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Incorporating Patient and Caregiver Feedback into Lung Transplant Referral Guidelines for Individuals with Cystic Fibrosis – Preliminary Findings from a Novel Paradigm

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Abstract

Background: Lung transplantation is a common therapeutic option for individuals with cystic fibrosis (CF) and advanced lung disease, yet many individuals with CF are not appropriately referred for evaluation. The present study sought to enhance CF transplant referral guidelines by integrating patient-centered input to identify possible psychosocial barriers contributing to suboptimal referral for appropriate CF transplant candidates.

Methods: As a component of developing the Cystic Fibrosis Foundation (CFF) Lung Transplant Referral Consensus Guidelines, we convened a focus group of lung transplant recipients with CF and two spouses of CF recipients. Each session involved standardized approaches to elicit qualitative, thematic content.

Results: CF patients and caregivers characterized five areas for improvement, which were integrated into formal CFF referral guidelines. These included 1) timing of transplant discussion with CF providers, 2) accuracy of transplant-related knowledge and expectations, 3) stigma associated with the need for transplantation, 4) treatment team transition issues, and 5) social support and mental health concerns. Earlier introduction of transplant, greater details regarding manageable aspects of treatment, and greater provision of social support were all associated with better psychosocial experiences.

Conflict of Interest: This study was supported by the CFF and the National Institutes of Health. The authors have no relevant conflicts of interest to the present manuscript.

Conclusions: Integrating patient-centered input into guidelines development yielded important and previously unknown psychosocial barriers contributing to suboptimal transplant referral.

Keywords

lung transplantation referral; guidelines development; self-efficacy; stigma; social support; locus of control; cystic fibrosis; transplant; psychosocial

Introduction

Despite numerous advances in the management of end-stage respiratory disease, lung transplantation may be the only effective option to extend survival and improve quality of life (QoL) for many individuals with cystic fibrosis (CF).[1] Among lung transplant recipients, individuals with CF represent the third most commonly transplanted patient group worldwide[1] and demonstrate the best clinical outcomes compared with other native disease groups, including greater survival[2] and improved QoL.[3] Despite the potential for improved longevity and QoL, available estimates suggest that 35-40% of potentially eligible individuals with advanced CF will die without referral for transplant evaluation.[4]

Published data are lacking to inform the understanding of the lived experience of individuals with CF prior to, during, and after the process of lung transplant referral and transplantation. Understanding and integrating patient-centered input in the process of guidelines development is increasingly recognized as critical to the ultimate success of guidelines implementation,[5, 6] yet is rarely attempted.[7] Engagement by patients appropriately acknowledges their expertise regarding their own clinical care, respects their rights in health policy development, empowers and informs the consumers of healthcare decisions, and leads to more patient-centered guidelines development, ultimately improving patient trust and acceptability.[8] Patient engagement may be particularly relevant among individuals with CF, many of whom have spent the majority of their lives engaged in complex medical self-care in conjunction with their caregivers to maintain optimal health. In contrast to other acquired health conditions, individuals with CF may be more adept at self-management and therefore experience the transition to transplantation differently than other chronic pulmonary conditions, such as idiopathic pulmonary fibrosis or chronic obstructive pulmonary disease (COPD).

In order to better understand the role of psychosocial factors during the lung transplant journey, we explored these issues with a CF focus group as part of the development of the CF Foundation (CFF) Lung Transplant Referral Consensus Guidelines. The focus group was used to better characterize patient and family experiences during the lung transplant referral process. Because of the small number of individuals in our focus group, the themes identified may not generalize to all individuals with CF referred for transplantation. Individuals with CF are a diverse and multifaceted group, for whom no single set of narrative themes could possibly encapsulate their entire experience. We therefore view the present findings as hypothesis generating and hope that the themes identified spur additional discussions, as well as larger studies. Thematic content from focus group sessions was

conceptually integrated using several codified psychological theories, including social cognitive [9, 10] and relational frame [11] theoretical frameworks.

