Pediatric lung transplant patients experience several transitions of care during the course of the lung transplant process. First, families may meet with new providers to obtain a diagnosis or receive a referral to a pediatric lung transplant center. Then, pediatric patients are referred to one of the pediatric transplant centers that complete pediatric lung transplants. Finally, patients might get referred back to local care after their successful lung transplant if they are not cared by the transplant center directly in the long-term. These multiple transitions can be extremely challenging for pediatric transplant patients and their medical providers to navigate. This manuscript will identify some of the challenges associated with these transitions and provide suggestions for improving the transition of care back to the local care providers if needed.

Due to the relatively small number of pediatric lung transplant centers; most families in North America must relocate to the transplant center to wait for transplant. Based on their child’s medical difficulties or insurance constraints, some patients may be afforded an extremely limited range of choice regarding which pediatric lung transplant center will provide them care. Thus, families relocate from all over North America while their child is listed for pediatric lung transplant; further, the relocation itself is usually long-term, not only for the period while the child awaits lung transplantation. In Europe, relocation to the transplant center is less frequently required.

If patients are not looked after by the transplant center in the long-term, families must generally stay near the transplant center for a few months after transplant in order to allow for close follow-up care by their pediatric transplant providers. While this follow-up varies from center to center, most centers see patients 1-2 times a week for the first month and then weekly for several months; then, they must see the patient every other week for several months, and finally once a month for sometimes up to a year. Couple the frequency of these follow-up appointments with the fact that so few transplant centers exist and patients have to travel long distances from home and the reality is that, often, families have to remain close to the center for 3-6 months after transplant. All in all, if we consider relocation prior to the transplant with the post-transplant follow-up, a family could potentially
be near the pediatric transplant center for over a year.

Most hospitals in North America afford families the use of their local hospitality house often the Ronald McDonald House in the USA, or the family may seek other transplant housing, or they may even be lucky enough to stay with friends or family. But in order to get their child the care he/she needs, parents often uproot and relocate siblings, pets, and may even be forced to quit jobs and seek employment in the new city. Alternatively, families may be separated for the duration, with one parent remaining at home to work, adding additional strain to the family. Understandably, these logistical requirements can be huge stressors, stressors that only add to the already-trying challenge of negotiating a lung transplant.

Most major transplant centers have responded to this reality and afforded families major support in order to lessen the strain. In addition to housing, the transplant team often works together to provide solutions to the family such as public transportation tokens, food discounts and coupons, entertainment, and countless other outreach services.

However, once the patient makes it through the relocation and successfully receives a new pair of lungs, he or she now faces intensive follow-up: surveillance bronchoscopy and trans-bronchial biopsy, physical examinations, and other forms of testing, some that she will have to undergo for the rest of her life. Now, the patient and the family face what is an equally daunting task; they must do the whole move again, this time in reverse. This transition home is an important turning point, and it is an event that can be incredibly stressful for families without adequate support. Potentially, the added stress could even negatively affect the child’s health.

The multidisciplinary team is an invaluable component of the overall success of lung transplantation. While children receive care at pediatric lung transplant programs, they benefit from a wide variety of specialty services. This is possible because a majority of the pediatric lung transplant programs are affiliated with large children’s hospitals. However, even pediatric lung transplant programs associated with an adult center provide a variety of specialist services. Just to name a few typical services that are often provided (in addition to pulmonologist and surgery support) include the following: respiratory therapy, occupational therapy, dietary/nutrition, physical therapy, speech therapy, exercise rehabilitation, psychotherapy for the patient and the parents, social work and case management. This is all well and good, and most would not be surprised by the breadth and depth of service that a child receives before and after transplantation. But there does remain a glaring gap in services, those that help the patient move back home, especially considering the level of care the patient and her family have enjoyed and become accustomed to over the past year.

Indeed, given the wide array of services that are provided at the transplant center, which ultimately provide a supportive environment, one that creates the optimal time and place for pediatric lung transplant patients, families need many of these same services
when they return home. However, upon leaving the transplant center, the patients often find a desert of similar services. Families are simply unable to obtain a majority of these services as easily as they did at the hospital upon returning home. In some locations, certain services are not available at all.

In addition to the black and white logistics of finding support near home, families experience other psychological stressors when they leave their pediatric lung transplant program and providers. Providers generally assume that families are desperate to return home so they may get back to the familiar and the comfortable. However, while they do indeed feel a certain relief when they can finally go home, leaving the pediatric transplant program carries with it a significant amount of stress and anxiety. Families worry that no one else will be able to provide the same level of care that the child received at the pediatric lung transplant center. The parents may worry that they do not have the ability, time, and experience to be able to care for their child without the support of the team. Additionally, they worry that they are losing valued relationships that they have developed and maintained for the last few months with the pediatric lung transplant team. Finally, the family may feel that the medical team is abandoning them. Undoubtedly, psychosocial stress associated with relocation and leaving the medical team can be intense; for some families it is almost as intense as the stressors of the diagnosis, the waiting, the surgery, and the recovery.

The key word here is "preparation," and there is no such thing as too much. As the providers begin to talk with the patient and the family about the upcoming move home and how major changes in the nature of their relationship will occur, they should also reach out and ease the transition in other areas as well. Each transplant center has a slightly different structure, but perhaps the most logical person to take the lead in preparing the family for their departure and also with maintaining contact with the families after the return home is the pediatric lung transplant coordinator. The pediatric transplant coordinator can often serve as the liaison for the rest of the team to follow-up on referrals, to inquire about psychosocial functioning, and—perhaps the most direly needed role—to triage communication between the transplant team and local providers.

