Models of Post-Transplant Care for Individuals with Cystic Fibrosis

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Introduction

Cystic fibrosis (CF) is a genetic disease caused by mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene leading to multisystem clinical manifestations. Most people with CF experience progressive lung manifestations and die from respiratory failure or undergo lung transplant. However, CF is a multisystem disorder that also affects the liver, gastrointestinal (GI) tract, sweat glands, sinuses, reproductive system, and pancreas. As adult CF lung transplant recipients experience a median survival of 10 years, these extra-pulmonary manifestations of CF are increasingly important to manage(1). Specifically, nutritional considerations (e.g. weight management, vitamin replacement), GI concerns (e.g. distal intestinal obstructive syndrome, gastroesophageal reflux, gastroparesis), sinus disease, CF-related diabetes, bone health, and mental health warrant specialized attention(2). How to best integrate and manage the non-pulmonary elements of CF care following lung transplantation is a topic of international concern.

There is no consensus on the best model of care for people with CF to manage the non-pulmonary complications that persist after lung transplant. Survey data (Supplement text and Tables S1 and S2) show that most clinicians would find shared care of CF lung transplant recipients to be helpful(3). The most appropriate model for people with CF may depend on many factors including the resources, knowledge, and experience of the transplant center, the CF center, and the individual needs and circumstances of the person with CF. Any care model should be determined through shared decision making between the transplant recipient, family, and CF and transplant care teams. The purpose of this white paper is to review models of care that may be used by centers that look after or share care of lung transplant recipients with CF to provide comprehensive care for this multisystem disease.

Methods

In June 2020, the CF Foundation virtually convened a group of international experts in CF and lung-transplant care. A preliminary literature search was conducted by the CF Foundation prior to this meeting to investigate shared models of post-transplant care. At this meeting, the committee shared the post-lung transplant model of care practiced by their programs, including the strengths and weaknesses of these models. The committee then developed a survey that was distributed internationally to both the clinical and patient/family audience, to determine the strengths, weaknesses, and preferences for various models of post-lung transplant care. A summary of the results of this survey are found in the supplemental materials. Based on the results of this survey, and committee discussion of the strengths and weaknesses of distinct care models, the committee outlined two main models of post-transplant care: i) Fully integrated shared care model between transplant centers and referring CF center and ii) transplant team manages and coordinates all aspects of transplant and CF care.

The committee has outlined the pros and cons of both models, how the model might work in ideal circumstances, and the staffing and/or expertise that would be needed to ensure optimal care within each model.

This white paper was distributed for public comment on February 9, 2022. The public comment period was distributed to international reviewers through the CF Foundation listservs, Community Voice, the ECFS listservs, and the Cystic Fibrosis Medical Association. The committee reviewed and acknowledged and/or addressed each of the comments received during the public comment.

The essential components of multi-disciplinary CF care after lung transplant should be established to ensure that all aspects of this multi-system disease are optimally addressed. Regardless of model, clear communication channels between the CF and transplant care teams should be established. Table 1 summarizes the care needs and expertise required for care of lung transplant recipients with CF. Table 2 outlines some variables for consideration in the identification of the optimal care model for an individual patient.

Table 1: Components of post-transplant cystic fibrosis (CF) care with provider requirements and related consensus statements/standard of care citations.

Component of Care	Provider Requirements	Relevant CF Guideline Citations
General Post-Transplant CF Care	Lung Transplant Physician, Gastroenterologist, Pharmacist, Dietitian, Psychologist/Psychiatrist/Social Worker, Clinic Coordinator, Endocrinologist	Shah P, Lowery E, Chaparro C, Visner G, Hempstead SE, Abraham J, Bhakta Z, Carroll M, Christon L, Danziger-Isakov L, Diamond JM, Lease E, Leonard J, Litvin M, Poole R, Vlahos F, Werchan C, Murray MA, Tallarico E, Faro A, Pilewski JM, Hachem RR. Cystic fibrosis foundation consensus statements for the care of cystic fibrosis lung transplant recipients. J Heart Lung Transplant. 2021 Jul;40(7):539-556. doi: 10.1016/j.healun.2021.04.011. Epub 2021 Apr 22. PMID: 34103223.
Assessments of lung allograft function, recognition and management of pulmonary complications, and management of immunosuppression and side effects	Lung Transplant Physician or Advanced Practice Provider with expertise in lung transplant Pathologist with expertise in lung transplant pathology Timely access to validated clinical laboratory services, including the monitoring of immunosuppression levels	Shah P, Lowery E, Chaparro C, Visner G, Hempstead SE, Abraham J, Bhakta Z, Carroll M, Christon L, Danziger-Isakov L, Diamond JM, Lease E, Leonard J, Litvin M, Poole R, Vlahos F, Werchan C, Murray MA, Tallarico E, Faro A, Pilewski JM, Hachem RR. Cystic fibrosis foundation consensus statements for the care of cystic fibrosis lung transplant recipients. J Heart Lung Transplant. 2021 Apr 22:S1053-2498(21)02283-X. doi: 10.1016/j.healun.2021.04.011. Epub ahead of print. PMID: 34103223. T. O. Hirche, C. Knoop, H. Hebestreit, D. Shimmin, A. Solé, J. S. Elborn, H. Ellemunter, P. Aurora, M. Hogardt, T. O. F. Wagner, and ECORN-CF Study Group. Practical Guidelines: Lung Transplantation in Patients with Cystic Fibrosis. Pulm Med. 2014; 2014: 621342.

Assessment of drug interactions and toxicities, and complex immunosuppression regimens	Transplant Pharmacist	UK Trust: Pharmacy Standards of Care, November 2011 https://www.cysticfibrosis.org.uk/sites/default/files/2020-12/Pharmacy%20standards%20of%20care.pdf
Nutritional assessment for maintaining normal BMI and fat-soluble vitamin levels	Dietician with CF experience	Stallings VA, Stark LJ, Robinson KA, Feranchak AP, Quinton H, Clinical Practice Guidelines on Growth and Nutrition Subcommittee, Ad Hoc Working Group. Evidence-based practice recommendations for nutrition-related management of children and adults with cystic fibrosis and pancreatic insufficiency: results of a systematic review. *J Am Diet Assoc*. 2008 May;108(5):832-9.PMID: 18442507 UK Trust Nutritional Management of Cystic Fibrosis, September 2016 https://www.cysticfibrosis.org.uk/sites/default/files/2020-12/Nutritional%20Management%20of%20cystic%20fibrosis%20Sep%2016.pdf
Mental health assessments and targeted interventions	Social worker, Psychologist, Psychiatrist or Mental Health Coordinator	Quittner AL, Abbott J, Georgiopoulos AM, et al. International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety. *Thorax*. 2016 Jan;71(1):26-34. doi: 10.1136/thoraxjnl-2015-207488. Epub 2015 Oct 9.
Insurance coverage and logistics of care	Social worker Transplant center financial coordinator	
Management of GI disease in CF, including pancreatic insufficiency, GERD, gastroparesis, DIOS, and	Gastroenterologist with significant knowledge and experience with CF	Borowitz DS, Grant RJ Durie PR, the Consensus Committee. Use of pancreatic enzyme supplements for patients with cystic fibrosis in the context of fibrosing colonopathy. *J Pediatr*. 1995; 127:681-84. Hadjiliadis D, Khoruts A, Zauber AG, et al. Cystic Fibrosis Colorectal Cancer Screening Consensus Recommendations. *Gastroenterology*. 2018