Methods

As part of the CFF lung transplant referral guidelines development, patient-centered input was elicited from a small number of patients and caregivers, who agreed to participate in a qualitative focus group to identify potential psychosocial barriers contributing to suboptimal referral for lung transplant. Consistent with prior guidelines development work,[12, 13] qualitative focus groups were conducted to explore potential psychosocial barriers using a focus group format allowing participants to build synergistically upon themes introduced by other focus group members either through elaboration or revision.[14] This technique provides parsimonious accounts from individual participants without the intention of generating or testing theoretical content. This approach allows themes to emerge inductively from the data rather than pre-specifying themes that may inadvertently omit subsequent thematic content.

The focus group of CF transplant recipients and/or CF caregivers was organized with members from Community Voice (<https://www.cff.org/Get-Involved/Community-Community-Voice/>) who applied to participate in the lung transplant initiative. All participants provided a digital consent to participate at the time of enrollment. However, the project did not meet the definition of human subjects research under 45 CFR 46.102 and additional institutional approvals were therefore not required for participation. Focus group content is increasingly recognized as an ancillary data source providing relevant evidence, particularly for areas that are not well-characterized in the literature.[15] This focus group consisted of seven transplant recipients and two spouses of recipients, for a total of nine participants (Table 1). The focus group was mostly comprised of transplant recipients (78%) and women (67%). Focus group members participated in seven, one-hour long video-calls using Bluejeans™, led by a transplant psychologist (PJS) and a CF patient leader (AL). All focus group sessions were transcribed for examination of thematic content.

As previously described[16], following an introduction session during which thematic content was identified and analyzed, focus group members participated on five content-specific calls and one summary review call, for a total of seven hours of focus group discussion. Each session for the focus group used standardized approaches to elicit thematic content, including engagement questions, exploration of elicited themes, and exiting questions (Table 2).[15] All calls were video- and audio-recorded in order to facilitate re-analysis by focus group leaders. Themes of particular importance are described in detail and supported with direct quotations from the interview transcripts. Thematic content was developed inductively based on participant responses, with elaboration and exploration of themes elicited through open-ended probing within specific content areas and integration of input from the entire focus group. Thematic content was provided to participants for revision or modification and participants were given an opportunity to provide feedback and additional contextual input for the final thematic results.

Results

Overall results from the CFF guidelines development have been previously reported.[16] As previously described, themes identified during the introductory call included: 1) timing of transplant discussions with CF providers, 2) accuracy of transplant-related knowledge and expectations, 3) stigma and loss of CF identity associated with the need for transplantation, 4) treatment team transition issues, and 5) social support and mental health concerns during the transition to transplant (Table 3).

Timing of Transplant Discussions with CF providers

“I remember that conversation [about transplant referral] very clearly because it was almost ... shocking.”

Focus group members reported a wide range in terms of the timing and context in which lung transplant referral was initially discussed with CF providers, as well as marked variation in the frequency of re-visiting this topic. Numerous focus group members noted that early introduction and de-stigmatization of lung transplantation facilitated a more effective transition process. When transplant was introduced at an earlier time point preceding symptomatic decline, it was associated with less fear, denial, or potential delays of important clinical elements of care (e.g. obtaining diagnostic testing, formalizing caregiver plans, coordinating with transplant providers). If transplant was introduced in the midst of clinical deterioration, it tended to evoke dire thoughts and fatalistic connotations, with many focus group members recalling that transplant had been characterized as ‘a death sentence’ or ‘the beginning of the end.’

Transplant-Related Knowledge and Expectations

“Knowledge is power, so, if you have the information [about partnering lung transplant centers] at your disposal, you’re more inclined [to pursue transplant] – you’d be less anxious, less nervous.”

Focus group members noted variation in the clarity of transplant expectations, including benefits in QoL and potential risks associated with transplant. Expectations regarding transplant often appeared to mirror the patients’ perception of CF providers’ own impressions / expectations of the transplant process. Focus group members reported that their CF providers were generally pessimistic and tended to elicit feelings of fear, anxiety, and self-directed feelings of failure. In addition, many focus group members reported hearing outdated statistics regarding median survival following transplant, most commonly that it was five years and that transplant was uniformly associated with the emergence of multiple comorbidities associated with transplant medications. It was noted that many of the common concerns regarding transplantation can be framed in more adaptive manners, while continuing to accurately reflect the inherent challenges transplant patients may experience. Similarly, although transplantation is associated with numerous potential long-term complications, the vast majority of post-transplant complications are *manageable* and could be accurately characterized as common, treatable features of chronic disease management.

