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Cystic Fibrosis and Transition to Adult Medical Care

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Cystic Fibrosis and Transition to Adult Medical Care

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abstract

Transition of young adults with cystic fibrosis (CF) from pediatric to adult medical care is an important priority, because many patients are living well into their fourth decade, and by 2010 more than half of all people living with CF will be older than 18 years. Transition to adulthood, a developmental process of skill-building in self-management supported by the health system, is important for the successful transfer to adult CF care. The US Cystic Fibrosis Foundation has been proactive in preparing for increasing numbers of young adults in need of specialized adult-oriented care by creating specialized clinical fellowships for physician providers and mandating establishment of adult CF programs. Despite these initiatives, how to best facilitate transition and to define and measure successful outcomes after transfer to adult care remains unclear. Many adults with CF continue to receive care in the pediatric setting, whereas others transfer before being developmentally prepared. In this state-of-the-art review we provide context for the scope of the challenges associated with designing and evaluating health care transition for adolescents and young adults with CF and implications for all youth with special health care needs. *Pediatrics* 2010;125:566–573

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KEY WORDS

cystic fibrosis, transition to adult care

ABBREVIATIONS

CF—cystic fibrosis

CFF—Cystic Fibrosis Foundation

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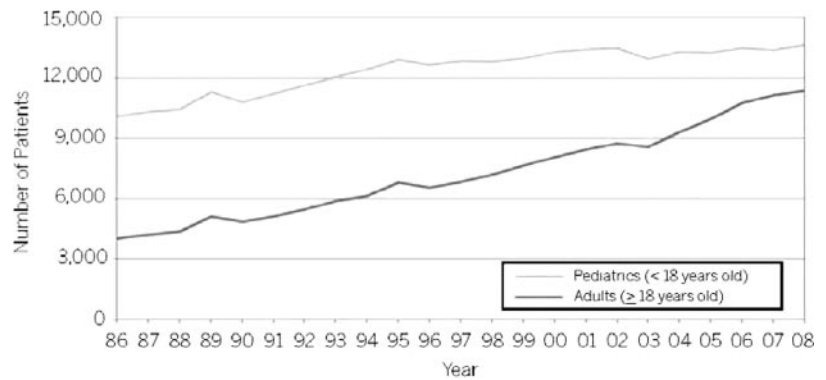
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The subject of recent Webcasts, sessions at national cystic fibrosis (CF) scientific meetings, and policy statements,^{1–7} transition to adult-oriented medical care has emerged as an important topic within the CF community as its patient population ages into adulthood. Providers and researchers who work with youth with chronic health conditions and special health care needs have looked to the CF literature for guidance in approaching transitional care. Recent efforts in CF have focused on broadening the scope of health care transition from simply the transfer of care between pediatrics and adult medicine to a comprehensive health delivery system that supports a developmental process. Despite this, there is a paucity of data describing rates, timing, barriers, and outcomes of transition. Progress in transitional care, including evolution of CF transition-related policies, summary of definitions, models of programs, empirical data, and future directions, are the subject of this state-of-the-art review.

EVOLVING EPIDEMIOLOGY OF CF

CF is the most common multiorgan genetic disease in the white population and leads to chronic lung disease, lung infection, bronchiectasis, and malnutrition secondary to pancreatic insufficiency.⁸ It is projected that individuals with CF born in the 1990s will live into their 40s and that current birth cohorts will live into their 50s.^{9,10} Therefore, most people with CF will require adult-oriented medical care during their lifetime. The timing of transfer to adult CF care often coincides with a dynamic period in adolescence and young adulthood when lung function may be declining and treatment burden¹¹ and complications of multisystem disease are increasing.^{9,12,13} In addition, the developmental and psychosocial challenges common to all adolescents, including the development of



The number of adults with CF has steadily increased over the past decade.
The number of children has remained relatively stable.

FIGURE 1

Trends in number of patients with CF, 1986–2008. (Reproduced with permission from Cystic Fibrosis Foundation. *Center Directors' Educational Slides*. Bethesda, MD: Cystic Fibrosis Foundation; 2009)

independent life skills, are magnified in the setting of a chronic illness and may lead to difficulty with adherence and disease self-management.^{14–16} Despite the chronic progressive nature of CF, survival, severity of lung disease, and nutritional status for people with CF continues to improve by birth cohort.⁹ Maintaining quality of life and improving life-span duration are continuing challenges for patients, their families, and CF care providers. Because the number of adults with CF has continued to increase (Fig 1), these goals are extended into adulthood, highlighting the importance of transition-readiness assessment and preparation to facilitate smooth transfer from pediatric to adult CF care.