colon cancer screening		Feb;154(3):736-745.e14. doi: 10.1053/j.gastro.2017.12.012. Epub 2017 Dec 29.
Management of CF Related Diabetes	Endocrinologist with knowledge and experience with CF-related diabetes and the effects of immunosuppression on glycemic control	Moran A, Brunzell C, Cohen RC, Katz M, Marshall BC, Onady G, Robinson KA, Sabadosa KA, Stecenko A, Slovis B; CFRD Guidelines Committee. Clinical care guidelines for cystic fibrosis-related diabetes: a position statement of the American Diabetes Association and a clinical practice guideline of the Cystic Fibrosis Foundation, endorsed by the Pediatric Endocrine Society. Diabetes Care. 2010 Dec;33(12):2697-708. doi: 10.2337/dc10-1768. PMID: 21115772; PMCID: PMC2992215. UK Trust: Management of Cystic Fibrosis-related Diabetes Mellitus June 2004 https://www.cysticfibrosis.org.uk/sites/default/files/2020-12/Diabetes%20mellitus%20management%20Jun%2004.pdf
Management of Bone health	Endocrinologist or other provider with experience managing bone disease in CF	Tangpricha V, Kelly A, Stephenson A, Maguiness K, Enders J, Robinson KA, Marshall BC, Borowitz D, for the Cystic Fibrosis Foundation Vitamin D Evidence-Based Review Committee. An Update on the Screening, Diagnosis, Management and Treatment of Vitamin D Deficiency in Individuals with Cystic Fibrosis: Evidence-Based Recommendations from the Cystic Fibrosis Foundation. *J Clin Endocrinol Metab.* 2012;97(4):1082-1093. Sermet-Gaudelus I, Bianchi ML, Garabédian M, Aris RM, Morton A, Hardin DS, Elkin SL, Compston JE, Conway SP, Castanet M, Wolfe S, Haworth CS. European cystic fibrosis bone mineralisation guidelines. J Cyst Fibros. 2011 Jun;10 Suppl 2:S16-23. doi: 10.1016/S1569-1993(11)60004-0. PMID: 21658635.
Management of renal disease	Nephrologist with expertise in post-transplant chronic kidney disease	
Management of sinus disease	Otorhinolaryngologist t with knowledge and experience managing CF sinus disease	Kimple A, Senior BA, Naureckas ET et al. Cystic Fibrosis Foundation Otolaryngology Care Multidisciplinary Consensus Recommendations. Int Forum Allergy Rhinol. 2022 **In Press**
Management of Infections	Transplant infectious disease or CF provider with	UK Trust: Laboratory Standards for Processing Microbiological Samples from People with CF. First edition. September 2010

	interest/experience in CF pathogens Lab facilities with experience identifying CF pathogens	https://www.cysticfibrosis.org.uk/sites/default/files/2020-12/Laboratory%20standards.pdf

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55 **Table 2: Factors influencing the selection of a post-transplant CF care model**

Factor	Implications for post-transplant CF care model
Longitudinal care approach at transplant center	Designated longitudinal outpatient care provider with expertise in CF versus group practice model for routine outpatient longitudinal care may affect quality of communication between CF and transplant centers
Geography	Distance to Lung Transplant and CF Centers may influence practicality of follow-up at one versus both centers
Insurance	May limit options for follow-up locations and choice of care providers
Local health care system	Access to tertiary care hospital, primary care providers and appropriate specialists depends on local health care system (related to geography, above)
Financial resources	Out of pocket expenses for costs of care, travel, lodging near Transplant or CF center and availability of resources from fundraising efforts may impact feasibility of either model
Patient preference	Patient's trust and acceptance of their post-transplant model of CF care
Physician preference	Physician's commitment to post-transplant model of CF care and interest/ability to provide longitudinal care
Social Support	Child care needs, employee-employer relationship when taking time off from work, and other social factors may influence feasibility of each model at the individual patient level (related to geography and financial resources, above)

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Models of Care for CF Lung Transplant Recipients.

Based on the post-transplant care requirements in Table 1, the following models of post-transplant care were discussed:

i) Fully integrated shared care model between transplant center and referring CF center
ii) Transplant team manages and coordinates all aspects of transplant and CF care.

The strengths and weaknesses of these different models of care are outlined below and shown in Table S3. Regardless of the model of care chosen, there was consensus that:

i) Lung transplant team should manage the pulmonary complications of lung transplantation indefinitely,
ii) Timely and clear communication between the transplant team and the referring CF center is essential, and
iii) Both models of care have strengths and weaknesses, each is a viable option, and the choice should be individualized based on factors listed in Table 2.

Model 1: Fully Integrated Shared Care Model between Transplant Center and Referring CF Center.

In this model of care, CF transplant recipients will attend their transplant center for all transplant-related issues, predominantly pulmonary complications and complications related to immunosuppression (Figure 1, Table 3). For the non-transplant related conditions and the extra-pulmonary complications of CF, recipients will continue to be managed by their CF center, either at the referring center or another CF care center.

Effective communication between the CF and post-transplant teams is essential and, optimally, should be established prior to transplant. Intentional, formal communication between the teams should be continued indefinitely after transplant for routine elements of post-transplant care, such as social work, endocrinology, GI, and other subspecialty care.

Pre-Transplant: The CF team, in conjunction with the transplant team, helps with preparing the individual with CF and his/her family for identification, prevention, and treatment of the following common complications that can occur around the time of transplant:

- Distal intestinal obstruction syndrome (DIOS)
- Gastroparesis
- Diabetes: identification, monitoring, and management of hyper/hypoglycemia
- Sinus disease
- Mental health concerns

Immediate Post-Transplant Period: To avoid overwhelming the patient and family during the demanding early post-transplant period, the CF team should be engaged only if acute CF-related issues requiring prompt attention develop (e.g. DIOS, newly diagnosed diabetes).

Post-Transplant: At one to three months after transplant, the CF team should receive a complete summary from the lung transplant team about the transplant, current issues, complications, and main medical aspects that require longitudinal follow-up. Ideally, a post-transplant CF clinic appointment would occur in parallel with the post-lung transplant schedule within 6 months following transplant.

Beyond the first 1-2 years after transplant, this could be operationalized as quarterly visits, split between the CF and transplant teams, with telehealth as an option for stable patients. Patients may also need to attend their local CF center prior to 6-months post-transplant or visit their specialty provider with CF experience for input from non-pulmonary specialists such as endocrinology, GI, and ENT.

Pros and cons, ideal circumstances, required expertise, and limitations of this model of shared CF care are outlined in Table 4.

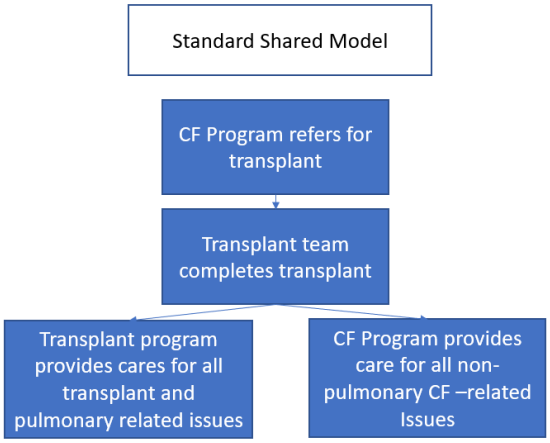

Figure 1: Fully Integrated Shared Care Model between Transplant Center and Referring CF Center

Geographic Considerations: One of the benefits of this model is the improved management of CF transplant recipients who live a distance from their transplant center, which may constrain routine travel to the transplant center. While not ideal, for these patients, closer follow-up in the referring CF center may be the only option, even for transplant-related complications. In this setting, the transplant center, after the acute period post-transplant has elapsed, reviews the patient routinely with the CF team and sees the recipient less frequently. For transplant-related complications occurring between transplant visits, the patient could attend their local CF center and receive their transplant-related complication management from the CF team, in close liaison with the transplant center. This would require a named CF physician in the CF center with interest and experience in transplant medicine including procedures and skills outlined in Table S4. This requires close communication between the CF physician and transplant team, as recommended in this fully integrated shared model of CF care. Transplant-related complications that could not be managed in the local CF center would result in prompt transfer of the patient to a transplant center. As outlined already, the patient would attend the CF center, in parallel with their lung transplant visits, for all non-transplant related complications of CF. In the case of geographic barriers to routine transplant center follow-up, it may be of benefit for the transplant team to provide the CF team with up to date education on current practice in transplant medicine.

Table 3: Proposed roles and responsibilities under Model 1: Fully integrated Shared Care for Management of Post-transplant and CF Related Complications in CF Lung Transplant Recipients.