Stigma and Loss of CF Identity associated with the Need for Transplant

“For me it felt like I was accepting defeat [by needing a transplant].”

Many focus group members noted that the idea of requiring lung transplantation may elicit self-directed judgements, specifically that they may have personally failed. These internal attributions appeared to be reflexive for most focus group participants, with some noting that their medical health has always been integrally tied to adherence-related behaviors, implicitly associating attributions related to their failing lung function to feelings of shame[17] or stigma.[18] This tendency to self-judge appeared consistent with the approach- or control-oriented coping styles that typify many individuals with CF, who frequently note the need to ‘fight’ or ‘beat’ CF through vigilant engagement with compliance behaviors.[19, 20] Because shame and self-judgmental tendencies may increase the risk of depression and anxiety, which are common among individuals with CF [21] and may adversely impact transplant outcomes [22], identification and management of these psychological factors appears warranted. [21] Additionally, some individuals reported experiencing a relative loss of cohesion and/or group identification during transplant, because most non-CF recipients will differ from them both in terms of medical background, age, and life-course.

Treatment Team Transition Issues

“The transplant team are super experts at making sure your lungs are working. But they are less compassionate than the CF team or your own doctor around the side effects [of transplant medications].”

The standard of care across the CFF network includes a multidisciplinary team designed to address physical and mental health for individuals with CF. In contrast to most other lung transplant candidates from other native disease groups, individuals with CF have often worked with their care team for decades. While transplant teams are often multidisciplinary as well, the priorities and care models of transplant teams often differ substantially from most patients’ primary CF care team. Because of the chronicity of their disease and multidisciplinary system of care, many individuals with CF may experience the transplant transition as the first time their care has been de-centralized. Many focus group members noted coordination issues between their primary CF care team and their transplant team. This occurred both before transplant and even more commonly afterwards, at which time there was a lack of clarity regarding which medical issues were ‘CF issues’ and which were ‘transplant issues’. For individuals who had CF providers who either worked directly with transplant patients, were members of a multidisciplinary transplant team, or had direct training in transplantation, the process of transition was better facilitated. In contrast, individuals who did not have CF providers with a direct connection to the transplant process often felt confused, sometimes received conflicting information about transplant eligibility, and had incomplete or inaccurate expectations regarding clinical outcomes following lung transplantation.

Social Support and Mental Health Concerns during the Transition to Transplant

“I found a lot of people [on Facebook] that were doing great [after transplant], just seeing that there are positive outcomes and really good qualities of life took away a lot of the fear and anxiety.”

Members of the focus group had differing experiences in terms of the ease with which they were able to access transplant-related care and/or support resources. In addition to providing insight regarding the process and outcomes of lung transplantation, talking to peers also served to validate CF patients' experiences with worsening health. In addition to social support, many focus group members noted a relative lack of integrated mental health care with their transplant teams. Many individuals expressed a desire for counseling, but were reluctant to discuss this with their transplant providers. Among those who did request counseling, many had to obtain mental health services from private providers outside of their transplant hospital because of lack of available services.

Prior to transplant, many patients were also tasked with balancing multiple treatment needs as part of their pre-transplant rehabilitation. This often placed substantial burden on both patients and their caregivers and, in many cases, caused a revisiting or alteration of relationship structure with family members or other social support providers. For example, many CF individuals identified self-management of their CF medical care as important to establishing independence and levying age-appropriate boundaries between themselves and their caregivers, who were often parents. Worsening health in the context of transplant referral often resulted in a softening of these boundaries and the need for temporary revisiting of family roles. In addition, many individuals noted co-existing tensions between the need for support and the strong desire to retain and protect their own independence.

Discussion

The present study underscores the importance of integrating patient-reported input into clinical guidelines development. While the guidelines methodology included thorough review of the literature, our preliminary, qualitative findings suggested several previously unidentified psychosocial barriers that may contribute to suboptimal transplant referral for appropriate CF candidates. The themes identified also encompassed multiple psychosocial dimensions that were not limited to a specific clinical context or single patient-provider relationship. Instead, these themes suggested that the delivery of transplant-related information, transition issues between CF and transplant treatment teams, and even loss of CF identity may all be relevant during this important transition time period.