DEFINITIONS OF TRANSITION-RELATED CONCEPTS

During adolescence, major developmental tasks including establishing independence in relationships, employment, and self-care¹⁷ may be disrupted in the setting of a chronic progressive illness such as CF. Health care transition represents a component of the overall developmental process of becoming an adult. In the literature, the definition of transition differs depending on the perspective of the authors.^{1,3,7,18–21} Most definitions state

that the transition process includes the movement of an adolescent or young adult from pediatric to adult-oriented health care. Some definitions describe a provider-focused process, the goal of which is to engage young adults in age-appropriate medical care,^{1,2,5} whereas others describe a more patient-focused process aimed at medical skill and knowledge acquisition.^{18,19} Current expert consensus has conceptualized transition within a broader developmental perspective.^{2,3,22} Therefore, transition planning and programming should anticipate developmental changes in the early adult years related to relationships, employment, and decision-making, as well as taking on increasing responsibility for medical self-management. The transition process (Fig 2) evolves over time,^{1,22} with the goal of successful transfer to, and engagement in, an adult CF program in which developmentally and medically appropriate care will be received. Transition should be coordinated, multifaceted, family centered, and gradual, addressing common concerns of patients and parents, promoting autonomy, and providing flexibility to meet individual and family needs.^{1,2}

Because CF is diagnosed in most individuals before the age of 1 year,^{23,24}

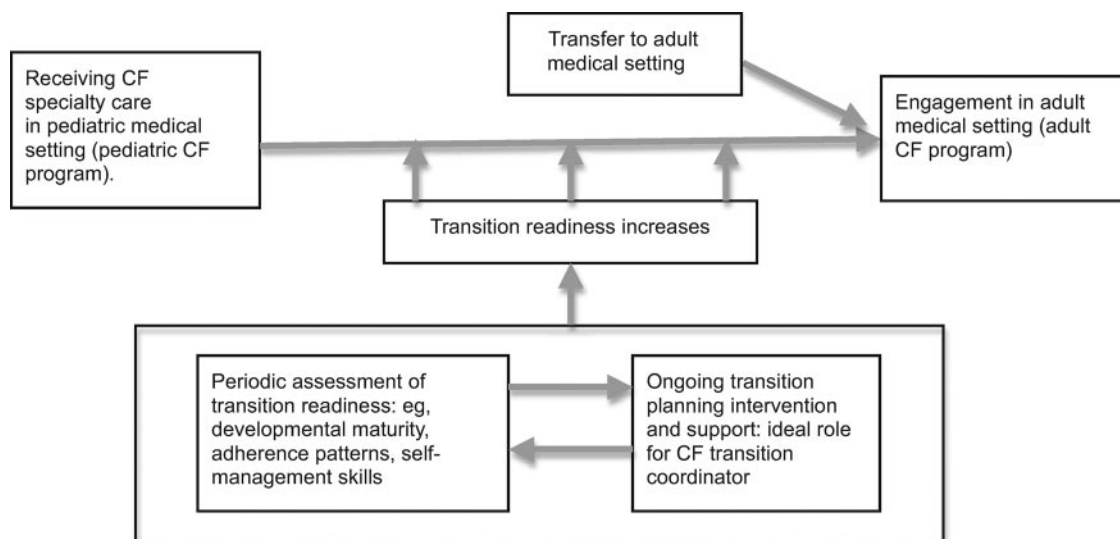


FIGURE 2

Transition process for patients with CF, from adolescence through engagement in adult CF care.

children and families have opportunities to develop knowledge and skills for disease self-management well before adolescence. The transition process should begin as early as possible by allowing developmentally appropriate participation in self-care (eg, young children learning how to administer their pancreatic enzymes, mixing aerosols, or becoming more active in airway-clearance therapies).

