS VIEWS OF LUNG TRANSPLANTATION AND ASSOCIATED SPECIALTY PALLIATIVE CARE REFERRAL PRACTICES

	Comments
View of transplantation as a temporary solution and associated SPC referral practices ( $n = 17/38$ , 45%)	
Transplant is a temporary solution or an exchange of problems	“(transplant is) definitely its own interesting specialty in that patients come in dying and eventually they die all over again...they’re facing death and then we try to save them, but they will face death again and we all know it” “transplant has a 5 year survival of 50–60% and that’s a one year survival of 85% and that’s very similar to most cancers so almost, almost every patient I see has a terminal diagnosis even with or without transplant”
Referring to SPC alongside disease-directed therapies	“we still have treatment options...but I think palliative care might be able to help her with symptom control...I would be referring her for that one end of the spectrum where they’d be complimenting the aggressive therapy that we’d be providing”
SPC helps patients cope with chronic rejection	“chronic rejection is such a devastating diagnosis ... and makes me more likely to refer (to palliative care), not necessarily for the physical symptom management, but also to talk about and process what that means for her life trajectory”
SPC helps prepare patients for transplantation	“We can use (palliative care) in two different ways...because we are going to relist her for transplant and try to manage her symptoms or try to make her more aware of not any other option...and try to maximize her well-being”
View of transplantation as survival focused and associated SPC referral practices ( $n = 21/38$ , 55%)	
Transplant is focused on treatment and survival	“most patients have gotten to a mindset where they’re undergoing a very major surgery certainly with potential for a lot of good, but also potential for complications that for the most part, across the board, I’d say most of our patients are very aggressive about trying to get things to work” “(Transplant is an) extremely limited one time offer in that that lung, if it goes to one patient and can’t go to another. So the sense within the medical community is that we need to do everything we can to help this person survive through a transplant”
Referring to SPC once disease-directed therapies are exhausted	“I don’t see an acute need (for SPC)...she’s being aggressively treated with therapies that could potentially either halt or reverse this process...before saying that we’ve exhausted all treatment modalities”
SPC and re-transplantation are different paths	“I’ve never referred someone that is a re-transplantation candidate to palliative care...that’s just not the pathway ... there’s an immediate transition made to re-transplantation and so that idea of palliative care probably gets, like, swept by the wayside...logistically there’s not a box that needs to be checked for palliative care”

describe referring to SPC while pursuing disease-directed therapies. One participant described how SPC could be used, “*not just for end of life type discussions and planning...but also to help us keep people comfortable who are dealing with either difficulties immediately after surgery...or down the road with medical complications.*” These participants often reported referring to SPC after the onset of chronic rejection, which they described as irreversible with an uncertain course and significant symptoms. They described how SPC could help with symptom management and coping. As one participant stated about patients with chronic rejection: “*in an environment of uncertainty...how you cope with all those symptoms and how you cope psychologically and physically with that, that is the biggest benefit. We are riding along in a roller coaster, let’s try to make the ride a little bit easier.*” Several participants also described how SPC could help optimize patients for re-transplantation. Discussing a hypothetical patient, one physician commented: “*if we want her to be a good candidate for a re-transplant... psychologically and medically stable and optimized to go through another stressful event*

*and to wait on the waiting list however long that might take...that would make me very inclined to refer.*”

Participants describing transplantation as treatment focused on survival tended to refer to SPC once disease-directed therapies were exhausted. As one explained:

*I refer once we’ve exhausted all therapies that I anticipate that might help the lung function stabilize and the lung function continues to deteriorate ... oftentimes recipients think things are going in a bad direction but then you can turn them around. So I don’t refer to Palliative Care until...in spite of everything we’ve done, the graft is continuing to fail.*

Re-transplantation was a common barrier to referral. Some described re-transplantation and SPC as different treatment paths or different goals. As one explained,

*If she was a candidate for a re-transplant I wouldn’t pursue Palliative Care. I view the two as sort of not convergent paths. If you’re gonna have a re-transplant, the path is a different one than if you’re gonna be in Palliative Care, where things like pulmonary rehab and so on are maybe not quite as important or not necessary.*

For others, the intense treatment approach required for re-transplantation precluded consideration of SPC. As one described, *"we probably would be so focused on maintaining her physical functioning, other good organ function, keeping her optimal, that (SPC) probably would just be crowded out and wouldn't even enter the thought process."*

### Unique barriers to SPC referral

Over a third of participants ( $n = 14/38$ , 37%) reported referral was less likely in the first post-transplant year (Table 4). Many expressed concern that referral could increase one-year mortality, a key metric by which programs are judged. As one explained, SPC referral is:

*harder when you have a fresher transplant...certainly within the first year when you're really worried about its impact on outcomes...(programs are) judged by how our expected outcomes match with our observed outcomes. And if we don't meet those criteria or they're significantly off then we're at risk of...being examined and audited.*

Others felt the focus on one-year survival deterred discussion of SPC even when patients might benefit. One participant explained the first post-transplant year is: *"such a huge benchmark for a program that I think it deters providers and patients (from discussing SPC)...it does impede sometimes early referral, particularly in patients who don't do well and we know that they won't do well, very early on."*

Another barrier to referral mentioned by about a third of participants ( $n = 12/38$ , 32%) was the potential use of opioids

and benzodiazepines for symptom palliation (Table 4). Several participants had concerns that SPC providers would prescribe opioids, which some centers consider inappropriate for re-transplant candidates. As one explained if *"the wish is actually to get to lung transplant...we're all set before transplant on medications...opioids to palliate dyspnea are not medications that we can really use a whole lot because we're trying to keep them mobile and awake and engaged."* Others expressed concern that opioids could cause harm to patients with advanced lung disease. One participant discussed, *"overzealous narcotic prescribing on the part of Palliative Care...(they) recommended relatively high narcotic doses and I was worried that (could) lead to a respiratory arrest."* Finally, several expressed worry about using opioids or benzodiazepines early in the course of chronic rejection because patients could become addicted. As one explained *"opioids, benzodiazepine, anything that can create some addiction...I feel that they (SPC providers) may start more liberally using them than what we use. So there is a little bit of a conflict of how much and how soon you will start certain therapies."*

### Discussion

Transplant pulmonologists' views of SPC may be key to understanding post-transplant SPC utilization. In this multicenter study, we found that transplant pulmonologists define SPC as a specialty focused on improving quality of life and distinguish SPC from hospice. Transplant pulmonologists who viewed transplant as a temporary solution to an incurable disease described earlier utilization of SPC

TABLE 4. EMPHASIS ON ONE-YEAR OUTCOMES AND CONCERNS ABOUT POTENTIALLY ADDICTING MEDICATIONS ARE UNIQUE BARRIERS TO REFERRAL IN LUNG TRANSPLANTATION

	Comments
Emphasis on one-year outcomes ( $n = 14/38$ , 37%)	
Emphasis on one-year survival makes SPC referral less likely	<p>"I think there's a real push for programs to...improve their statistics such as more than 5 year survival and so if patients are sick and in need of palliative care and they're prior to their, especially, one year survival mark I think there's a tendency to try to do everything possible to focus on patient survival and I think sometimes we tend to overlook focusing on patient's comfort"</p> <p>"I think that there is a barrier in the way that transplant success is judged with like one-year mortality being incredibly important, that if somebody has a rough first year, I think there is a hesitation to involve palliative care because I think the transplant team in general doesn't want to hear that we should stop"</p>
Concern about use of opioids and benzodiazepines for symptom palliation ( $n = 12/38$ , 32%)	
Compatibility with re-transplantation candidacy	"if we are focusing on anxiety and pain and if we've got someone with really poor prognosis...use of narcotic medications and benzodiazepines is common, and if we're evaluating someone for re-transplantation or considering re-transplantation, we would not want those patients to use those medications while they're still under evaluation or in preparation for a second transplant"
Concern about adverse events due to medications	"maybe another reason that I wouldn't (refer to SPC) is that we often think about narcotics and things like that to try and ease, to ease work of breathing, lessening dyspnea, while at the same time could depending on the dose cause worsening symptoms or worsening CO <sub>2</sub> retention and things like in some of our patients"
Concern about addiction	"I would worry about her being started on opioids kind of early in her disease process (chronic rejection)...I'm obviously mindful of some of the negative aspects of opioids use...I would worry a little that they may have quite a long life ahead of them still and that they might get dependent on opioids if that's chosen as the primary way of managing their shortness of breath"

alongside disease-directed therapies, whereas those who viewed transplant as survival focused described utilization of SPC after disease-directed therapies were exhausted. We also identified concerns about one-year survival outcomes and use of opioids and benzodiazepines as unique barriers to SPC referral.