Understanding potential psychosocial barriers to optimal referral for lung transplant evaluation is particularly important as a high number of CF patients do not appear to be appropriately referred,[4] although the specific psychosocial barriers to referral are not adequately understood.[24] Indeed, a growing body of data suggest the psychosocial factors, including coping strategies,[20, 25] depression,[26-29] and social support,[27] are important predictors of lung transplant outcomes even after accounting for traditional prognostic factors,[30] such as background characteristics,[27, 28] post-transplant pulmonary function,[29] and primary graft dysfunction.[26] More specifically, individuals who exhibit avoidant or passive coping strategies,[31] a low sense of control over their healthcare,[32] or denial regarding their health, demonstrate an array of maladaptive behaviors, experience worse QoL before and after transplant,[19, 25] and are at increased risk for adverse clinical outcomes.[33]

Although these psychological factors appear multifactorial, they are all conceptually unified in that they reflect different aspects of **self-efficacy**, [34] defined as an *individual's beliefs about their capacity to exert behavioral control over events that affect their lives*. [34] More concretely, *the more individuals with CF are aware that transplant can benefit them the more likely they are to engage with the transition process*. In contrast, misperceptions of transplant-related risk, beliefs that transplant outcomes are completely out of their control, and lack of representative examples of 'successful' transplant recipients will increase the likelihood of denial and avoidance behaviors. Within this framework, individuals with CF who are aware of favorable transplant outcomes (**outcome expectancies**), believe they have some degree of control over their health outcomes (**locus of control**), and have had exposure to other individuals who effectively coped with the transplant transition (**social modeling**) will likely do better. Specifically, individuals with CF should be more likely to use approach-oriented / active coping styles to manage their worsening health and optimize their transition to transplant (**self-mastery**).

The preliminary themes identified from the present focus group, if replicated, may suggest several strategies that providers could consider using to improve CF-related psychosocial functioning during the transition to transplant. First, early conversations regarding transplant may be more effective if introduced when individuals with CF are healthier and have yet to significantly experience functional limitations or impaired QoL, [16] which may decrease anticipatory fear and facilitate proactive engagement with transplant providers once appropriate. CF providers must therefore attempt to calibrate discussions regarding the benefits and risks of transplantation with an appreciation that individuals with CF likely have never been as sick as they will become preceding transplantation, a time at which the potential to improve their longevity and QoL outweighs the inherent risks associated with transplant. Individuals with CF may respond favorably to strategies used to increase both real and perceived control, which is a prominent feature of successful self-management in the years prior to transplant referral. During this period of continual health decline, many individuals with CF are faced with health-related stressors that cannot be overcome with vigilant behavioral management, typified by the 'CF Fighter'. In other words, as the transition to transplant approaches, the coping strategies that individuals with CF have used effectively for most of their lives to control their health may be rendered ineffective for the first time. Because control-oriented coping styles are less effective in the presence of uncontrollable stressors (e.g. end-stage pulmonary function), acceptance-based coping strategies that refocus attention away from uncontrollable stressors to controllable elements of their care may be more effective. [35] For example, instead of focusing on reducing dyspnea and other end-stage disease symptoms, individuals with CF could be encouraged to focus on learning about transplant-related care to increase their confidence to self-manage after transplant (*self-mastery*) or directed to online resources where they could elicit support from other individuals with CF who have received a transplant previously (*social modeling*).

Second, increasing access to readily available, accurate, and contemporary information on transplant outcomes would likely increase the knowledge base and self-efficacy for individuals with CF acclimating to the transplant process. [23] Many participants noted experiencing increased self-efficacy through peer modeling, which is a core element of self-

efficacy interventions.[23] It may therefore benefit CF patients eligible for transplant to have access to additional patient resources to facilitate the transplant transition. Remote resources could include social media groups or mentoring programs such as the CFF's Peer Connect video-conferencing program. One-on-one resources could be via a local support network in which clinical social workers link CF patients electronically with transplant recipients who are willing to answer questions and address concerns, and who may provide calibrated feedback to help guide potential recipients during this critical time. In addition, underscoring components of the transplant process that are controllable may increase patient engagement with the transplant process. For example, emphasizing that many, if not most, of the untoward effects of transplantation are manageable will likely reduce the risk of learned helplessness and associated depressive symptoms. CF providers should be aware that clinical interactions introducing uncertainty about patients' *eligibility* for transplantation may serve to increase ambivalence[24] and ultimately avoidance of transplant-related knowledge or health decisions.[36, 37] Development of an updated decision aid or other transplant educational materials that could be widely distributed across CF centers could also serve to reduce decisional conflict surrounding lung transplantation.