Children with CF, as with other chronic diseases, rely on their parents to monitor and oversee their medical care and therapeutic regimens. Adolescence is often when concrete efforts to evaluate preparedness and transition plans are implemented.²² For teenagers with chronic illness, transition-readiness efforts occur during a time in normal adolescent development when adherence is challenging because of emerging complicated psychosocial changes, thus intensifying the needs.^{1,17,25–27} Transition readiness is the capacity of the adolescent and those in his or her primary medical system of support (family and medical providers) to prepare for, begin, continue, and finish the transition process.^{22,28} In contrast, transfer is a discrete event. The terms “transition” and

“transfer,” therefore, should not be used interchangeably, because they represent different, albeit embedded, concepts.

Until recently, CF transition policy has largely focused on the transfer, including the credentials of medical providers and capability of the multidisciplinary team, and less on systematic programs that address these developmental processes of transition.^{7,29}

EVOLUTION OF TRANSITION PROGRAMS AND ADULT CARE

The Cystic Fibrosis Foundation (CFF) is a large, well-resourced nonprofit organization that supports CF research, advocacy, and clinical care and acts as a source of patient, parent, and provider educational information. Established in 1955, the CFF now accredits a network of 115 CF care centers. In the late 1980s, with improving and more targeted medical therapeutics, CF centers’ young adult population grew and was in need of specialized adolescent and adult care. In response, many CF centers started to recruit adult care providers. Over the past decade, within the framework of CFF-accredited centers, criteria were formalized for the development of adult CF programs. Be-

fore the early 1980s, when life expectancy for people with CF was, at best, early adulthood, there were only pediatric-oriented CF centers because of inherent disease demographics. Currently, the CFF mandates that an adult program be established and accredited when any CF center population includes 40 or more adults older than 18 years.²⁹ With the inception of adult CF programs, this created a “1 center, 2 program” model for many CF centers, usually with the 2 programs sharing resources such as clinic space and clinical personnel. When introduced 10 years ago, this policy was controversial. From a recent survey of CF center providers, 80% of respondents were reported to support a CFF mandate for transition services.³⁰ Both outpatient and inpatient care services are mandated to be provided in an adult hospital or in an adult unit with in-house physicians who treat predominantly adult patients with medical problems. In practice, however, many adult patients continue to be hospitalized in pediatric institutions.

To accommodate the variable access to resources and adult CF providers willing to accept transferred patients, the CFF has described 4 acceptable

TABLE 1 CFF Mandates That All CF Centers/Programs Provide Adult CF Care to Patients That Conforms to One of the Following Models

Models for Adult CF Programs	Primary Care Provider	Providers of CF-Specific Care	Location of Outpatient Clinics	Role of Program Director	Inpatient Location
1	All adult patients have an adult care specialist as a primary care provider	CF-specific care is provided by the local CF-center team	Adult patients are cohorted to adult-specific clinics for routine CF-center visits	Programs with ≥ 20 adult CF patients are strongly encouraged to identify an adult care provider to attend the adult clinic, with the understanding that this individual will begin to develop expertise to become the adult-program director as the adult population grows	An age-appropriate setting is encouraged for inpatient care
2	Adult program director and other adult-program physicians provide CF inpatient and outpatient care to all patients in the adult program	The CF center team and coordinator have adult CF experience and routinely interface with the adult-program physicians	Outpatient care is provided in either adult clinic areas or pediatric clinics with adults cohorted	Adult-program director or colleague sees patients for sick visits; telephone calls are received by the adult-program director, partners, fellows, or nurse coordinator	Patients are hospitalized in an adult unit or in an adult hospital
3	Same as for model 2, except there is a separate coordinator for the adult program				
4	Same as for model 2, except there is 1) A separate adult team and coordinator provide team care and 2) Outpatient care is provided in the adult outpatient department.				

All but model 1 are eligible to apply for CFF approval.

models for CFF-accredited adult CF programs (Table 1).²⁹ Since 2000, expectations are that for each pediatric program, >90% of patients past their 21st birthday will be transferred to an adult program.⁷ Thus, chronologic age remains the most cited criteria for transition readiness.^{20,30} In a 2008 study, less than half of CF centers reported routinely providing transition-related educational materials or time lines for patients and families. Of those CF centers that reported conducting readiness assessments, only 18% had specific programs to support development of self-management skills,⁴ and fewer than 10% of CF centers had a written list of desirable self-management goals to guide transition-readiness assessment.³⁰

CHALLENGES TO TRANSITION

Health Systems

A major gap in CF transition care is the mandate to transfer patients on the basis of age without clear direction regarding provision of supportive devel-

opmental and psychosocial services. This lack of formalized guidance is likely related to variability in the presence of structured transition programs, provider philosophy about transition, and access to adult CF care providers among CF centers, making a 1-size-fits-all approach impractical.

