

Transition Programs in Cystic Fibrosis Centers: Perceptions of Pediatric and Adult Program Directors

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Summary. There is a growing population of adults with cystic fibrosis (CF) and a need for development of adult CF programs. Recommendations for transfer of patients to an adult program include a transition program. Our goal was to assess the current status of transition programs in US CF centers. In addition, we sought to determine the problems related to the transfer of patients to adult programs as perceived by CF center program directors.

A survey was sent in 1998 to 110 pediatric and 44 adult program directors at CF centers approved by the Cystic Fibrosis Foundation (CFF), with a response rate of 65.5% and 72.7%, respectively: 22.2% of pediatric centers reported having a non-CFF-approved adult program, and 38.9% had no specific adult program. About one fifth of pediatric centers cited lack of an adult CF physician as an impediment to establishing an adult program. Age (82% of programs; mean, 18.5 years), but not marriage (17.1%) or pregnancy (24.8%), was used as a criterion for transfer. Criteria precluding transfer included patient/family resistance (51.4%), disease severity (50.5%), and developmental delay (46.7%). The concept of transfer is introduced to the patient and family at the time of diagnosis in a minority (14%) of programs. Over one half of the patients did not meet the adult team until the time of transfer. Pediatricians reported higher perceived parent, patient, pediatric staff, and adult staff concerns about transition issues than did adult program directors.

We conclude that there is a lack of standardized programs for transfer of CF patients from a pediatric to an adult care setting, and that there are differences between pediatric and adult program directors' perceptions of concerns that CF patients, their families, and the medical teams have about transfer. These differences may impede the successful transition of patients into an adult program. **Pediatr Pulmonol.** 2001; 31:443–450. © 2001 Wiley-Liss, Inc.

Key words: cystic fibrosis; transition of care; adult programs.

INTRODUCTION

Patients with cystic fibrosis (CF) are living longer, with the median age of survival currently about 29 years.¹ Thus, there is a growing population of adults with CF, and a greater proportion of CF patients who are adults; approximately 38% of CF patients are over age 18 years.¹ The focus of healthcare of the CF child can now expand from trying to achieve survival into adulthood to preparing the child for the challenges of adulthood. Eventually, as would be the case for any child, there will be a need for medical care by a physician trained in the care of adults. Specifically, there is a need for physicians trained in the care of adults with CF. The Cystic Fibrosis Foundation (CFF), an organization that certifies and supports CF centers, has advocated the development of adult programs.²

With the development of adult programs, CF adults who have long received their care from pediatricians would have their care transferred to adult practitioners. This transfer of care may be beset with problems that can disrupt the care (and health) of the patient. There may be

issues of concern for the patient, the patient's family, or for the pediatrician, any of which could impair the successful transfer of care of the patient to an adult caregiver within a center. Adolescent CF patients may be dependent on their parents for financial support and physical care, and may have difficulty developing separation and independence from their parents;³ this may, in turn, lead to difficulty separating from the pediatric CF clinic where they have established long-standing and trusting relationships with pediatric staff.^{4,5}

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Parents who are accustomed to managing their child's illness may be reluctant to allow their children to assume responsibility for their own healthcare and may feel excluded from healthcare decisions by physicians in adult-care settings.^{3,6} In the past, there was a lack of adult practitioners with experience in managing chronic conditions of childhood such as CF;⁷ pediatricians have been reluctant to transfer patients because of concerns about the internists' ability to provide adequate medical care.^{8,9} There may also be a disincentive to transferring patients out of the pediatric clinic because of loss of financial support where funding is directly related to the number of patients served.¹⁰

Though there are models for adult CF programs, there is no standardized plan for the way to transfer the care of patients to an adult program. Many experts recommend that the transfer of care between pediatric and adult healthcare providers be through a smooth transition,^{5,6,8,10-18} though most of the literature focuses on describing the need for such programs rather than evaluating existing programs with respect to medical and psychological outcomes.^{8,9} Our purpose here was to assess the current status of transition programs in US CF centers. In addition, we sought to determine the problems, as perceived by CF center program directors, related to the transfer of CF patients to adult programs.

METHODS

For this paper, transition will be defined as the purposeful, planned preparation of patients, families, and caregivers for transfer of a CF patient from a pediatric to an adult care program.⁸ Transfer is defined as the actual responsibility of care of the patient being moved from a pediatric setting to an adult care setting. This study was approved by the Medical University of South Carolina Institutional Review Board for the Protection of Human Rights.