Third, there was the implicit tendency for individuals in the focus group to exhibit and internalize the focus of blame, to stigmatize, judge, and shame themselves for perceived failure at the time of transplant referral. Providers should be aware and, where possible, attempt to correct misattributions regarding the interpretation of the need for transplant as a personal failure rather than the natural culmination of worsening health. Because the theme of 'CF fighter' appeared salient within the focus group, providers may even consider referencing widely known, public figures for whom their 'fighter' personality could readily be delineated from their underlying disease process (e.g. Muhammad Ali [Parkinson's], Wilma Rudolph [polio], John McCain [cancer], Venus Williams [Sjögren's syndrome], Jim Valvano [cancer], etc.). This may help to disabuse misattributions that just because their health is failing does not mean that they have failed. An additional, related theme was the suggestion of existential anxiety associated with transplant referral, particularly with regard to their identity as someone with CF. Many focus group members characterized the importance of being a 'CF fighter', underscoring the pervasive importance of this tenacious coping style. Providers could leverage this enduring coping style by directing individuals with CF to available transplant resources, where they may benefit from refocusing their self-management behaviors towards transplant-related preparatory information, whereas vigilant health compliance may no longer be as effective in slowing the progression of CF-related lung disease. Importantly, some individuals with CF do not experience these feelings of failure or loss of identity and members of the focus group were apt to point out that every person has a unique experience with CF.

Finally, providers are encouraged to elicit patient concerns and use clinical approaches that are attuned to their current level of motivation for possible transplant referral. Because of their younger age, many individuals with CF may have age-appropriate, underlying concerns regarding family planning, relationship issues, and educational / career concerns that could influence their approach to the transplant process. In addition, many individuals with CF may become increasingly reliant on their social support system, creating a shift from internal to external locus of control and a revisiting of boundaries established with their caregivers.

One useful heuristic prevalent in cognitive-social models of health policy,[38] as well as psychological theories of behavior change,[9] proposes that two dimensions prevail in determining health behaviors: perceived threat and self-efficacy.[38] Individuals who have an accurate understanding of the potential danger to themselves if they do not receive a transplant and also know they are capable of modifying their potential future health outcomes are the most likely to make the necessary changes to impact their health. In contrast, individuals who are either unconcerned, overwhelmed, or believe they cannot change their future outcomes will be the least likely to act, and therefore may require a different clinical approach. Providers are encouraged to ‘meet the patient where they are’ in order to provide the most effective clinical intervention.

Limitations. The present, preliminary findings must be viewed with several important limitation in mind. First, we elicited patient and caregiver participation in the context of consensus guidelines recommendations and the present qualitative focus group data therefore did not adhere to more stringent methodological criteria used in formal focus group paradigms to identify and validate thematic findings. For example, contemporary recommendations suggest that multiple coders should be utilized across at least three focus groups in order to comprehensively identify thematic content, although nearly two-thirds (64%) of thematic content is typically elicited within the first focus group.[39] Additional focus groups are therefore needed to extend the present thematic content and/or replicate our preliminary findings, which were identified in the context of a broader guidelines development project.[12] Second, future focus groups should systematically sample a wider and more diverse group of CF transplant recipients and their caregivers in order to increase the representativeness of findings. Our focus group was comprised of a small number of individuals who generally had favorable clinical outcomes following transplant and may therefore not provide generalizable inferences among all individuals with CF referred for transplantation. For example, all of the individuals in the present focus group were transplanted within North America, most within the United States healthcare system, and may therefore differ in their experience from individuals undergoing transplant in other healthcare systems. Third, because our focus group was intended to qualitatively capture themes from different patient experiences for incorporation into the CF Lung Transplant Referral Guidelines, sampling of patients closer to the time of transplantation, optimizing representation from both patients and caregivers, and including wider geographical representation of participants would all improve the methodological quality of data. This is particularly relevant as the present study included both patients and caregivers to identify thematic materials, which may have influenced the themes identified. Future studies may wish to conduct focus groups separately among patients and caregivers in order to identify representative thematic information.

