

Transition of transplant patients with cystic fibrosis to adult care: today's challenges

One of the most trying ordeals for patients with cystic fibrosis is moving from one care setting to another. When the patient is facing the crisis of failing health and the need for lung transplantation, the transition can seem even more overwhelming. In Toronto, patients are transferred from pediatric to adult care at age 18. Moving a teenager with cystic fibrosis to the adult system presents many challenges, and even greater challenges arise when the patient has received a lung transplant or is awaiting one. Two pediatric and adult cystic fibrosis teams have worked closely with the lung transplant teams to create a smooth transition system. This article outlines both programs and presents a case study to explore the challenges for the teams in deciding the best place to meet the needs of the patients and their families. These families offer us a look at coping with change at a time of great stress and at how we as healthcare providers can support them through the system. (*Progress in Transplantation*. 2006;16:329-335)

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Notice to CE enrollees:

A closed-book, multiple-choice examination following this article tests your ability to accomplish the following objectives:

1. Discuss indicators for lung transplantation in patients with cystic fibrosis (CF)
2. Identify common concerns for young adults needing a lung transplant for CF
3. Describe issues related to transitioning children with CF to adult care

Transitions are a part of life and are always challenging. Families faced with chronic illness are constantly adjusting to the sequelae of the disease. One of the most trying ordeals for patients with chronic disease is moving from one care setting to another. Whether the change is because of age, illness severity, or lifestyle, patients and their families must deal with moving from the familiar into the unknown. When the patient, young or old, is facing the crisis of failing health and the need for lung transplantation, the transition can seem even more overwhelming. These patients are at their most vulnerable and must make changes

not only in their medical care setting, but often in their lifestyle as well. In this article, we describe how 4 complex and unique programs have worked together to meet the needs of these patients as their care is transferred.

Background

Transition is defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from [a] child-centered to [an] adult-oriented health care system."¹ The transition from pediatric to adult healthcare has become an important issue because many chronic conditions that would have been uniformly lethal in childhood a decade ago are now associated with survival into adulthood.² Such is certainly the case with cystic fibrosis, and this issue has been a very important one in the Canadian cystic fibrosis community. The other relevant issue that relates to the cystic fibrosis community as it ages is lung transplantation, and how we transfer these older teens to an adult program either before or after transplantation.

Lung transplantation has been available as a realistic option for end-stage lung disease since 1988, when the first lung transplantation for cystic fibrosis was carried out. Lung transplantation can be considered in a select group of patients with end-stage lung

disease and poor quality of life who are unable to carry out activities of daily living. The first successful single lung transplantation in Toronto was done in 1983, with the first successful bilateral transplantation following in 1986. In 1995 at the Hospital for Sick Children, the pediatric lung transplantation program in Toronto was created.

Cystic Fibrosis

Cystic fibrosis is a genetically inherited disease that primarily affects the pulmonary and digestive systems. Cystic fibrosis is caused by the autosomal recessive mutation of the cystic fibrosis transmembrane conductance regulator (CFTR) protein, which is located on chromosome 7. In nonaffected individuals, the CFTR protein is transcribed and then migrates to and creates the chloride channel in the cell wall for passage of anions. In patients with cystic fibrosis, this channel is missing or defective.³ This defect does not allow water and chloride to flow properly through the mucus lining the various organ systems. This thick and sticky mucus clogs the small airways in the lungs and tubules in the pancreas, causing obstruction. Less vital organ systems like the reproductive system, sweat glands, and sinuses are also affected.

Cystic fibrosis is the most common lethal genetically inherited disease in the white population. One in 3600 live births per year in Canada are affected with cystic fibrosis, and the country has approximately 3500 patients with cystic fibrosis.⁴ Survival for patients with cystic fibrosis has paralleled the improvements in medical care; the median age of survival in 1964 was 6 years, and in 2001 it was 35.9 years. With an aging population of patients with cystic fibrosis, the need to provide treatment in an adult setting has become a significant issue.⁴ Pediatric centers are ill equipped to deal with many issues, including employment, reproduction, and even retirement to name a few. Many adults with cystic fibrosis and end-stage lung disease eventually benefit from lung transplantation, and until recently, adult centers were the only places that patients with cystic fibrosis could go for transplant assessment because no pediatric centers existed. Presently, cystic fibrosis is the primary indication for lung transplantation for children under age 18 referred to the relatively newly formed pediatric lung transplant centers.