Team	Aspects	Medication Adjustment and Prescription
Lung Transplant	Pulmonary Decline in spirometry Symptoms Radiographic changes (e.g. chest x-ray, CT chest) Transplant Immunosuppression management (e.g. therapeutic drug monitoring) Rejection concerns (e.g. bronchoscopy with transbronchial biopsies; treatment decisions) Safety monitoring with labs (e.g. creatinine, complete blood count, liver enzymes) *Malignancy screening Infection Pulmonary *Sinus Transplant-related (e.g. CMV) *Mental health concerns *Social work needs	Immunosuppression Treatment for rejection Prophylactic/treatment antibiotics
Cystic Fibrosis	Endocrinology Diabetes Bone Health Gastroenterology/Hepatology Nutrition (e.g. weight, vitamin levels) Gastroparesis DIOS *Colorectal cancer screening Liver Disease *Mental health concerns *Social work needs *Sinus disease	Insulin and other diabetes management Treatment for bone disease GI medications, including pancreatic enzyme replacement therapy Vitamins Chronic sinus management
***May be shared between CF and transplant teams, as outlined by local expectations for responsibilities**		

Model 2: Transplant team manages and coordinates all aspects of transplant and CF care.

In this model, all components of CF multi-disciplinary care are located at the transplant center. While limited to a few transplant centers, the ideal circumstance is that the primary longitudinal physician overseeing CF lung transplant recipients has expertise in both lung transplant and CF such that they are

competent to address all aspects of routine post-transplant and CF-related care and make referrals to appropriate consultants when needed (Table S3).

Ideal lung recipients for this model live near the transplant center and would have been referred for transplant by a nearby CF program or a CF program at the same institution, in some cases with shared overlapping providers and staff with expertise in both CF and lung transplant. In institutions with CF and transplant centers in the same hospital, there are often multi-disciplinary care team members who know the transplant recipient from their pre-transplant care and can provide longitudinal input that spans the pre- and post-transplant time periods. A good example of this is a CF dietician who has time allocated to help manage post-transplant nutritional needs. Communication between the CF team and post-transplant teams, optimally established prior to transplant, can be continued after transplant for consultation on other elements of post-transplant care, such as social work, endocrinology, and other subspecialty care, even if the transplant team is managing all aspects of CF care.

Communication

In 2016, the US CF Foundation launched the CF Lung Transplant Initiative (CFLTI) which aims to maximize the opportunity for transplant as a life-sustaining therapy, extend post-transplant survival, and improve quality of life for individuals with CF. To inform the direction of the CFLTI, the CF Foundation created and funded a Consortium of academic transplant centers dedicated to improving lung transplantation outcomes and establishing a robust clinical research infrastructure. Based largely on feedback from individuals with CF and their families, a primary focus of the CF Lung Transplant Consortium (CFLTC) Quality Improvement (QI) efforts is to improve the transplant journey, particularly, the experience of transition from CF center care to transplant center care and subsequent shared post-transplant care. To support this aim and foster a culture of effective, ongoing QI at CFLTC sites, the CF Lung Transplant Transition Learning and Leadership Collaborative (LTT LLC) and Regional Dissemination Network (RDN) were established. Through the CF LTT LLCs and RDN, transplant centers work in partnership with referring CF Care Centers to improve communication, education, and relationships between CF and Lung Transplant Care Teams. This QI network has expedited the implementation of recently published CF and transplant-focused clinical guidelines and sharing of best practices for treatment of CF advanced lung disease before and after lung transplantation.

This work organically evolved to focus not just on the initial transition through the transplant referral process, but shared care between CF centers and transplant centers after transplant. Several key themes persist in optimizing the lung transplant journey from referral through post-transplant management including communication between the CF and transplant teams; establishment of relationships between CF and transplant care providers; development and exchange of discipline-specific education tools between CF and transplant teams; inclusion of individuals with CF and their support persons in CF and transplant QI teams.

Best practices identified through the QI work include:

- Regularly scheduled virtual meetings between CF and transplant programs (quarterly or monthly)
- Virtual monthly educational teaching sessions for CF and transplant teams - each month focuses on a different topic and is presented by an 'expert' in the field from one of the centers (CFRD, GI/Nutrition, Chronic rhinosinusitis, optimizing medications in the post-transplant CF patient, etc.)
- "Refer back" form or a post-transplant handoff sheet
- Create and provide contact list of transplant care team members to CF care team and vice versa
- Co-management of post-lung transplant patient document - describes what tests and support are required after transplant and who is responsible

Expertise and Continuing Medical Education

CME is available for CF and lung transplant providers and teams interested in learning more about special considerations for caring for individuals with CF who undergo lung transplantation. The most comprehensive information is available through the Division of Continuing Medical Education at the

Indiana University (IU) School of Medicine, with sponsorship from the Cystic Fibrosis Foundation and in partnership with IU eLearning and Design Services (https://medicine.iu.edu/cme/specialized/cystic-fibrosis). These CME courses are intended to support CF team physicians and interprofessional team members in their efforts to provide the most up to date care for individuals with cystic fibrosis. In addition to formal CME programs, the CF Foundation also convened a multidisciplinary working group that developed guidelines on post-transplant care for individuals with cystic fibrosis(2). The North American Cystic Fibrosis Conference and European Cystic Fibrosis Society annual meetings also provide excellent education for multi-disciplinary CF Care.

Pediatric Considerations

Since it is common for the pediatric transplant center and CF center to be geographically distanced, ongoing, intentional communication between the referring CF center and the transplant team is of the utmost importance. While local CF teams can contribute to the evaluation of patients at the time of an acute illness, support ongoing pulmonary surveillance (e.g., pulmonary function tests), obtain respiratory viral samples when indicated, and manage other ongoing complications of CF (e.g., endocrine, GI), it remains critical to coordinate management with the transplant team. Since there are no clear transplant-specific recommendations for nutrition in pediatric CF transplant recipients, the patient's local CF dietitian can provide ongoing guidance.

Patient Preferences

The logistics behind patients receiving efficient and effective care can be extremely complex. While a health care provider may structure their program(s) based on available resources, patients do not typically have the luxury of choosing many options and may be limited predominantly by two factors: geography and insurance.

From a patient's perspective there are advantages and disadvantages to each model.
With respect to Model 1, the fully integrated shared care model, where the transplant center manages all post-transplant care with a CF team managing non-transplant related CF manifestations, the advantage is that the patient will have the expertise of both trusted CF specific practitioners and transplant practitioners. If the CF team and the transplant teams are distinct, a major advantage is having input from specialized care teams with extensive experience in lung transplant or CF. While this model allows for members of the CF team that are more familiar with the transplant recipient to continue care, the time and travel burden may be considerable.

Another challenge to Model 1, the fully integrated shared care model, is communication for various needs. This model requires delineation of first contact for transplant or CF-related concerns, which may not obviously fall to the transplant or CF program. CF and transplant concerns are often interrelated. Transplant recipients are best served by having a plan for communication based on the preferences of the transplant and CF programs.

In Model 2, where the patient has one CF Transplant team, the main advantage is obvious: ease of care and having one point person oversee all issues and concerns. Also, this facilitates building core relationships, which means not having to provide the same information to multiple providers. With

respect to cost, insurance may dictate who can provide care; patients who have private health insurance are compelled to use only those programs that are covered so having care at one institution is simpler for insurance coverage.

Crucial to either care model is the relationship recipients develop with each individual team member. Whether that consists of one cohesive team at one hospital with one point of contact, two separate teams at two different hospitals, or a combination of the two, communication between all team members must strive to be as open and streamlined as possible and that must also include the recipient, whose responsibility is to communicate concerns clearly and concisely and to consider the opinion and direction of all team members to make the best possible decisions and to ensure the most efficient and effective care.

Conclusion

Care of CF manifestations in lung transplant recipients should follow best practices in the management of the non-pulmonary aspects of CF. Two models are proposed to accomplish optimal CF care after transplant. The first model incorporates the CF team into the care of CF lung transplant recipients and proposes delineation of responsibilities for the CF and transplant teams. Model 1 is reliant on outstanding communication between the teams, while leveraging the expertise of the CF team for management of the non-pulmonary manifestations of CF. The transplant team manages all aspects of the transplant, including pulmonary concerns and management of immunosuppression. The second model may be more practical for transplant programs that have expertise managing CF and have access to CF multidisciplinary care team members (e.g., located in the same institution). In either model, CF lung transplant recipients require a clear delineation of the roles and responsibilities of their providers and mechanisms for effective communication.