Conclusions and clinical implications

We have identified psychosocial stressors for individuals with CF during the transition to transplant and propose potential strategies to reduce the burden of those stressors. The approaches included discussing transplant earlier in the disease process, providing accurate information about transplant outcomes, greater integration of transition care, and addressing

implicit misattributions of blame regarding the need for transplant referral in order to optimize the transition to transplant care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

CF	cystic fibrosis
CFF	cystic fibrosis foundation
FEV₁	forced expiratory volume in one second
QoL	quality of life

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TABLE 1.

Focus group participant demographic, clinical, and geographical information

Focus Group ID	Gender	Role	Transplant Year / Location	Re-Transplant?	Number of Calls
FG #1	F	CF lung transplant recipient	2012 / United States	N	4
FG #2	F	CF lung transplant recipient	2016 / United States	N	6
FG #3	M	Spouse of recipient	2005 / United States	N	5
FG #4	F	CF lung transplant recipient	2016 / United States	N	2
FG #5	F	CF lung transplant recipient	2011 / United States	Y	5
FG #6	M	Spouse of recipient	2013 / Canada	N	4
FG #7	M	CF lung transplant recipient	2016 / United States	N	5
FG #8	F	CF lung transplant recipient	2012 / United States	N	5
FG #9	F	CF lung transplant recipient	2017 / Canada	N	7

Table 2.

Example questions from each content-specific focus group.

Topics	Questions
Timing of first transplant conversation	<ul style="list-style-type: none"> • What comes to mind when you think about the timing of your first conversation about transplant? • How did you feel the first time transplant was discussed? • How often was the topic of transplant revisited? How, if at all, did this influence your opinion of transplant? • What, in particular, do you see as barriers to discussing transplantation?
Transplant expectations	<ul style="list-style-type: none"> • When you think about your expectations regarding transplantation, what comes to mind? • How did your expectations match your experience? • What, in particular, do you feel influenced your expectations about transplantation? • What do you wish you'd known about transplant before beginning the process? • How did your expectations influence your transition to transplant?
Treatment transition issues	<ul style="list-style-type: none"> • What are some of the challenges you experienced during the transition to transplantation? • How did your care and treatment requirements change during this time period, if at all? • How would you characterize the communication between your CF team and your transplant providers?
Stigmatization and self-judgment	<ul style="list-style-type: none"> • Tell me how you felt when you first learned you'd need a transplant? • What did it mean to you to need a transplant? • How, if at all, did the need for transplant affect how you viewed yourself? • At the time of your referral, how did you view your medical compliance as being related to your need for transplant, if at all? • What were some of the attributions you had about transplant at the time of your referral?
Support-related issues	<ul style="list-style-type: none"> • In what ways did having or not having enough support impact your transition to transplant? • What were some of the specific support-related challenges you faced during the transition process? • In what ways did you utilize support during your transition? • In what capacities, if at all, did your CF or transplant team provide support during the transition?

Table 3.

Quotes from focus group participants within each thematic domain.