The CF Transition Survey was sent in 1998 to all program directors of CFF-certified CF centers; a CF center incorporates a pediatric program and sometimes an adult program. At the time, there were 110 pediatric and 44 adult programs sanctioned by the CFF. A second mailing was sent after three months. The 35-item survey (see Appendix) contained both forced-choice and open-ended questions covering three main areas including: 1) type of transition and transfer program (if any) at that center; 2) perceptions of concerns of patients, parents,

and pediatric and adult center staff about the transfer process; and 3) ratings of receptivity and success of the transfer program.

The perceptions of the program directors were evaluated using Hotelling's T^2 test, comparing the results of pediatric program directors to those of adult program directors. Comparisons between directors from the same center could not be made, as the surveys were anonymous. Correlations between perceived concerns expressed by all program directors and perceived receptivity to transfer, as well as perceived success of transfer, were performed in an attempt to describe which factors predicted success. The threshold of statistical significance was set at $P = 0.05$.

RESULTS

Surveys were sent to 154 program directors (110 pediatric, 44 adult) and were returned by 104, for an overall response rate of 67.5%. Seventy-two pediatric directors (65.5%) and 32 adult directors (72.7%) responded. Of the pediatric programs that responded, 34.7% have a CFF-approved adult program, 22.2% have an internist on the team (but without CFF criteria for an adult program), and 38.9% have no specific adult program. About one fifth (22%) cited lack of an available adult CF physician as an impediment to establishing an adult CF program.

The survey contained three criteria that might commonly be used for transfer. Age (82%) was frequently considered a criterion for transfer, but marriage (17.1%) and pregnancy (24.8%) were not. Many respondents added additional criteria, with the most commonly cited being "maturity." For those who thought age was an appropriate criterion for transfer, 18 years (69%) and 21 years (15.5%) were the most commonly cited ages. The average reported age for transfer was 18.5 ± 1.8 years (range, 15–30 years). Criteria precluding transfer of patients included patient and family resistance (51.4%), medical severity (50.5%), and developmental delay (46.7%).

The average age reported at which transfer to the adult CF program was introduced to patients and families was 15.9 ± 1.7 years (range, 0–18 years). The concept of transfer was introduced to patient and family at the time of diagnosis in 14% of programs, and only 5% of newly diagnosed cases met adult team members. Over one half (52%) of respondents reported that patients did not meet the adult team until the time of transfer.

There were considerable differences between the perceptions of pediatric and adult program directors as to the concerns of patients, parents, pediatric staff, and adult staff (Table 1). Generally, pediatric program directors perceived greater concerns for all parties involved than did adult program directors. Specifically, the

ABBREVIATIONS

CF	Cystic fibrosis
CFF	Cystic Fibrosis Foundation
MANOVA	Multiple analyses of variance
SEM	Standard error of the mean
US	United States

TABLE 1—Comparison of Pediatric and Adult Program Directors' Evaluation of Transition Concerns¹

Concern	Pediatric directors' perception	Adult directors' perception
Parent concerns		
Unfamiliarity with adult staff	1.41 ± 0.12	1.18 ± 0.17
Strong relations with pediatric staff	1.90 ± 0.12	1.57 ± 0.17
Adult staff meeting medical needs**	1.35 ± 0.13	0.71 ± 0.15
Adult staff meeting developmental needs	0.86 ± 0.12	0.59 ± 0.14
Adult staff meeting emotional needs	1.25 ± 0.13	0.85 ± 0.16
Reluctance to leave pediatric setting	1.41 ± 0.13	1.22 ± 0.17
Difficulty in relinquishing control	1.32 ± 0.12	1.37 ± 0.16
Patient concerns		
Unfamiliarity with adult staff	1.70 ± 0.13	1.31 ± 0.16
Strong relations with pediatric staff**	2.07 ± 0.12	1.52 ± 0.15
Adult staff meeting medical needs**	1.39 ± 0.13	0.83 ± 0.17
Adult staff meeting emotional needs*	1.27 ± 0.14	0.72 ± 0.16
Reluctance to leave pediatric setting***	1.75 ± 0.14	1.00 ± 0.16
Difficulty in assuming control	1.62 ± 0.11	1.31 ± 0.16
Pediatric staff concerns		
Adult staff meeting medical needs***	1.22 ± 0.14	0.47 ± 0.15
Adult staff meeting developmental needs	0.93 ± 0.12	0.63 ± 0.16
Adult staff meeting emotional needs**	1.28 ± 0.14	0.70 ± 0.16
Perceived loss of patient and family	1.15 ± 0.12	1.14 ± 0.18
Financial impact	0.71 ± 0.12	0.75 ± 0.20
Adult staff concerns		
Adult staff meeting medical needs*	0.88 ± 0.15	0.39 ± 0.11
Adult staff meeting developmental needs*	0.74 ± 0.13	0.39 ± 0.10
Adult staff meeting emotional needs	0.83 ± 0.14	0.45 ± 0.12
Poor relationship with pediatric staff	0.33 ± 0.10	0.32 ± 0.11