Supplement:

1. Results of Survey

Supplemental material

Models of Post-Transplant Care for Individuals with Cystic Fibrosis: Survey Results

Methods:

A survey was distributed internationally to both clinicians and individuals with CF/families to determine the strengths, weaknesses, and preferences for various models of post-lung transplant care. The survey was distributed on November 2, 2020 to: CF Foundation listservs, Community Voice, the European CF Society listservs, and the International Society for Heart and Lung Transplantation listserv.

Results:

We received responses to the survey from 225 clinicians (CF and Transplant Clinicians n=45; CF Clinicians n=142; Transplant Clinicians n=38) and responses are shown in Supplemental Table 1. We received 129 patient and family survey responses (North America n=46; Europe n=64; Other locations n=19) and responses are shown in Supplemental Table 2.

Clinicians identified two major barriers to shared care: a lack of communication between CF and transplant teams and unclear roles and responsibilities between them (Figure 1). More CF clinicians than transplant clinicians felt there was a lack of expertise in CF on the transplant teams; when asked about a lack of lung transplant expertise on the CF teams more transplant clinicians endorsed this than did CF clinicians. Only 15% of CF physicians had transplant education provided by the transplant team, and 14% of transplant physicians said the CF team provided them with CF education. About a quarter of clinicians surveyed thought there were no barriers to shared care.

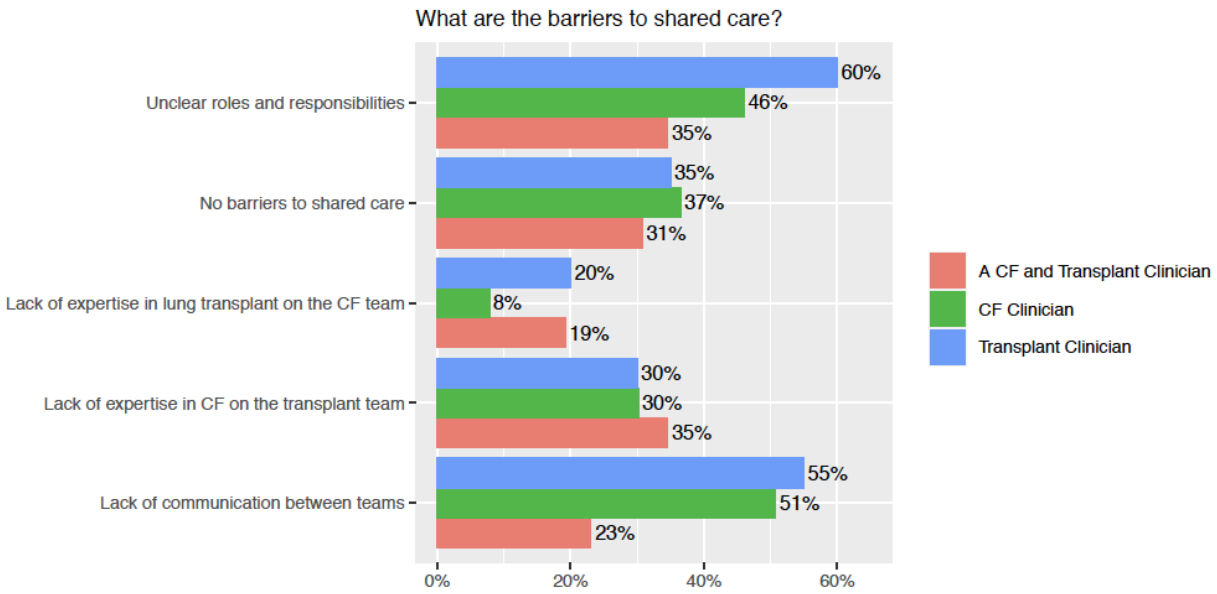

Figure 1: Clinician identified barriers to shared care. Survey participants were allowed to select all options that applied.

Shared care is desirable, a sentiment endorsed more frequently among CF clinicians (95%) than transplant clinicians (81%). Most respondents reported that they would like to have the CF team manage non-pulmonary aspects of care while the transplant team manages the pulmonary and immunosuppression aspects (Figure 2).

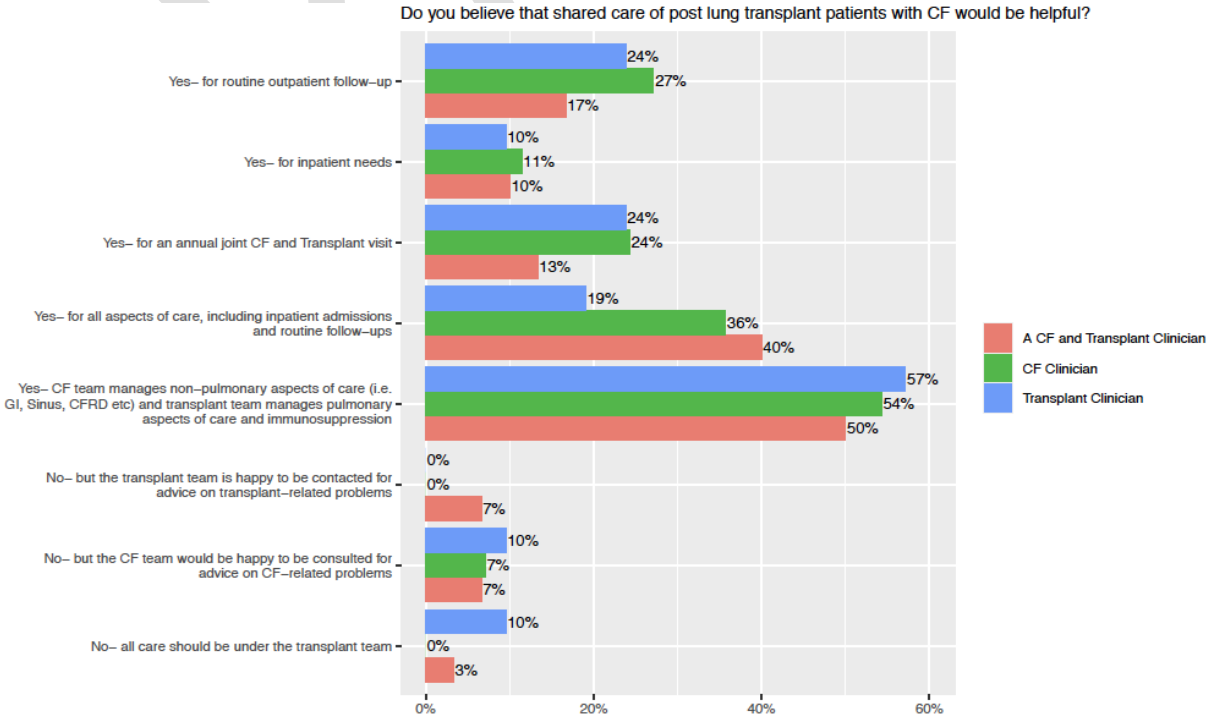

Figure 2: Clinician preferences for a model of shared care.

Clinicians were allowed to select from several options describing how the ideal model of shared post-transplant care could work, and all of the presented options had a reasonable amount of support (Figure 3). While clinicians identified a lack of communication and unclear roles and responsibilities as barriers to shared care, the two options for ideal models that were most often selected identified clear communication channels between CF and transplant teams and have both sides understand protocols and expectations across teams.