Timing of transplant discussion with CF providers	<p>"I remember that conversation [about transplant referral] very clearly because it was almost, like, shocking for me. I think I was ... in a little bit of denial that I was going to need [a lung transplant], especially because my team never discussed it and it was never, ever something we talked about. And the one time I did bring it up seven years earlier I was kind of told 'We don't really ... we think about [transplant] when the time comes and we never bring that up...' So, when it happened, I remember going in for what I thought was a routine appointment and leaving feeling upset and traumatized because I didn't see it coming."</p> <p>"I really never brought [transplant] up either, so, I'm just as guilty [as the doctor] – because I was in denial... I think that would be better if [transplant] was part of the routine conversations that occur between patient and doctor."</p> <p>"For me [transplant] was always a matter of 'when?' ... 'How much farther down the ladder can I go before I need this transplant?' And I had my good days and my bad days. So, on really bad days I'm like 'Thank God I'm on the list.' And on really good days I'm like 'Take me off the list, I'm fine, I can keep going, it's OK.' ... I never felt 100% confident with my decision the first [transplant]... and I wasn't prepared for that mentally."</p> <p>"I had never really struggled with CF most of my life... once I got really sick, it just went downhill within a few months, and my CF Center was like 'hey, we need to think of transplant'. That was very jarring to me because I had literally never heard the word transplant with respect to myself – and that was at the age of 30."</p> <p>"If I'm perfectly healthy, and my lung function is great, then a natural response would be well, why are you discussing [transplant] with me now?... That should be an expected reaction from the patient, but the patient will ultimately realize 'They're not trying to scare [me] to death. It's more of a kind of dialog about what could happen.'"</p> <p>"I think earlier [discussion of transplant] is better. But I also think maybe general at first, you know. Like when you're normalizing it, everyone doesn't need to know every detail way early on."</p> <p>"You have to take into consideration that each patient is different and how you approach it depends on their experiences."</p> <p>"My [CF] team, for two years, was on the fence about when I needed [transplant]... I was very unsure. So, I think part of that is the 'window', right? The whole [CF] team it's 'What's the window?'"</p> <p>"I can't imagine dealing with physicians that are debating where you are and the need [for transplant/listing] at that time. That's really unfair because you are looking for guidance and for their expert opinion."</p>
Transplant-related knowledge and expectations	<p>"Everyone tells you that you're trading one disease for another. The important message ... is that there will be challenges, but all of these challenges are manageable challenges."</p> <p>"I didn't know much about [transplant], so, [I asked] 'what can I expect?' 'Well, you know five years is about the average. You try to hit milestones. Make it to a year. Then maybe make it to five years. And then after that we don't know. But the average is five. And you know you're trading one disease for another ... you're gonna have a lot of complications. You're gonna go through a rejection period... a lot of people end up needing a kidney transplant... you're probably gonna be diabetic... you're gonna lose muscle mass and have osteoporosis and skin cancer' ... and I'm just like 'Okay.' You know just so, I don't die right now. But very low expectations."</p> <p>"I'm actually someone who loves all the information. I want every little bit of information. I always have. And it's not the information that scares me – it's just that I didn't get all of the information. But some people don't want any of it really until it's forced."</p> <p>"[Reaching out to other transplant recipients] was really helpful, just hearing other people's stories. Especially success stories, was really helpful. To see people really, really living quite a long time with a really good quality of life. And also acknowledging the bumps that came along for them but saying like, 'Look, we got through that, and there are ways to treat rejection.' ... and some people were saying 'Oh, I've actually had chronic rejection for 15 years.' Hearing that 'you can get through this and still have a good quality of life' ... it's not just doom and gloom like it can sound initially."</p> <p>"I found a lot of people [on Facebook] that were doing great [after transplant], just seeing that there are positive outcomes and really good qualities of life took away a lot of the fear and anxiety. I was still cautious and I knew that there could be issues, but knowing that it was something I needed to do, seeing that there were people that were having a lot of success, started to actually make me hopeful and excited about the idea of being able to breathe again and do fun things."</p> <p>"My experience... was more positive. Like, 'let's be positive. This is your only chance.' ... I wasn't really made aware of the potential side effects of the drugs."</p> <p>"Going into transplant I had 20 plus years of the understanding that transplant was a death sentence. That's just what my CF pediatrician had told my parents when I was diagnosed."</p>
Stigma associated with the need for transplantation and loss of CF identity	<p>"For me it felt like I was accepting defeat [by needing a transplant]. And I was accepting that my body and my lungs weren't going to be able to keep fighting together anymore, it was time to pass the baton to the next set of lungs and try again ... and it really just felt sad, like a defeat. Because that was my identity, being a 'CF fighter' and always just scratching and clawing my way back to health ... it was just who I was and it was my whole identity... it was my life, and it just felt like a loss, a sadness, a defeat. Like a failure."</p> <p>"[Transplant] was presented almost like 'if you fight hard enough maybe [transplant] isn't something you'd need.' So, when I did need it, it felt like 'well, obviously I didn't fight hard enough then.'"</p> <p>"I knew it was something that was going to happen [transplant] but was trying to kick that can down the road as far as possible. So, when it first was like 'Yes, this is real' it was a lot of sadness for me ... that was my first emotion, more than fear, and I did not expect that. And I really felt a grieving of, like, my lungs. I mean, they worked so hard for me all these years and my body that had worked so hard, even though it was sick, I felt like I didn't want to give up on it and I just felt sad about the loss of the life that I had, even though it had been very hard for a long time there was still a sadness for me and that surprised me... After that I was terrified."</p> <p>"I wasn't embarrassed, but... it was the pride in me – I had always taken care of it. I was always okay until I wasn't... I talked to [my family] and said 'should I start telling people? I've gotta start telling people – I'm carrying around a frickin' oxygen tank.'"</p> <p>"I think the longer you fake it in the public world then the harder it is to accept transplant. Because when you go on oxygen, and when you're on the transplant list, there's really no</p>