Some programs have created novel online environments or online medical charts where families can communicate directly with their providers about patient care related issues (e.g., My Chart via EPIC). In this digital age, the options for quick and effective communication are limitless, and they may not always even require a transplant coordinator. My Chart®, Skype®, email, instant messaging, texting, bulletin boards, blogs, etc: all of these allow patients (especially those in rural areas) options for accessing their transplant team.

With the help of the transplant coordinator, each team member should designate a time and means to follow-up with the family. This ensures that the patient and family
feel supported by the transplant team, but it also allows them a forum through which they can receive ongoing education about the various multidisciplinary tasks they will face. These interactions between the team and the families should focus on how parents and patients are adjusting to the return home. Have they adjusted to a new daily routine in a new environment? Do they need help working on a new schedule? Are they finding the appointment schedule back at the transplant center manageable? Do they need help establishing a modified timeline to help with follow-up appointment schedules? This engaged communication creates an environment where patients and parents feel safe to communicate with the providers about questions related to medication, exercise, and symptoms; plus, this kind of communication goes a long way in ensuring adherence and keeping the patients on track with expectations.

Pediatric lung transplant patients need close follow-up to ensure the health of the transplant and to maintain a good quality of life, and that long term follow-up plan post-transplant includes almost everyone: the pediatric transplant team, the patient, the patient’s family, local physicians, and local allied health providers. Emotional, physical, psychological, and medical follow-up between all parties are all crucial aspects of the follow-up plan. That plan does indeed demand that patients and families are able to return to a certain level of normalcy upon returning home, but they cannot immediately fall off from the transplant center’s care completely. It is important to make sure that families are supported and connected to providers near home for a variety of subspecialty services so they can maintain their quality of life.

This could potentially be a difficult task. Due to the small number of pediatric transplants that are performed annually, this creates a challenge for the community transition. Considering the rarity of the procedure, the local provider has probably never worked with a pediatric lung transplant patient before. That is why it is of the utmost importance that the overall goal of providing the optimal level of care for each patient includes this local outreach. Each member of the transplant team should take responsibility for linking the patient and his or her parents with care closer to home for each specific specialty service. For example, the physical therapist from the pediatric lung transplant team should help the patient and family identify resources near home where they can obtain quality physical therapy follow-up. An ideal continuity of care means that all providers should communicate directly and regularly with the local care provider. Transfer or referral paperwork is a daunting task, and it may vary between the transplant center providers and the local providers. However, communication between them all will lessen the strain on the family.

Once the contact is established between the transplant center and the local providers, the families can then troubleshoot plans for optimal care with the new provider. Likewise, reaching out like this creates an environment where the new provider or home provider can directly communicate with the pediatric lung transplant provider. This can be
an excellent strategy for addressing difficulties or anticipating any struggles with medical care that might impact the patient's medical condition. At times, the local provider may need support from the pediatric lung transplant provider for things to anticipate, for treatment planning, for education about pediatric lung transplant, or even to share relevant literature. Additionally, these local referral providers can serve as excellent eyes for the pediatric lung transplant team until the patient returns for the next post-transplant appointment. The local providers can communicate with the team if they notice any difficulties with adherence or if they notice any changes in the health status of the patient.

Another way to continue to instill these connections of care is to provide updates with the use of electronic medical records by which letters or other communications can easily be sent to the primary care doctors and other local specialty providers throughout the relocation to the pediatric transplant center. This allows for the referring providers and other specialty care providers to remain cognizant while the patient and family are relocated to and from the pediatric lung transplant center. Additionally, this deepens the relationship between the home provider and the referring provider. Finally, if the home provider feels that the pediatric lung transplant team values the input of the local provider, the provider will be more likely to refer patients to these centers, and he or she will be more likely to reach out to the pediatric lung transplant center if there are any changes in the patient's health status.

Communication between the team and the local provider will also help in the event that a family fails to show up for the required follow-up appointment. The willingness and ability of a patient to maintain the rigorous therapy, daily monitoring, and re-evaluation schedule is part of the evaluation process to be listed for pediatric lung transplant in the first place; however, some families need more support to follow through on the complex regimen. Communication with the local provider will allow the pediatric lung transplant team another avenue by which they can communicate with the family and inquire about the obstacles they may be facing. The transplant center should continue to communicate with the care providers closer to the patient's home to enlist their help and support for the follow-up, and for other recommended treatments. For example, if the team recommended that the patient receive psychotherapy for 3-6 months upon return home, and the patient is not adhering to the plan, the pediatric transplant provider should follow-up with the family on this recommendation. Again, communication and initiative is key. The family may need a different provider or more education about the importance of lifelong follow-up. This kind of additional work may seem cumbersome for the pediatric transplant provider or team, but these psychosocial issues related to follow-up could determine components of the survival outcome for the patient. Adequate follow-up for medical, emotional, psychological, educational, and physical factors all help to make the complex make-up of the aspects of outcome.
Given the emphasis placed on communication with the other multidisciplinary providers, adequate time should be made available for providers to communicate and ensure ongoing relationships with local providers for their patients. Supported or protected time for coordination of care ideally would be given for each member of the team to have regularly scheduled times to communicate with local providers and to follow-up on success toward treatment goals. This creates families who feel completely supported, with excellent patient care, and who meet with fully informed local medical providers.

The transition to local care has been an under-investigated topic in pediatric lung transplantation. Care coordination and appropriate discharge planning can likely positively influence outcomes for patients related to coping, quality of life, adherence, and family functioning; however, the relationship between these factors needs to be examined systematically. Continuing research efforts should focus on improving the transition to local care and understanding how successful transitions impact health outcomes for pediatric lung transplant recipients.

References

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