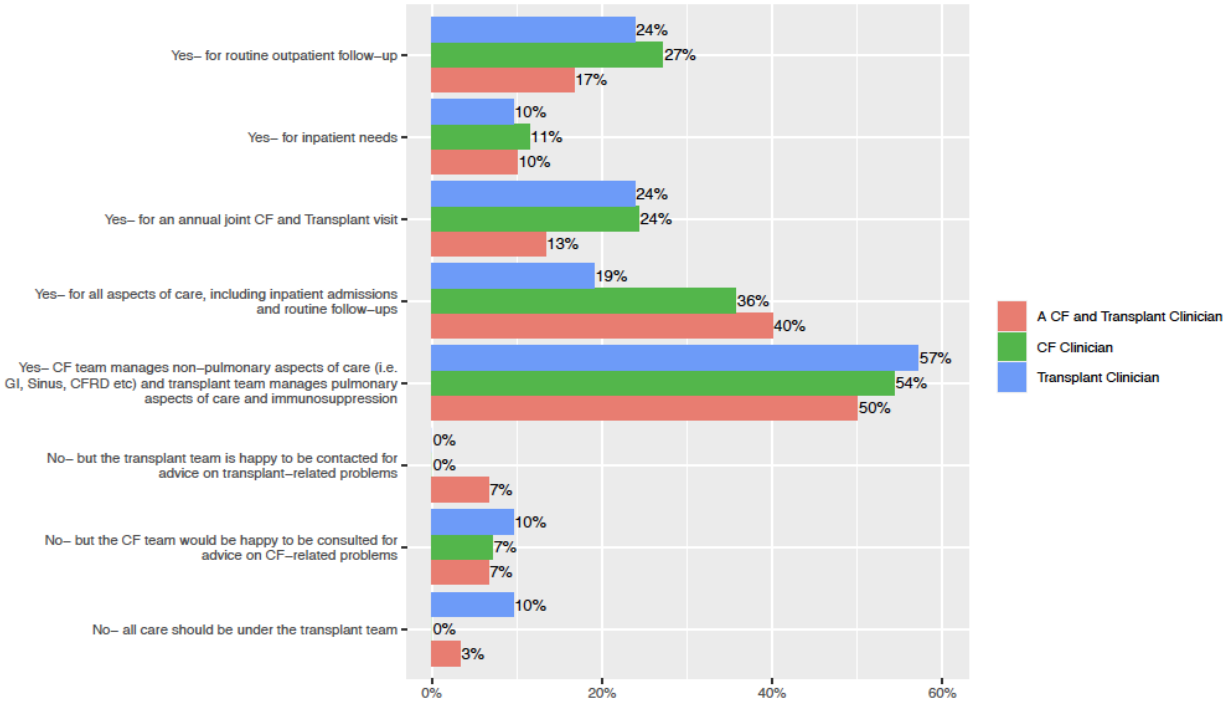

Figure 3: Clinician options for an ideal model of shared care.

In addition to CF and transplant clinicians, individuals with CF and their families were asked what their ideal model of shared post-transplant care would be (Figure 4). Almost all the presented options received noticeable support, with the exception of having the transplant team refer them back to the CF team for extra pulmonary complications. Notably, a large proportion (approximately 40%) of individuals with CF and their families endorsed wanting mental health care available pre and post-transplant.

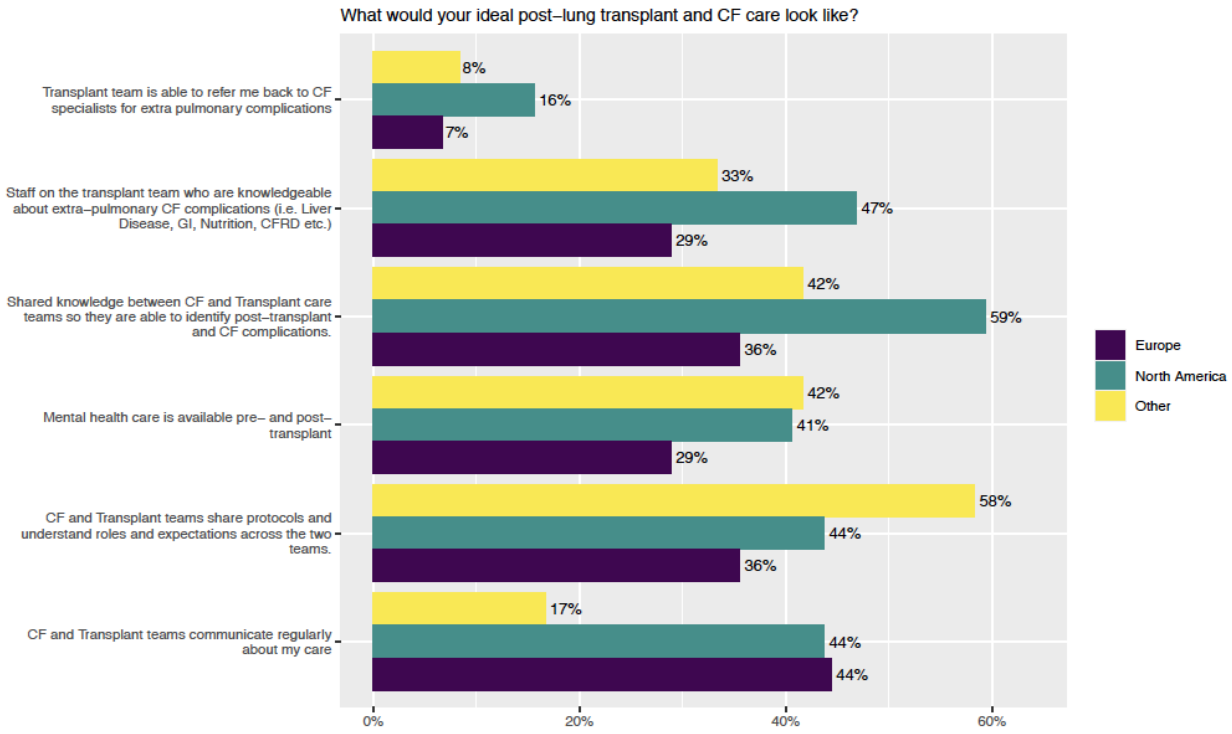

Figure 4 Individuals with CF and their families' ideal model of shared care

Individuals with CF and their families were asked about concerns related to shared care after transplant (Figure 5). Similar to clinicians, individuals with CF and their families reported concerns about communication and understanding roles and responsibilities (e.g. knowing who to contact with a problem or question). Interestingly, lack of proper infection control and mixing with the pre-transplant CF population were frequent concerns for survey respondents. Travel to the site for care was also a common concern for individuals with CF and their families.