¹Values reported are mean ± SEM based on Likert scale; range 0–3, with 0 = no concerns and 3 = serious concerns.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

pediatric program directors reported higher perceived parent ($F(1,80) = 5.72, P < 0.05$), patient ($F(1,80) = 5.97, P < 0.05$), pediatric staff ($F(1,80) = 8.88, P < 0.01$), and adult staff ($F(1,80) = 4.77, P < 0.05$) concerns about the adult CF team's ability to meet the medical needs of the patient, and higher perceived patient ($F(1,80) = 6.50, P < 0.05$), pediatric staff ($F(1,80) = 5.22, P < 0.05$), and adult staff ($F(1,80) = 4.06, P < 0.05$) concerns about the adult CF team's meeting the emotional needs of the patient. Pediatric directors also viewed patients as having significantly greater concerns about severing strong relationships with the pediatric staff ($F(1,80) = 6.70, P < 0.01$) and reluctance to leave the pediatric setting ($F(1,80) = 11.45, P < 0.01$). Pediatricians did not express greater concerns regarding perceived loss of patients and families or about loss of financial support.

Despite these concerns, pediatric physicians generally perceived the transition process as moderately successful (Table 2). However, the pediatric program directors felt that patients and families ($F(1,80) = 6.71, P < 0.01$) and the adult CF team ($F(1,80) = 6.02, P < 0.05$) were less receptive to transition than did the adult program directors.

Correlations were run between survey items addressing perceived concerns of all program directors and those pertaining to perceived receptivity to, and success of, the transition process. A correlation matrix was generated to measure associations between perceived concerns and ratings of receptivity to and success of transition programs. Of the 88 correlations run, 22 (25%) were significant, with moderately low correlation coefficients ranging between 0.22–0.34. Broadly speaking, ratings of success of transition programs were inversely correlated with concerns about adult staff meeting patients' medical and emotional needs. That is, if the physicians perceived greater concerns for the patient, the family, or either pediatric or adult staff, then they also perceived lower success of transition. Perceived concerns of pediatric staff regarding the adult staff's ability to provide for the medical needs of patients were correlated inversely with perceived success of transitioning ($r = -0.34, P < 0.01$), and perceived receptivity of families ($r = -0.25, P < 0.05$), pediatric staff ($r = -0.25, P < 0.05$), and adult staff ($r = -0.23, P < 0.05$). Ratings of successful transition were also inversely associated with pediatric physicians' concerns

TABLE 2—Comparison of Pediatric and Adult Program Directors' Evaluation of Success of Transition Programs¹

	Pediatric directors' perception	Adult directors' perception
Transition program, overall success	1.90 ± 0.13	2.23 ± 0.16
Receptive to transition program		
Patients and Families**	1.90 ± 0.10	2.35 ± 0.12
Pediatric staff	2.23 ± 0.12	2.29 ± 0.15
Adult staff*	2.22 ± 0.14	2.74 ± 0.11

¹Values reported are mean ± SEM based on Likert scale; range 0–3, with 0 = poorly receptive/poorly successful and 3 = very receptive/very successful.

** $P < 0.05$.

** $P < 0.01$.

about a financial impact on the pediatric clinics ($r = -0.23$, $P < 0.05$), i.e., greater concerns about a financial impact were associated with lower perceived success of transition.

A MANOVA procedure was performed in order to examine whether two program factors (i.e., when the idea of transitioning is first introduced to patients and when patients first meet the adult CF team) predict receptivity to transfer and overall success of transitioning. Results failed to support the proposed model, indicating no difference in perceived receptivity or success scores between those patients introduced to the idea of transition between ages 12–15 compared to those introduced to the idea at age 16 years and over, and no difference in scores between those patients introduced to adult staff at time of diagnosis, prior to transitioning, or at time of transition.