Previous studies of physicians' views of SPC in other populations suggest physicians who equate SPC with hospice or end-of-life care may be less likely to refer patients to SPC.<sup>10,12,21,22</sup>

A decade ago a multicenter study of 40 lung transplant providers found that many considered palliative care equivalent to end-of-life care.<sup>9</sup> In contrast, transplant pulmonologists in our study distinguished between SPC and hospice care and viewed hospice as only one component of the more broad scope of SPC. Our results suggest that transplant pulmonologists' SPC referral practices may be related to factors other than their understanding of SPC.

Transplant pulmonologists in our study described two distinct views of transplant and two different SPC referral practices. Participants describing transplantation as a temporary solution reported referring to SPC alongside disease-directed therapies, whereas those describing transplantation as survival-focused reported referring after disease-directed therapies were exhausted. One potential explanation is that transplant pulmonologists' beliefs about appropriate post-transplant treatments and goals may influence whether or when SPC referral is offered. Previous work in other settings illustrating associations between physician beliefs and treatment options offered to patients support this interpretation.<sup>23–27</sup> Our finding that some transplant pulmonologists view transplantation as focused on survival and incompatible with SPC is supported by previous studies. First, an international survey of 158 lung transplant providers perceptions of SPC referral barriers for transplant candidates found that many perceived the goals of transplantation and SPC to be contradictory.<sup>14</sup> Second, a small qualitative study of transplant recipients' caregivers and transplant pulmonologists suggested that re-transplantation was the sole focus of care until disease-directed therapies were exhausted.<sup>28</sup> Although previous studies do suggest that transplant recipients prioritize graft survival, understanding the extent to which physicians' views of transplantation and SPC are shared by transplant recipients is an important area for future investigation.<sup>29–33</sup>

We also identified two unique barriers to SPC referral in lung transplantation. First, concerns about decreasing one-year survival rates were described as a reason not to refer to SPC. Risk-adjusted one-year survival is used to judge transplant program quality, and lower than expected survival rates can lead to loss of program accreditation.<sup>34,35</sup> Our results suggest that this metric may discourage SPC referral, despite no evidence that SPC affects mortality.<sup>36</sup> Focus on one-year survival also suggests an implicitly agreed upon approach to post-transplant care akin to surgical “buy-in.”<sup>37,38</sup> “Buy-in” is the informal negotiation of a commitment where surgeons agree to take risk and operate, and patients agree to the postoperative care surgeons deem necessary. In lung transplantation, this implicit negotiation may mean that programs undertake the risks of transplantation and patients agree to care to achieve one-year survival. To our knowledge, this is the first study to identify this concept in lung transplantation.

A second barrier to SPC referral was concerns about use of opioids and benzodiazepines for symptom palliation. Use of chronic opioids is considered a contraindication to re-transplantation at some centers. To our knowledge, this is the first study to identify this as a barrier to SPC referral. Concerns about respiratory depression and addiction are known barriers to using opioids for refractory breathlessness for patients with advanced chronic obstructive pulmonary disease.<sup>39–43</sup> Our results suggest these concerns are shared by transplant pulmonologists and a barrier to SPC referral. One center has successfully used low-dose opiates to manage breathless pretransplantation.<sup>44,45</sup> Other studies suggest chronic post-transplant opioid prescription may be associated with mortality.<sup>46,47</sup> Finally, concerns about addiction may also reflect the impact of the opioid epidemic and increased understanding of the long-term risks of these medications in populations without serious illness. Better communication between SPC and transplant providers about requirements for transplant eligibility and the benefits of these medications may help overcome this barrier.

Our study has limitations. We attempted to recruit a diverse sample of participants from large transplant volume centers; our findings may not reflect the views of participants from lower volume transplant centers, centers that do not have SPC services, or centers outside North America. Although we had a participation rate similar to other studies, our results may not reflect views of transplant pulmonologists who chose not to participate.<sup>12</sup> Our results may not be applicable to the pretransplant setting, which should be a focus of further study. Finally, given the qualitative nature of this study, our finding of associations between different views of transplant and SPC referral practices are exploratory and should be used to inform future quantitative work.

In conclusion, transplant pulmonologists distinguish between SPC and hospice care and describe two different views of transplantation that may be related to different SPC referral practices after lung transplantation. Further work is needed to understand transplant recipients' views of lung transplantation and perceptions of SPC, to understand how SPC providers view their roles in caring for transplant recipients, to define the scope of practice for SPC in lung transplantation, and address issues of access and workforce shortages. Optimizing use of SPC in lung transplantation will require an improving communication between transplant and SPC providers to ensure a collaborative effort to achieve transplant candidates' and recipients' goals.

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## Author Disclosure Statement

No competing financial interests exist.

## Supplementary Material

Supplementary Data



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