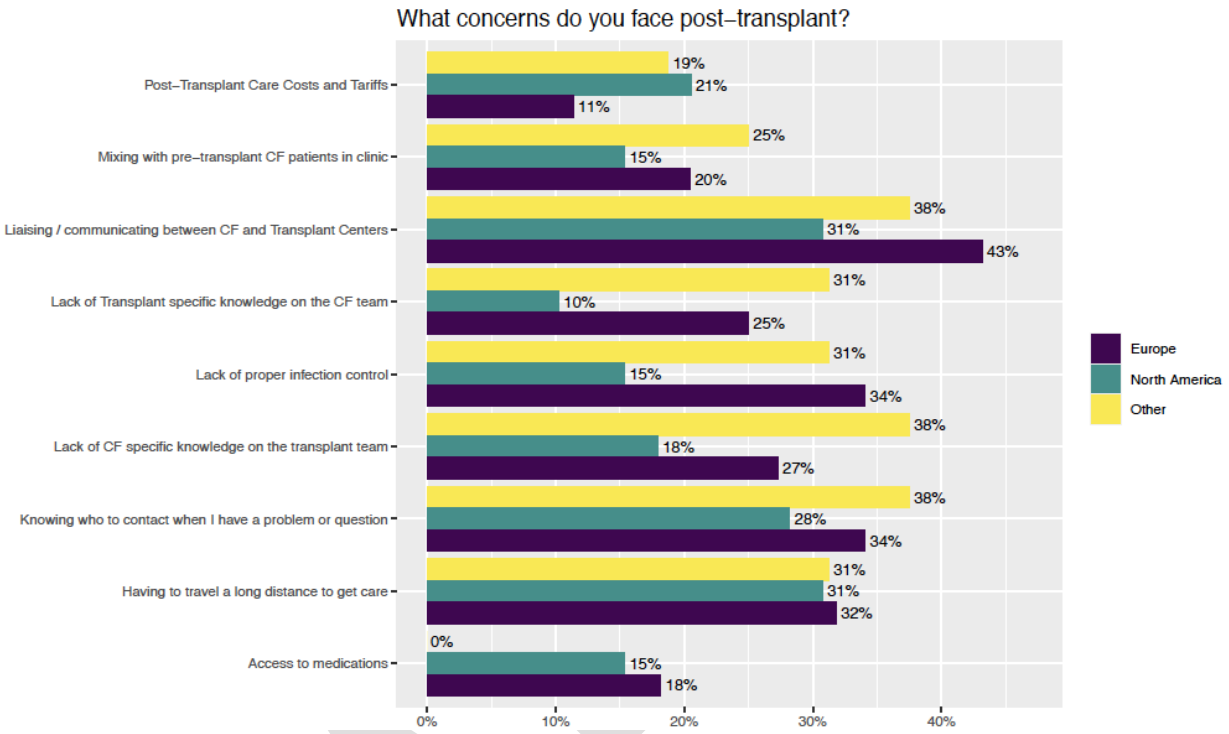

Figure 5 Individuals with CF and their families' concerns after transplant

Granular survey data

Supplemental Table 1: Physician data

	CF and Transplant Clinicians (n=45)	**CF Clinicians (n=142)**	**Transplant Clinicians (n=38)**
How long have you been providing care for individuals with CF?			
0-5 years	7 (16%)	28 (20%)	7 (18%)
6-12 years	12 (27%)	39 (27%)	15 (39%)
13-20 years	9 (20%)	33 (23%)	9 (24%)
> 20 years	17 (38%)	42 (30%)	5 (13%)
How do you most often care for individuals with CF post-lung transplant?			
Ad hoc through consults post-transplantation (i.e. another provider/care team contacts you for advice)	2 (5%)	2 (2%)	3 (8%)
As needed for non-pulmonary aspects of care only (i.e. diabetes, sinuses, GI, mental health)	0 (0%)	12 (11%)	1 (3%)
At an annual, outpatient visit	1 (2%)	19 (18%)	0 (0%)
At outpatient visits 2 or more times/year as needed	13 (30%)	57 (54%)	17 (45%)
Occasionally when they are hospitalized (i.e. you care for them when they are hospitalized)	4 (9%)	5 (5%)	2 (5%)
Other	24 (53%)	11 (10%)	15 (39%)
What is your current practice?			
CF Team assumes all responsibility post-lung transplant	2 (5%)	6 (4%)	0 (0%)
CF Team manages non-pulmonary issues (GI, CFRD, Sinus) and Transplant teams manage pulmonary and immunosuppression	12 (27%)	71 (53%)	7 (18%)
Transplant team manages all aspects of care	18 (41%)	30 (22%)	25 (66%)
Other (please specify)	12 (27%)	27 (20%)	6 (16%)
Where do you spend the majority of your time? (If a CF and Transplant Clinician)			
In CF	12 (28%)	--	--
In Transplant	11 (26%)	--	--

Shared	20 (47%)	--	--
What is your role?			
Dietician	3 (7%)	13 (9%)	--
Internist	0 (0%)	5 (4%)	--
Nurse	0 (0%)	10 (7%)	--
Nurse Practitioner/ Physician Assistant	2 (5%)	13 (9%)	--
Physical Therapist	3 (7%)	2 (1%)	--
Psychologist	1 (2%)	4 (3%)	--
Pulmonologist	25 (57%)	57 (41%)	--
Respiratory Therapist	0 (0%)	4 (3%)	--
Social Worker	2 (5%)	11 (8%)	--
Other	8 (18%)	20 (14%)	--
How many individuals are seen at your CF Program?			
< 50	0 (0%)	7 (5%)	--
50-99	8 (19%)	30 (22%)	--
100-149	11 (26%)	31 (22%)	--
150-250	9 (21%)	32 (23%)	--
>250	15 (35%)	39 (28%)	--
Does your CF program include post-transplant patients in the total CF patient count?			
Yes	30 (70%)	100 (72%)	--
No	10 (23%)	31 (22%)	--
Unknown	3 (7%)	7 (5%)	--
How many post-transplant patients are seen at your CF center?			
0-10	15 (35%)	77 (56%)	--
11-50	16 (37%)	42 (31%)	--
51-100	6 (14%)	5 (4%)	--
> 100	4 (9%)	1 (1%)	--
Don't Know	2 (5%)	12 (9%)	--
How many individuals with CF, post-lung-transplant, are seen at your transplant program?			
0-10	7 (16%)	--	2 (5%)
11-50	20 (47%)	--	11 (29%)
51-100	10 (23%)	--	13 (34%)
> 100	3 (7%)	--	12 (32%)
Don't Know	3 (7%)	--	0 (0%)

How satisfied are you with the current arrangements post-lung transplant between your CF and transplant center? (mark only one)			
Very Unsatisfied	1 (2%)	7 (5%)	0 (0%)
Moderately Unsatisfied	3 (7%)	31 (24%)	9 (25%)
Neutral	2 (5%)	26 (20%)	4 (11%)
Moderately Satisfied	16 (36%)	31 (24%)	14 (39%)
Very Satisfied	16 (36%)	18 (14%)	9 (25%)
Other	6 (14%)	18 (14%)	0 (0%)
For the majority of your patients with CF, do you continue to provide care post- lung transplant?			
Our CF program does not routinely provide care for our CF patients after transplant	7 (18%)	33 (25%)	--
Our CF program is updated by the transplant team about care, but do not share care	10 (25%)	8 (6%)	--
Our CF program provides the majority of care after transplant	0 (0%)	3 (2%)	--
Our CF program shares care with the transplant team after transplant	19 (48%)	84 (65%)	--
Other (please specify)	4 (10%)	2 (2%)	--
For the majority of your patients with CF, how involved are you in care post-transplant?			
Our transplant program provides the majority of care after transplant	--	--	29 (76%)
Our transplant program shares care with the CF team after transplant	--	--	8 (21%)
Other (please specify)	--	--	1 (3%)
Focusing on post-transplant, how do you communicate with the Lung Transplant Program/CF Center you work with the most about shared patients? (Check all that apply)			
Routine face-to-face meetings with both teams	19 (48%)	14 (11%)	6 (17%)
Routine phone/video calls	8 (20%)	13 (10%)	5 (14%)
Routine emails between the teams	17 (42%)	26 (20%)	8 (22%)
Meeting only when the need arises	3 (8%)	23 (18%)	9 (25%)
Phone/video calls only when a need arises	7 (18%)	56 (43%)	20 (56%)
Email correspondences only when the need arises	13 (32%)	71 (55%)	21 (58%)
Patient acts as the messenger	5 (12%)	29 (22%)	7 (19%)
Virtual multidisciplinary team clinics (MDT)	4 (10%)	5 (4%)	0 (0%)
Sharing Medical Records	15 (38%)	60 (46%)	21 (58%)

Other	9 (22%)	16 (12%)	3 (8%)
None	1 (2%)	7 (6%)	1 (3%)
Does the transplant team you work with most often have clinicians who specialize in CF?			
Yes	34 (85%)	73 (56%)	13 (35%)
No	5 (12%)	39 (30%)	22 (59%)
Unknown	1 (2%)	18 (14%)	2 (5%)
How does your team remain current on transplant care? (Check all that apply)			
CF/Transplant team provides education for the Transplant/CF team	10 (25%)	20 (15%)	5 (14%)
Transplant team has a liaison with the CF team who advises us on transplant matters	21 (52%)	32 (24%)	14 (38%)
The CF/Transplant team does not have transplant/CF education	7 (17%)	73 (56%)	12 (32%)
Other	6 (15%)	22 (17%)	6 (16%)
Do you have a model of post-lung transplant CF care that you feel works well?			
Yes	33 (82%)	45 (35%)	27 (73%)
Ideally, who should take responsibility for CF post- lung transplant care? (Check all that apply)			
The transplant team manages all care straight away and continues long term ("one stop shop")	7 (18%)	11 (10%)	9 (30%)
The transplant team takes responsibility for all care short term (i.e. the first year) and then shares care with the CF team long term (transplant team manages pulmonary issues and immunosuppression; CF team manages non-pulmonary issues)	15 (39%)	61 (54%)	13 (43%)
The transplant and CF teams share responsibility straight away (transplant team manages pulmonary issues and immunosuppression; CF team manages non-pulmonary issues)	16 (42%)	52 (46%)	11 (37%)
Other	5 (13%)	12 (1%)	1 (3%)
Do you believe that shared care of post lung transplant patients with CF would be helpful? (check all that apply)			
Yes- for all aspects of care, including inpatient admissions and routine follow-ups	15 (39%)	54 (48%)	10 (33%)
Yes- for inpatient needs	6 (16%)	15 (13%)	3 (10%)
Yes- for routine outpatient follow-up	7 (18%)	27 (24%)	6 (20%)