	<p>faking it anymore.”</p> <p>“You might need to make sure that patients really understand that this is a treatment option for a reason. It’s not your fault. You didn’t do anything wrong. You know, this is CF.”</p>
Treatment team transition issues	<p>“The transplant team are super experts at making sure your lungs are working. But they are less compassionate than the CF team or your own doctor around the side effects [of transplant medications]. It’s great that the lungs are working really well, but if I’m having trouble walking because of these growths on my foot or if I’m in early menopause because of reactions to a drug those things didn’t seem like big deals because it was like ‘Oh, your lung function is 125%, you should be happy’. Yeah, of course, but if I’m doing this to have better quality of life [the transplant team] should look at the whole quality of life not just the lungs.”</p> <p>“In terms of who’s concerned about cross-infection and how... from what it sounds like, every [transplant] center is kinda different [about infection control policies], which I thought there was more consistency for that.”</p> <p>“I had been with my CF team for 8, 9 years, and they knew me as a patient – they trusted me. And this [transplant team] was all new doctors and people. And so it was just a big adjustment trying to form a relationship with them where I felt comfortable and they felt comfortable.”</p> <p>“I found the CF team would take care of those CF-related issues very seamlessly... And [after transplant] it was all very siloed, like, ‘Here’s your kidney specialist. Here’s a diabetes specialist.’ And then you have to tie it all together. It’s left up to you. Whereas the CF team, they kind of connected the dots for you.”</p> <p>“My nurse practitioner on the CF team is also a nurse practitioner with the transplant team... so I think it’s really advantageous to the patient obviously, but I think to the [CF and transplant] programs too.”</p> <p>“I’m lucky that my CF clinic and the transplant team are all part of the same medical system so they can look up my test results and all of that.”</p>
Social support and mental health concerns	<p>“[Individuals with CF] have a tough mentality. Sometimes, like everyone, we feel like we’re weak if we say we need mental counseling.”</p> <p>“When I got sick my mom moved in with us so my husband could go to work. And we had a new baby. So, my mom stayed with us for about 14 months with me through transplant and without my mom I wouldn’t have been able to do anything. I mean appointments, my son, just doing everything around the house, taking care of him and taking care of myself... we wouldn’t have been able to do it. We would’ve had to hire nurses or aids to come help out... [she] was critical.”</p> <p>“One tactic to try to get people who are reluctant to accept support is asking them to volunteer to help others... if you are asked to help to talk to other people that are pre-transplant like yourself, I think you’re more willing to do that because of this service, and you want to help others, but eventually you actually help yourself.”</p> <p>“Just having the support of people that can say ‘Oh, I went through that. You don’t need to panic, they can treat that’... has been really helpful. And it was helpful to me pre-[transplant] to see people getting through complications and still having this great quality of life.”</p> <p>“One of my very good friends was transplanted two years before me... I kind of got a realistic expectation [of transplant] from my friend that had been transplanted. There’s stuff you can’t read on the internet and that your doctors aren’t gonna tell you.”</p> <p>“Once you start to see other people/talk to other people that have been through [transplant] and really get, like, the details and understanding of the reality of what it can be, it starts to be less scary.”</p> <p>“I feel like [the CF team] were supportive emotionally but I requested mental support via a therapist... many, many times, and they really didn’t have anything to offer... As far as friends and family, I think that was always [my] biggest support.”</p> <p>“Everybody’s waiting on a list and it’s stressful... just the not knowing... is it ever gonna come?... So, the transplant team, my pre-transplant coordinator was very helpful and supportive, and all the responses we got from the medical team were very supportive, and kinda letting us know that it wasn’t abnormal to have a wait, and just encouraging.”</p>