Cystic Fibrosis Programs in Toronto

The cystic fibrosis program in Toronto has been running for more than 40 years at the Hospital for Sick Children, and in 1992 an adult program was established. The combined programs have offered clinical care as well as basic science and clinical research. The pediatric center was one of the first in the world to introduce the high-fat diet to patients with cystic fibrosis and has seen the ensuing rise in median age of sur-

vival. The cystic fibrosis gene was discovered in the laboratory of Dr Lap Chee Tsui in conjunction with Drs Jack Riordan and Francis Collins in 1989. Before 1990, the clinical program had more than 600 patients to care for and the pediatric resources were stretched to their limits. The need to transfer older patients to a more appropriate care setting was great, but the process was complicated. The pediatric center was unable to meet the needs of the adult patients with cystic fibrosis and subsequently worked with the adult hospitals in the area to set up a program to meet the requirements of such patients.

Transition of care to an adult care facility was not necessary for teens with cystic fibrosis 30 years ago. Few with the disease survived into adulthood. The few adults with cystic fibrosis were often sick and were taken care of at their pediatric center until their death. Neither adult caregivers with expertise in cystic fibrosis nor many physicians willing to take on such patients' burden of care were available. The need was not great, and the willingness of the pediatric team to send these adults off to an unknown care situation was low.

Once the immediate need to transfer the older patients with cystic fibrosis to the adult center was recognized, the task of systematically transferring the care of teenagers with cystic fibrosis to an adult center on a regular basis became a priority. Transition is a process that takes years before the actual transfer to the adult facility occurs. To help establish independent behaviors, the pediatric team uses developmental milestones to begin involving the children in their care long before they are ready to leave. The aim is for the patients to be seen on their own with the physician or nurse practitioner by age 14 or 15, and with independence by the age of 17 if all goes well. The age of transfer to the adult center is the year that the patient turns 18. Palliative patients stay on at the pediatric center if their death is imminent.

By the last complete pediatric visit, it is expected that adolescents will understand their medical condition, care routine, illness symptoms, and medications before the transfer. The patients' understanding is evaluated through an interview with either a physician or a nurse practitioner. A portfolio is created for each patient before the actual transfer of care. This packet includes a summary of the patient's medical and psychosocial history, complications, current medical history, and any psychosocial concerns. The adult team assesses the patient in the pediatric setting when they meet for their first visit in a combined clinic.

Adult Cystic Fibrosis Program

The adult cystic fibrosis program in Toronto was established in 1992. This program was a result of extensive planning once the need to have adults treated in a more appropriate setting had been recognized.

Today, the adult program at St. Michael's Hospital in Toronto is the largest adult program in North America, providing ongoing care for more than 350 adults with cystic fibrosis. The program adopts a multidisciplinary approach to provide comprehensive care to adults with cystic fibrosis. Care is focused on delaying the progression of disease process and on prevention and early detection of complications resulting from the improved survival. Those complications include diabetes related to cystic fibrosis, osteoporosis, and more severe forms of gastrointestinal problems such as liver disease and gastrointestinal cancer. All patients are encouraged to become partners in their care.

The team concept is highly valued in working with patients who have cystic fibrosis, and the best care is that provided by using a multidisciplinary approach.⁵ The goal of the cystic fibrosis team is to provide ongoing education to enable young adults to reach their optimal potential. With increased understanding of cystic fibrosis, these young adults learn to manage and live better with their illness. The cystic fibrosis team is available to assist them in making informed decisions about career choices, reproduction, and treatment options that are most suitable to their lifestyles. Although this change from a pediatric care model of prescriptive, protective, and nurturing care to an adult care model of collaborative and empowering care may be totally in keeping with the young adult's developmental stages, a few patients and their families find it difficult to adapt.⁶

Common concerns for young adults include exposure to infectious organisms, inadequate understanding of their disease, inadequate access to specialty care services, and the potential loss of continuity with their cystic fibrosis nurse.⁷ As for the parents, many of them feel deprived of their previous close involvement with the care of their children. Parents are often concerned that their child's health will be compromised after the transition to adult-based medical care. For those patients and their parents who are facing the prospect of lung transplantation shortly before or after transition, those feelings may be more intense. Some may view the transition as abandonment in a time of crisis and as a rejection by their previous healthcare team.⁸ These young adults and their family members are meeting many new healthcare professionals and getting a great deal of information from both the adult center and the lung transplantation program at the same time. All this new information and the new settings can be more than a little overwhelming.