Yes- for an annual joint CF and Transplant visit	9 (24%)	27 (24%)	9 (30%)
Yes- CF team manages non-pulmonary aspects of care (i.e. GI, Sinus, CFRD etc)	16 (42%)	59 (52%)	17 (57%)
Yes- transplant team manage pulmonary aspects of care and immunosuppression	14 (37%)	52 (46%)	10 (33%)
No- but the CF team would be happy to be consulted for advice on CF-related problems	4 (11%)	11 (10%)	3 (10%)
No- but the transplant team is happy to be contacted for advice on transplant-related problems	3 (8%)	0 (0%)	0 (0%)
No- all care should be under the transplant team	1 (3%)	0 (0%)	5 (17%)
Other	7 (18%)	5 (4%)	3 (10%)
Do you see telehealth playing a role in your ideal model of care for post transplant patients?			
Yes	32 (84%)	97 (86%)	25 (83%)
Do you continue to enter data into your country's (and/or the ECFS) CF Patient Registry on patients post-lung transplant long term?			
Never	3 (8%)	7 (6%)	2 (6%)
Sometimes	0 (0%)	2 (2%)	3 (10%)
Most of the Time	3 (8%)	10 (9%)	4 (13%)
Always	18 (47%)	52 (46%)	5 (17%)
Only those we see for annual review	0 (0%)	4 (4%)	0 (0%)
Only those we see regularly	2 (5%)	13 (12%)	0 (0%)
We do not have a CF Patient Registry	0 (0%)	1 (1%)	2 (7%)
Unknown	10 (26%)	22 (20%)	12 (40%)
Other (please specify)	2 (5%)	1 (1%)	2 (7%)
What challenges do you face when looking after CF patients post-lung transplant (check all that apply)?			
Lack of proper infection control in the outpatient setting	3 (9%)	8 (7%)	11 (38%)
Infection control in the inpatient setting	2 (6%)	8 (7%)	6 (21%)
Managing patient expectations	12 (35%)	32 (30%)	12 (41%)
Lack of communication between the CF and transplant teams	12 (35%)	61 (57%)	14 (48%)
Post-transplant CF patients mixing with pre-transplant CF patients	7 (21%)	17 (16%)	5 (17%)
Access to medications	4 (12%)	16 (15%)	4 (14%)
Deciding who is the primary care center post-transplant	2 (6%)	28 (26%)	1 (3%)

Other	12 (35%)	24 (22%)	10 (34%)
Most often, when patients with CF receive post-lung transplant care:			
The CF program and transplant program are at separate institutions and located at a physical distance from each other	8 (21%)	69 (61%)	14 (47%)
The CF program and transplant program are at separate institutions but located physically close to each other	2 (5%)	10 (9%)	2 (7%)
The CF program and transplant program are in the same institution	28 (74%)	35 (31%)	14 (47%)
What are the barriers to shared care? (Check all that apply)			
Unclear roles and responsibilities	12 (32%)	37 (41%)	13 (41%)
Lack of communication between teams	9 (24%)	46 (51%)	14 (44%)
Lack of expertise in CF on the transplant team	10 (27%)	28 (31%)	6 (19%)
Lack of expertise in lung transplant on the CF team	12 (32%)	8 (9%)	7 (22%)
No barriers to shared care	9 (24%)	31 (34%)	9 (28%)
What would your ideal shared care model look like? (Check all that apply)			
CF And Transplant teams share, understand protocols, and expectations across multidisciplinary teams	25 (68%)	55 (60%)	14 (44%)
Shared knowledge between Transplant and CF physicians to be able to identify post-transplant complications	16 (43%)	40 (44%)	13 (41%)
Member(s) of transplant team are knowledgeable on non-pulmonary CF complications (i.e. Hepatology, Gastroenterology, Nutrition, Endocrinology)	16 (43%)	32 (35%)	16 (50%)
Clear communication channels between CF and transplant that are regularly used	21 (57%)	63 (69%)	14 (44%)
Defined roles and responsibilities between teams	16 (43%)	49 (54%)	13 (41%)
Staff member liaison to ensure consistent care between pre- and post-transplant care (i.e. mental health, gastroenterology, endocrinology)	18 (49%)	40 (44%)	9 (28%)
Transplant Teams refer back to the CF expertise for non-pulmonary complications (i.e.	15 (41%)	43 (47%)	12 (38%)

Otolaryngology, Gastroenterology, Hepatology, Endocrinology)

Supplemental Table 2: Individuals with CF

	Other (n=19)	**North America (n=46)**	**Europe (n=64)**
I am:			
Personally living with CF and had a transplant	13 (68%)	38 (83%)	55 (86%)
The loved one of someone living with CF who has had a transplant	6 (32%)	8 (17%)	9 (14%)
Who do you/loved one primarily see for their care?			
Both CF and Transplant teams about equally	3 (16%)	10 (22%)	15 (23%)
CF Team	1 (5%)	2 (4%)	10 (16%)
Transplant Team	15 (79%)	34 (74%)	36 (56%)
Other	0	0	3 (5%)
When did you/loved one receive their lung transplant?			
Less than 1 year ago	4 (21%)	2 (4%)	2 (3%)
1-5 years ago	6 (32%)	25 (54%)	22 (34%)
6-10 years ago	4 (21%)	10 (22%)	16 (25%)
More than 10 years ago	5 (26%)	9 (20%)	24 (38%)
Which of the following best represents how your CF and transplant teams communicate?			
I am the go between for my CF and transplant teams	4 (21%)	9 (21%)	13 (21%)
My CF and Transplant teams communicate frequently	5 (26%)	19 (44%)	29 (50%)
My CF and Transplant teams communicate infrequently	3 (16%)	8 (19%)	6 (10%)

I do not know if/how my CF and transplant teams communicate	8 (42%)	11 (26%)	11 (19%)
Is there anyone on your transplant team who specializes in CF?			
Yes	12 (67%)	30 (70%)	34 (58%)
No	4 (22%)	8 (19%)	12 (20%)
I Don't Know	2 (11%)	5 (12%)	13 (22%)
Did Not Respond	1	3	5
Is there anyone on your CF team who specializes in lung transplant?			
Yes	10 (53%)	50 (53%)	24 (41%)
No	4 (21%)	11 (26%)	19 (33%)
I Don't Know	5 (26%)	9 (21%)	15 (26%)
Did Not Respond	0	3	6
How satisfied are you with how your post-transplant care is currently managed between your CF and transplant teams?			
Very Satisfied	7 (39%)	20 (47%)	31 (53%)
Moderately Satisfied	5 (28%)	11 (26%)	15 (26%)
Neutral	3 (17%)	6 (14%)	8 (14%)
Moderately Unsatisfied	2 (11%)	5 (12%)	2 (3%)
Very Unsatisfied	1 (6%)	1 (2%)	2 (3%)
Did Not Respond	1	3	6
Ideally, who should take responsibility for your (individual living with CF)/your loved one with CF's post-transplant CF care?			
The transplant team should take responsibility for all care straight away, and continue all care long term ("one stop shop")	6 (33%)	11 (25%)	6 (12%)

The transplant team should take responsibility for all care short term (i.e. in the first year) and then shares care with the CF team long term (transplant team manages pulmonary issues and immunosuppression; CF team manages non-pulmonary issues i.e. DIOS, CFRD, Sinus Disease)	8 (44%)	12 (27%)	18 (35%)
The Transplant and CF teams should share responsibility right away (transplant team manages pulmonary issues and immunosuppression; CF team manages non-pulmonary issues i.e. DIOS, CFRD, Sinus Disease)	3 (17%)	20 (45%)	24 (46%)
Other (please specify)	1 (6%)	1 (2%)	4 (8%)
Did Not Respond	1	2	12
What concerns do you face post-transplant (please select all that apply):			
Lack of proper infection control	5 (26%)	6 (13%)	15 (24%)
Liaising / communicating between CF and Transplant Centers	6 (32%)	12 (26%)	19 (30%)
Mixing with pre-transplant CF patients in clinic	4 (21%)	6 (13%)	9 (14%)
Access to medications	0 (0%)	6 (13%)	8 (13%)
Knowing who to contact when I have a problem or question	6 (32%)	11 (24%)	13 (22%)
Post-Transplant Care Costs and Tariffs	3 (16%)	8 (17%)	5 (8%)
Having to travel a long distance to get care	5 (26%)	12 (26%)	14 (22%)
Lack of CF specific knowledge on the transplant team	6 (32%)	7 (15%)	12 (19%)
Lack of Transplant specific knowledge on the CF team	5 (26%)	4 (9%)	11 (17%)
Other	5 (26%)	10 (22%)	3 (5%)
Did Not Respond	3	7	20