DISCUSSION

The results of our study demonstrate a lack of consistent criteria for transferring CF patients from a pediatric to an adult setting, suggesting that there is no programmatic method for transfer among US CF centers. Our survey was not performed to justify the transfer of patients from a pediatric to an adult setting. The need for age-appropriate care has already been expressed by expert opinion^{2,4,10,12,17} and by adult patients,¹⁹ who generally support the movement to an adult program and report that internists are more likely to address issues such as birth control, family planning, and drug abuse than are pediatricians.¹⁹ Nor was the study done to justify transition as a process to precede transfer of patients, though this, too, has been recommended by physicians,¹⁰ patients,^{6,19} and expert panels.^{2,8,17,20,21} Rather, our study sought to evaluate the current state of transition programs in US CF centers and what, if any, problems exist, at least as perceived by physicians, specifically CF program directors. At the time of our survey, only 29% of CFF-approved centers had accredited adult programs, though to qualify as an adult program there had to be at least 40 adult patients at the center. It should be noted that the

survey was sent prior to the CFF Initiative 2000, which strongly encourages the development of adult programs. From the response that we received, 57% of programs had internist involvement of some sort. This means there remain a great many centers without significant internist involvement, for reasons not determined by our survey. This may include centers with too few adult patients to interest an internist, centers which believe that internists are not needed, and centers that desire an adult program but have been unable to recruit an internist. Indeed, 22% reported lack of support as an impediment to establishing an adult program.

It is important to note that our survey inquired into the perceptions of the program directors, but that the results may not represent what actually occurs. The most common criterion for transfer of a patient to an adult clinic was age. Eighteen years was the most commonly cited age, although there was a wide range. Most societal milestones mark 18 years as age of adulthood (e.g., ability to gain independence from one's parents, ability to vote), and patients often cite an age around 18 years (i.e., 17–20 years) as the appropriate time for transfer.²² It would seem an appropriate time, as this is when other major changes are occurring in the person's life, such as graduating from high school and preparing for work or further schooling. The American Academy of Pediatrics selected 21 years as the upper age limit for the field,¹⁸ and there is obviously agreement from some CF program directors that some patients would benefit from further care in a pediatric setting beyond age 18 years. This is shown by the number of surveys returned which listed 21 years as the appropriate age for transfer (15.5%) and by the high frequency of "maturity" listed as a criterion for transfer. What is meant by maturity is not evident in the survey, but it could be inferred that the patient was not yet emotionally or intellectually prepared for independence. Our choice of the term "developmental delay" was perhaps unfortunate, as this description is used in the pediatric nomenclature to define delay in achievement of neurological milestones, and it is typically used to describe the young child rather than an adolescent. It

was interesting to see that other "adult" events, mainly marriage and pregnancy, were not considered to be major criteria for transfer, having been selected by less than 25% of respondents.

There were specific criteria selected by approximately half of the respondents that would preclude transfer, including patient and family resistance, medical severity, and developmental delay. It may seem inappropriate to put a patient nearing the end of life through an additional change that may be stressful, but we are notoriously poor at predicting the end of life in some patients. Patients who have met criteria considered appropriate for lung transplantation often live for years longer than was predicted.²³ Although it may be evident that some patients are ready for adulthood earlier than others, there are some disadvantages to transferring patients at different ages. By not transferring a patient who is the same age as others who have been transferred, we could be sending a message to the patient that he is different than his peers, a feeling most CF patients strive to avoid. It has been suggested that maintaining individuals with CF in a pediatric setting is "tantamount to telling them that their lives will be too short to warrant the bother of moving on."¹³

Why there is a lack of standards for transfer may be related to the differences noted here between pediatric and adult program directors' perceptions. Pediatric program directors clearly perceive that patients, their families, the pediatric staff, and even the adult staff have concerns about the adult CF team's ability to meet the needs of the patient, both medical and emotional. There are two general conclusions that may be made here. First, it is possible that the pediatricians' perceptions of the patients' and families' concerns are accurate. It is not unreasonable for the patients and their families to have some concerns about making a change such as transferring to the adult program. The patients should be expected to be apprehensive, as they would for any other change in their life (e.g., changing schools, getting a job, moving to a new city); these are the same changes all adolescents will experience. However, these apprehensions alone should not be a reason to preclude transfer to an adult clinic. Second, it is possible that pediatricians are overestimating the concerns that patients and families have about transfer. The finding that pediatricians perceive greater concerns about the adult staff than do the adult program directors themselves suggests that pediatricians may be projecting their own concerns to others. There may be other reasons why pediatricians may have concerns transferring patients to an adult setting, besides concerns about the adult team's ability to meet the medical needs of the patient. These would include perceived loss of the patients and family, and the potential financial impact.¹⁰ These two concerns were not highly rated by the pediatricians, and there was no

difference between their responses and those of their adult program counterparts. It was interesting, however, that there was an inverse relationship between concerns about financial impact and the success of the transition program. Perhaps centers which are less likely to be affected financially by the transfer of a patient to the adult program are more likely to transfer the patient, thus making the transfer program more successful.