This period of adjustment is most likely also true for those adults of any age coming from other cities or provinces to join the waiting list for lung transplantation. These patients are also followed by the adult cystic fibrosis program from the time of arrival for assessment until after lung transplantation. Such patients

often come from small rural towns and have been cared for by one practitioner their whole life. The transfer to a big city and the experience of dealing with a diverse care team in a large teaching hospital can be overwhelming and intimidating. The emotions they experience are most likely similar to the emotions that the teens experience when care is transferred to the adult care team.

Infection control measures are made known to all newly transferred adults and their families, and a contact phone number to reach a cystic fibrosis nurse and physician is given to the patients at the transition clinic and again during the first visit to the hospital. At the formal transfer visit, the nurse practitioner from the adult program explains that it is understandable that patients and their families may need to contact their pediatric nurse, especially during the first year after the transition. It is made clear that the adult and pediatric cystic fibrosis nurse practitioners will communicate with each other and work together to help deal with the patient's issues.

The adult cystic fibrosis center has a respirologist (pulmonologist) who floats between the adult cystic fibrosis program and the lung transplantation program. This physician forms a bridge for both programs. The teams value this expertise in both programs and see the respirologist as an invaluable resource to both programs. Her distinctive position provides a unique connection between the patients and the care team.

A recent study and our experiences have taught us that if we show genuine care and support, keep open communication between patients and team members, provide ongoing education, and make ourselves available to address any new problems or concerns, most people eventually adapt to their adult program. As they are able to establish a trusting relationship with their adult cystic fibrosis team, the patients begin to appreciate the care and guidance they receive and eventually find comfort and security in their adult healthcare team.⁹

The Lung Transplantation Program in Toronto

As of 2005, 604 patients from 8 to 71 years old have received lung transplants in Toronto. The program has grown significantly since its early days and now averages 45 to 60 lung transplantations annually. Most recipients are adults, and 20 transplantations have been performed in 19 child recipients. Cystic fibrosis is the indication for lung transplantation in nearly 70% of the pediatric cases.

Survival rates for patients with cystic fibrosis who opt for transplantation should be examined in 2 separate categories: patients with lungs colonized with the bacteria *Burkholderia cenocepacia* and patients without such colonization. After transplantation, overall 1-year survival rates for patients with cystic fibrosis who are not infected with *B cenocepacia* is approxi-

mately 85% to 90%, with a follow-up 5-year survival rate of approximately 50% to 60%. The added complication of infection with *B. cenocepacia* reduces these statistics to a 1-year survival rate of 60% to 70% and a follow-up 5-year survival rate of 30% to 40%. It should be noted that many North American transplant centers regard infection with *B. cenocepacia* as a contraindication to lung transplantation.

The Toronto lung transplantation program reviews requests for possible transplantation from all of Canada. All patients referred for transplantation must partake in a comprehensive and thorough multidisciplinary process to assess suitability from not only a medical viewpoint but also a psychosocial aspect with emphasis on stress and coping. Patients who are subjected to this assessment process are aware that contraindications for transplantation may be identified at any time. The overall process from start to end usually takes approximately 2 to 3 months.

Many challenges arise when a teenager with cystic fibrosis is transferred to the adult system, and even greater challenges occur when the patient has either received a lung transplant or is awaiting one. As an increasing number of young people survive into adulthood after receiving a transplant, the development of transitional care is a major challenge for pediatric and adult providers alike in the 21st century.¹⁰ Transition presents an additional problem for young patients referred for transplantation. Many patients are referred to the transplantation program at age 16 or 17 years, when the discussions of transition have already been started at the pediatric center. The prospect of a transition to a new adult team at the same time as to a transplant team can be overwhelming.

Building an open and effective communication relationship is paramount for ongoing support and encouragement while the patient is waiting for a transplant. Many challenges are encountered during this period for the patient's family and for the healthcare team. One of the questions facing the teams is whether the patient referred for assessment between the ages of 16 and 18 years should be sent directly to the adult center. The logical answer would be yes—the young patient and his or her family would have to familiarize themselves with only one new set of team members. This may not be the right solution for every family. Adolescents may have strong feelings of abandonment at being “farewelled” by the healthcare professionals whose medical presence has been long-standing, even life-long.¹¹ The healthcare team wants to provide the ideal start on the long stressful road to lung transplantation.