When I (an individual with CF)/ my loved one with CF receives post-transplant care:

The CF Program and Transplant Program are in the same institution	8 (44%)	27 (61%)	23 (49%)
The CF Program and Transplant Program are located at a physical distance from each other	6 (33%)	5 (11%)	14 (30%)
The CF Program and Transplant Program are at separate locations but located physically close to each other	1 (6%)	9 (20%)	5 (11%)
I don't know	3 (17%)	0 (0%)	2 (4%)
Other (please specify)	0 (0%)	3 (7%)	3 (6%)
Did Not Respond	1	2	17
How satisfied or unsatisfied are you with your overall CF and post transplant care?			
Very Satisfied	6 (33%)	22 (50%)	19 (41%)
Moderately Satisfied	5 (28%)	10 (23%)	12 (26%)
Neither Satisfied or Unsatisfied	2 (11%)	2 (5%)	1 (2%)
Moderately Unsatisfied	2 (11%)	6 (14%)	9 (20%)
Very Unsatisfied	3 (17%)	4 (9%)	5 (11%)
Did Not Respond	1	2	18
What would your ideal post-lung transplant and CF care look like? (select up to your top 3)			
CF and Transplant teams share protocols and understand roles and expectations across the two teams.	11 (58%)	20 (43%)	25 (40%)
Shared knowledge between CF and Transplant care teams so they are able to identify post-transplant and CF complications.	9 (47%)	29 (63%)	21 (33%)
Staff on the transplant team who are knowledgeable about extra-pulmonary CF complications (i.e. Liver Disease, GI, Nutrition, CFRD etc.)	6 (32%)	22 (48%)	19 (30%)
CF and Transplant teams communicate regularly about my care	7 (37%)	20 (43%)	26 (41%)
Mental health care is available pre- and post-transplant	9 (47%)	21 (46%)	17 (27%)

Transplant team is able to refer me back to CF specialists for extra pulmonary complications	2 (11%)	7 (15%)	3 (5%)
Other (please specify)	0 (0%)	2 (4%)	0 (0%)
Did Not Respond	1	2	17
Would incorporating telehealth make acquiring care easier?			
Yes	11 (61%)	31 (70%)	26 (55%)
No	1 (6%)	6 (14%)	7 (15%)
I Don't Know	6 (33%)	7 (16%)	14 (30%)
Did Not Respond	1	2	17
How would incorporating telehealth make acquiring care easier? (check all that apply)			
For well visits	9 (47%)	20 (43%)	12 (19%)
For education (i.e. medications, home spirometry use)	3 (16%)	15 (33%)	10 (16%)
More efficient use of time (i.e. less time away from school/work/home)	8 (42%)	31 (67%)	19 (30%)
Cost saving	7 (37%)	17 (37%)	10 (16%)
For follow up with non-pulmonary specialists (i.e. dietitian, social work, mental health)	7 (37%)	21 (46%)	14 (22%)
Other (please specify)	1 (5%)	2 (4%)	2 (3%)
Did Not Respond	8	15	38
What are your concerns about incorporating telehealth? (check all that apply)			
Lack of access to appropriate technology	0 (0%)	2 (4%)	6 (10%)
Lack of insurance coverage	0 (0%)	1 (2%)	1 (2%)
Not offered by my CF and/or Transplant Team	3 (16%)	3 (7%)	9 (14%)
Lack of space to have these calls (i.e privacy)	1 (5%)	1 (2%)	2 (3%)
I (adult with CF)/ my loved one with CF receive a better quality of care in person	2 (11%)	11 (24%)	16 (25%)
I (adult with CF)/ my loved one have to go in for other tests	4 (21%)	12 (26%)	8 (13%)

I have no concerns	6 (32%)	14 (30%)	9 (14%)
Other (please specify)	0 (0%)	4 (9%)	1 (2%)
Did Not Respond	7	9	31

Supplemental Table S3: **Comparison of two potential models of post-transplant CF care. Model 1 incorporates fully integrated shared care between the lung transplant center and the referring CF center. In Model 2 the transplant team manages all aspects of transplant and CF care without coordination with the CF team.**

	Model 1: Shared care model between transplant centers and referring CF center.	**Model 2: Transplant team manages and coordinates all aspects of transplant and CF care.**
Pros:	Expert care received for both transplant and non-transplant related complication of CF. Increased confidence for patient, family and health care providers Facilitation of shared knowledge Facilitation of communication between patient, family and teams For patients living a distance from transplant centers, reduced travel for patient with CF-related complications For patients living a distance from transplant centers, ability to be near family and friends during transplant-related hospitalizations	Continuity of care by single transplant multi-disciplinary team Long term relationships with care team members Convenient for patient/family Potentially reduces cost to patient Facilitates communication and reduced clinic visits as occurs at single site Efficient for medical records

	Continuity of care in CF center for non-pulmonary complications of CF such as diabetes, sinus disease and GI/liver disease. Extensive education about CF and Lung transplant complications and treatment is not required for all members of both teams. Lung transplant team knows how and when to contact CF team and vice versa.	
Cons:	More than one team managing the patient, with the potential for poor communication leading to management errors. Need to attend more than one hospital with different physicians involved in different hospitals. Difficulties with overlap between transplant and non-transplant related complications of cystic fibrosis.	Limited number of CF transplant providers to make this a universally viable model Requires engaged local provider if transplant recipient lives a distance from transplant center Potential inexperience of transplant center in managing non-transplant related complications of CF, especially if not co-located with CF center
How this model will work in ideal circumstances	Ideally, occurs in an institution with both CF and transplant teams having established, effective communication between transplant and CF MDT. Effective communication is paramount and best modes and patterns of communication are established Consideration of telehealth/regular case conferences Access to clinical records at both sites	Transplant Center and CF Center in same institution with shared positions with expertise in Transplant and CF (ie. Dietitians, Mental health providers) Clear communication is paramount, especially for patient geographically distant that may receive aspects of care in local CF center Consideration of telehealth/regular case conferences CF specific CME with education/training for transplant team

	Clear written protocols on delineation of first line of contact for specific issues	
Staffing/Expertise	Local CF Center caring for post-transplant patients Transplant coordinator for liaison between CF and transplant center Consultant CF Physician with interest & experience in transplant medicine CF Dietician, Psychologist and SW with interest & experience in transplant medicine CF Pharmacist with experience and training in transplant medications	Transplant physician with experience in CF CF Center on same site: • CF dietician and Mental Health Provided shared between CF and transplant center • Continued input from non-pulmonary specialists (GI, ENT, Endocrinology) No CF Center not on same site: • Transplant Dietician & Psychologist with knowledge of CF • Input from non-pulmonary specialists (GI, ENT, Endocrinology) • Pharmacist with working knowledge of CF related pharmacologic issues (medication doses, drug-drug interactions, and specifics on CF medications) CF Center caring for patient geographically distant to transplant center • CF Physician with experience in transplant medicine
Limitations	For Transplant and CF Centers Geographically Distant: Establish clinic visits with close communication between transplant and CF Center. Options - In Person Clinic Visits - Telehealth - Video Conference - Phone Call/Email	This model is not appropriate when the lung transplant provider is not dually trained in CF, as there may be lack of expertise in non-pulmonary aspects of CF care If patient attending CF center for transplant-related issues, crucial to establish close communication between transplant and CF Center Options - Telehealth - Video Conference

		- Phone Call/Email

Supplemental Table S4: Examples of areas of expertise required to be delivered by transplant physician and/or CF clinician for effective post-transplant follow up

What	Expertise required	Distance Implications
Transbronchial biopsies	Transplant Team Only	N/A
Management of Immunosuppression	Transplant Team Only	N/A
Assessment for Rejection	Transplant Team Only	N/A
Differential diagnosis of acute pulmonary deterioration	All clinicians who are comfortable in close liaison with the Transplant Team	Good Communication is key
Data gathering (viral swabs, PFTs, imaging)	All clinicians who are comfortable in close liaison with the Transplant Team	Good Communication is key

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