If the adult-oriented health system cannot accommodate an individual's needs on transfer, even a willing and prepared patient is unlikely to be successful.

Pediatric providers' distrust of the receiving adult CF program to provide a similar level of care represents a major barrier to transition.²⁰ If the individual philosophies of team members differ regarding the transition process, mixed messages and projected anxiety can hinder successful engagement in adult care.^{20,31} Lack of health outcome data likely contributes to pediatric provider perception that transition to adult CF providers will result in poor health outcomes that could be avoided

by remaining in the pediatric CF team's care.

Authors of qualitative studies have described adult patients with CF who have been transferred reporting low levels of concern regarding the transition process.¹⁹ However, it is not clear if concern was similarly low before and during the transition process. Others have shown ambivalence and negative perceptions before care transfer, with more positive perceptions once the patients were engaged in adult care.^{32,33} Although patients who transferred to adult CF care having participated in a structured transition program in the pediatric setting have reported satisfaction with their care and the transition process, there is currently no clear evidence that satisfaction translates into stability of health status after transfer.^{11–13,33}

Infection Control

Concern about transmission of respiratory pathogens between patients has increased among CF clinicians and

patients in the past decade. After early reports of outbreaks of resistant bacteria among patients at single CF centers, more attention was paid to the possibility of cross-infection generally; documentation of transmission from patient to patient, and from CF center to CF center, even in the face of contact and respiratory-droplet precautions, became particularly worrisome.^{7,34,35} Opportunities for formal or informal interaction among patients with CF have almost vanished, with the resulting loss of opportunities for group education, exchange of ideas, and mutual support.³⁶

Insurance

Although often underemphasized in the assessment of transition readiness by pediatric care providers,³⁰ health care coverage affects which provider a young adult will be able to see and can also facilitate payment for high-cost treatments. It is estimated that individuals with CF have health care expenditures that are 22 times that of individuals without CF.³⁷ Type of health coverage also affects health care utilization. One study of children with CF revealed that those with managed care insurance options attended CF centers significantly less frequently than those with non-managed care insurance.³⁸ Therefore, proactive planning is essential, because eligibility for publicly funded insurance options end at 21 years of age. State laws requiring health insurance to continue coverage for dependent young adults with special health care needs, and state-sponsored pharmaceutical assistance programs are both important options to the maturing CF population. In pediatric CF centers, team members often help coordinate insurance options, but this is likely not the case in less well-resourced adult CF centers. The CFF encourages the CF center team to actively advocate for health care coverage options for adult

patients, primarily by providing letters of medical necessity when coverage by an insurer is denied.⁷ Dealing with medical coverage poses many challenges, but encouraging patients and families to read all insurance material, become familiar with requirements, keep organized records of all insurance-related correspondence, and respond quickly to deadlines can facilitate more efficient provision of health care services and reduce individual financial burden.²²

ADDRESSING BARRIERS

To help young adults navigate this care transition, the 2004 Adult Cystic Fibrosis Care Consensus and others have recommended that CF centers designate a coordinator to schedule appointments, track appointment-show rates, and address psychosocial and health care coverage issues that may come up during the transition process.^{7,39} Investment in this position could provide a psychosocial safety net by continuing to support patients after medical transition to adult care. However, a transition coordinator will only be successful when the entire multidisciplinary team is engaged in the transition process.

To address availability and access to adult CF providers,^{20,30} the CFF has invested in the recruitment of new care providers and the increased capacity of CF centers to deliver age-appropriate medical care for adults.⁴⁰

To address infection-control concerns, many CF centers have used alternative communication formats such as parent-only support groups, online discussion boards, and live Web chats for patients and have had considerable success.⁴¹

CF-specific transition resources are available at www.portCF.org, the CFF Registry portal and resource repository, including a transfer summary template for when patients switch cen-

ters, self-management tools, a transition manual and workbook entitled "Cruising On: Next Stop Adulthood," and reproductive health information for adults with CF. Many of these resources are available in Spanish. Registration is required for access to this Web site.