Although moving into the adult healthcare system carries a message that the young person is now capable of accessing adult care, these young persons and/or their families may be reluctant to do so.¹⁰ This

reluctance could be perceived as defiance or nonadherence, especially if no experienced adult team members are also knowledgeable about the challenges of transition. Adult healthcare professionals may feel that pediatric care is too paternalistic; may have higher expectations for learning, personal choice, self care, and independent follow-up; and may be reluctant to acknowledge the process of transition.¹⁰ Patients with cystic fibrosis, regardless of whether it is before or after lung transplantation, must be mature enough to move into the adult system with the support of their family and team.

One should not expect even a mature teen patient to deal with the transplant assessment program in the same manner as would an adult patient. Would they be better served if they were sent directly to adult care rather than passing through the pediatric center, albeit for a short time? The few families at our center that have been in this position found that going directly to adult care was not the best solution. The smaller volume pediatric program had the resources to deal with the issues of multiple changes and challenges for the sick teen with cystic fibrosis when moving from city to city and program to program. When the patient is referred to any transplant center for assessment, be it adult or pediatric, it is that center's responsibility to coordinate or transfer that patient's care. If a hospital assesses and lists a patient for transplantation, should they maintain the responsibility of seeing that patient through the transplantation, regardless of the age of that patient at the time of transition? The Toronto centers have discovered that the adult system is often too overwhelming for a 16 or 17 year old. Pediatric centers may be better equipped to offer the teens the support they need and ease them into the adult system, and staff at adult centers should feel comfortable referring teens to the pediatric center if it is appropriate.

The actual numbers of patients transferring from the pediatric center to the adult center around the time of transplantation, be it before or after, has been very small. The challenges have arisen around the timing—and the solutions may be different for every family. It is vital to assess each family and child and not just consider the patient's age. The following case study tells the story of our most recent transition patient and illustrates many of the issues encountered.

Case Study: Sarah

Sarah is a 16-year-old with cystic fibrosis referred from an outside cystic fibrosis center to the pediatric transplant center to be assessed for double lung transplantation. Her issues on arrival were numerous, including her intermediate age and the fact that she would have to move from the familiarity of her own city and local cystic fibrosis care center to all new surroundings and caregivers.

Sarah had cystic fibrosis diagnosed at birth because of meconium ileus and had been followed by the same medical team in her local pediatric cystic fibrosis center for her whole life. Sarah's family and her cystic fibrosis team had formed a close emotional relationship. The team had provided all of her clinical care as well as emotional support for Sarah and her family. Sarah was an excellent candidate for double lung transplantation, and the family came to Toronto for assessment. Once accepted to the program, the family reluctantly made the move to Toronto.

During the assessment phase, it was noted that Sarah was relatively close to the age of transition, which is 18 years. Since the family did not have long-term support systems already in place in Toronto, the question was raised, "Would Sarah be better served by starting the waiting process with the adult transplant team?" The decision was made to register her as a patient at the adult center.

The pediatric transplant nurse accompanied the family to the adult transplant center to ease the transition. Also, Sarah would continue at the pediatric cystic fibrosis center for her regular follow-up. The adult transplant center is not located in the same hospital as the adult cystic fibrosis center. The family settled and began to form close ties with the staff of the pediatric cystic fibrosis team as she was seen and admitted there frequently. The family was finding it stressful to be followed in 2 different centers though, with 2 new teams, in a city where they were strangers. Before lung transplantation, patients undergo intensive rehabilitation while waiting for new organs. The rehabilitation schedule that Sarah was following often conflicted with her appointments at the pediatric cystic fibrosis center. Sarah and her family found it increasingly difficult to be involved with 2 separate hospitals. Sarah and her mother asked if they could amalgamate their transplant and cystic fibrosis visits at the pediatric center. They found the adult center overwhelming as they had no experience with and had not been exposed to an adult hospital system before. The plan to consolidate care early was not working for this family, and they had the wherewithal to inform the team about the problem.

The teams agreed, and Sarah was followed for her transplant care by the pediatric center with the understanding that all of her care would be transferred to the adult centers when she was 18. The pediatric team saw the family for the next year and a half. This arrangement gave both teams—transplant and cystic fibrosis—ample opportunity to prepare the family for the challenges of transition. For this family, the overlap was beneficial because it gave them time to familiarize themselves with the teams, the programs, and the city. Both teams learned that every family must be looked at individually with respect to their transition issues.

The timing of the move should be flexible but there also must be an end point in mind for final transfer.