In conclusion, our survey of CF program directors demonstrates a lack of standardized programs for transfer of CF patients from a pediatric to an adult care setting. We also found considerable differences between pediatric and adult CF program directors' perceptions of concerns that CF patients, their families, and the medical teams have about transfer. There appears to be a correlation between the physicians' perceptions of patient, family, and staff concerns regarding transition and their perception of the success of a transition program. Though our study was not meant to prove that a transition program is necessary, our findings support the notion that transition is likely to be beneficial, if not for the patient and family, then certainly for the physicians involved in their care.

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Appendix 1

1. Please check the box that best describes your medical specialty:

	Pediatrician	Internist
General		
Gastroenterology		
Pulmonology		
Other		

2. _____ How many pediatric patients (under the age of 18) are followed in your CF center?
 _____ How many adult patients (over age 18)?

3. _____ Are your adult patients seen separately from your pediatric patients?

IF NO: Why not? Check all that apply.

Insufficient funds to establish an adult center

Inability to recruit appropriate personnel

Other (please specify) _____

Who currently follows your adult CF patients?

Pediatric CF physician

Internist who comes to Pediatric clinic

Other (please specify) _____

[Proceed to question 4.]

If YES:

A. Where are adult patients seen? (Please check one of the following).

In the same facility as pediatric patients by same staff

In the same facility as pediatric patients by separate staff

In a separate facility from pediatric patients by same staff

In a separate facility from pediatric patients by separate staff

Other (please specify) _____

B. What criteria do you use to determine when to transition a patient to the adult clinic?

Please check ALL that apply.

Age (what age _____)

Marital status

Pregnancy

Other (please specify) _____

- C. What criteria would preclude transition? (Please check ALL that apply).
 Patient/and or family resistance
 Medical severity
 Patient developmental delay
 Other (please specify) _____
- D. When is the idea of transitioning from the pediatric to adult clinic introduced?
 At the time of diagnosis or first contact with family
 At a certain age (what age? _____)
 Other (please specify) _____
- E. Who introduces the idea of transitioning?
 Pediatric staff member
 Adult staff member
 Both
 Other
4. Have you perceived any problems with the transition of patients from the pediatric to adult setting? If so, what are they?

The following are a list of obstacles that other centers have encountered in the transition process. How much of an obstacle has each of the following been for your center?

Please circle ONE appropriate number based on the following definitions:
 0 = Not a Problem 1 = A Mild Problem 2 = A Moderate Problem 3 = A Severe Problem

Concerns of parents

- 0 1 2 3 Unfamiliarity with adult clinic staff
 0 1 2 3 Strong relationships with pediatric clinic staff
 0 1 2 3 Concerns about adult clinic staff being able to meet medical needs of patients
 0 1 2 3 Concerns about adult clinic staff being able to meet emotional needs of patients and their families
 0 1 2 3 Reluctance to leave pediatric setting where parents have controlled medical decision making
 0 1 2 3 Parental difficulty in relinquishing control of their CF youngster's care
 0 1 2 3 Other (please specify) _____

Concerns of patients

- 0 1 2 3 Unfamiliarity with adult clinic staff
 0 1 2 3 Strong relationships with pediatric clinic staff
 0 1 2 3 Concerns about adult clinic staff being able to meet their medical needs
 0 1 2 3 Concerns about adult clinic staff being able to meet their emotional needs and those of their families
 0 1 2 3 Reluctance to leave nurturing environment of pediatric clinic and children's hospital setting
 0 1 2 3 Reluctance to assume appropriate independence for their medical care
 0 1 2 3 Other (please specify) _____

Concerns of pediatric staff

- 0 1 2 3 Concerns about adult clinic staff being able to meet needs of patients and family
 0 1 2 3 Perceived loss of patients and their families
 0 1 2 3 Concerns about financial impact on pediatric clinic
 0 1 2 3 Other (please specify) _____

Concerns of adult clinic staff

- 0 1 2 3 Concerns about being able to meet needs of patients
 0 1 2 3 Poor relationship with pediatric CF clinic staff
 0 1 2 3 Other (please specify) _____

For questions 26, please check the appropriate answer redefining the numbers as:

0 = Not successful 1 = Mildly Successful 2 = Moderately Successful 3 = Very Successful

0 1 2 3 How successful has your transitioning process been overall?

For questions 27- 29, please check the appropriate answer redefining the numbers as:

0 = Not at All 1 = Mildly Receptive 2 = Moderately Receptive 3 = Very Receptive

0 1 2 3 How receptive have patients and families been to transitioning?

0 1 2 3 How receptive have pediatric staff been to transitioning?

0 1 2 3 How receptive have adult staff been to transitioning?