Sarah had a successful transition to the adult center for transplantation as well as the adult cystic fibrosis center at around the time of her 18th birthday. Looking back, both Sarah and the transplant team realize that initially Sarah was not ready for a change to the adult system even though she was 16 and mature. During Sarah's 17th year, all 4 teams worked closely together with the family to make the transitions as smooth and uncomplicated as possible. Sarah has stated that the short sojourn at the pediatric center was instrumental for her and her family's successful adjustment to life in Toronto before transplantation. It was also beneficial for the teams to form relationships with the family. Sarah has since successfully received a transplant in the adult center, and she has moved back home to her city of birth, where she is attending college.

Sarah's case illustrates some challenges in transferring care of the complicated cystic fibrosis patient from a pediatric cystic fibrosis center in one city to another—and then from the pediatric transplant center to adult care for both cystic fibrosis and transplantation. This family was able to realize and verbalize their wishes, which assisted the teams in meeting their complex needs. This case has made all teams more aware of the need to reach out to patients' families because other families may not be as able as Sarah's family was to express or even anticipate their needs.

Conclusion

The 2 cystic fibrosis teams in Toronto have established a transition program from pediatric to adult care. Patients and their families as well as the medical teams have been satisfied that both the medical and the emotional needs of the patients have been met. The pediatric and adult lung transplant teams have worked closely with the cystic fibrosis teams to create a smooth transition system that, although new, should evolve into a system that serves the few patients moving through it well. All 4 teams have shared information and made an effort to meet the needs of these vulnerable families.

Sarah's case is an example of how the patient's family may not be ready for transfer at an early age. Her experience illustrated how having a transition protocol to follow is important, but the specific needs of the patient and the patient's family must be closely evaluated throughout the process. All teams should use a systematic approach to assess how the family is coping, and that information must be communicated to all involved.

As numbers of referrals to the transplant centers increase, it will be important to survey this group of patients and their families and systematically look at their experience of transition through proper research methods. A pretransition assessment of needs and a posttransfer survey of the experience will assist in mak-

ing changes for families in the future. These families will offer a look at change under great stress and how healthcare providers can support them through the system. A survey of the families and subsequent analysis would allow the team to offer recommendations once the issues are clarified through assessment of the results. It would also be interesting to look at the reactions of the staff in both the pediatric and adult cystic fibrosis and transplant centers to assess their experiences as well.

The issues involved with transition are ever changing and the added stress of transferring care of the sickest patients with the most complex conditions will offer even more challenges in the future. Healthcare providers must be aware of the incredible stresses on patients and their families and must work together to meet their needs for care and support.

Acknowledgments

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Written consent was obtained from the patient and her family to use their story as the case study for this article. Names were changed for confidentiality.

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CE Test Test ID 4000-J47: Transition of Transplant Patients With Cystic Fibrosis to Adult Care: Today's Challenges

Learning objectives: 1. Discuss indicators for lung transplantation in patients with cystic fibrosis (CF) 2. Identify common concerns for young adults needing a lung transplant for CF 3. Describe issues related to transitioning children with CF to adult care

1. In what year was the first lung transplantation performed for cystic fibrosis (CF)?

- a. 1968
- b. 1978
- c. 1988
- d. 1998

6. How many patients have received lung transplants in Toronto as of 2005?

- a. 406
- b. 500
- c. 604
- d. 720

2. When was the first successful single lung transplantation performed in Toronto?

- a. 1963
- b. 1973
- c. 1983
- d. 1993

7. What percentage of pediatric lung transplant patients have CF?

- a. 40%
- b. 50%
- c. 60%
- d. 70%

3. When was the first successful bilateral transplantation performed?

- a. 1976
- b. 1986
- c. 1996
- d. 2006

8. What is the 1-year survival rate for CF patients after lung transplantation?

- a. 55% to 60%
- b. 65% to 70%
- c. 75% to 80%
- d. 85% to 90%

4. CF is caused by the autosomal recessive mutation of which protein?

- a. CF transmembrane conductance regulator protein
- b. CF membrane cofactor protein
- c. CF leukocyte adhesion protein
- d. CF recombinant protein

9. What is the 5-year survival rate for CF patients after lung transplantation?

- a. 30% to 40%
- b. 40% to 50%
- c. 50% to 60%
- d. 60% to 70%

5. What is the median age of survival for patients with CF?

- a. 12 years
- b. 20 years
- c. 28 years
- d. 35 years

10. At what age are pediatric patients with CF referred to a transplantation program?

- a. 15 to 16 years
- b. 16 to 17 years
- c. 17 to 18 years
- d. Any age—it depends on the severity of the disease

Test answers: Mark only one box for your answer to each question. You may photocopy this form.

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