ASSESSING OUTCOMES OF CF TRANSITION: RESEARCH EVIDENCE AND OPPORTUNITIES

Many professional organizations and federal agencies have issued policy statements and position papers regarding transition to adult-oriented health care.²⁻⁷ However, empirical research and evidence-based guidelines for transition have been lacking.^{22,42,43} Suggested transition service models in the literature have been based on clinical experience or a best-practice approach that has not been validated by evidence or systematically studied.²² Most of the published literature on transition of young adults with CF has been descriptive, reporting qualitative outcomes such as satisfaction and perceptions but not quantitative health outcomes.^{19,20,32,33,43-45}

Attempts to define and measure health status outcomes after transfer to adult CF care have been sparse. In a French study, pulmonary function of young adults seen at 1 CF center the year before, and 1 year after, transfer to adult care was measured. The authors found that health status remained relatively stable except for an increased rate of hospitalization the year after transfer.⁴⁶ A recent abstract reported US CFF Registry data from 990 patients, aged 15 to 25 years, who had transferred from a pediatric to adult CF program ID between the years 2003 and 2007 (22% of all "eligible" patients [990 of 4509]) according to chronologic age and similar baseline characteristics.⁴⁷ Data from populations with other chronic illness (such as pa-

tients who have had a liver transplant and patients with congenital heart disease) suggest a decline in adherence and health status⁵ and increased rates of hospitalization after transfer to adult-oriented care.⁴⁸ These studies were limited by small sample sizes, sample-selection biases, and lack of control groups.

ROLE OF QUALITY IMPROVEMENT

Quality improvement methodology and quality improvement collaboratives have successfully improved nutrition and respiratory care in the past 8 years.^{49–51} Similar approaches could be applied to the development, testing, and implementation of transition programs for CF. In general, there is a need for further study of transition models to identify which approaches work best in specific settings for specific patients and to evaluate whether the transition process helps individuals with CF to be successful in other areas of adult life.⁸

DISCUSSION

With the changing epidemiology of CF comes a critical need to design health systems to preserve the achievements of pediatric medical care into adulthood. A successful patient- and family-centered health care–transition process is a critical component of such a health care system. Despite the importance of health care transition for patients with diseases such as CF and the existence of transition programs around the world, little is known about the factors that can yield a successful transition to adult care. Furthermore, although many CF cen-

ters have transition programs or practices in place, they typically lack a standardized approach to supporting developmental maturity and increasing self-management skills.²⁹

Existing research has focused mostly on only 1 aspect of the transition process (ie, the attitudes and practices of clinicians and CF centers) and has not fully addressed the host of other factors that are influential in a successful transition. Expert consensus recognizes broader relevant factors (eg, emotional well-being, relationships, disease stability, expectations about adult care) and have called for more research to identify evidence to develop transition programs and policy.^{1,42,44,52–57} Thus, although it seems to be understood that transition is complex and multifaceted, empirical research beyond descriptions of perception and experience has been scant. Perhaps the lack of transition-related theoretical frameworks and validated assessment tools have hindered efforts to operationalize and measure transition readiness. Once theoretical frameworks are established, identifiable targets of intervention and outcomes of transition planning can inform transition programs during this vulnerable period in the lives of individuals with CF.

Concerns among pediatric providers about the ability of adult staff to meet their patients' medical needs have been reported and may contribute to pediatric pulmonologists delaying transfer to adult CF care.^{20,31} In 1 study, reticence among adult and adolescent patients to transition because of concerns over maintaining strong

relationships with their CF physicians was documented,¹⁹ and a second study identified doctor attitude and provision of information as important determinants of successful transition experiences.^{32,33,43,44} Yet, a comprehensive patient- and family-based study of transition for patients with CF has not been performed.

FUTURE DIRECTIONS

As more individuals with CF continue to reach the point of transition and transfer from pediatric to adult-centered medical care, the need for a comprehensive evidenced-based approach to this process will continue to increase. The transition and transfer process needs to be integrated into the patient and family medical home. Implementing a systemic transition policy for patients with CF has been limited by a lack of outcome-related research, clinical guidelines, and clear and consistent definitions.^{45,58,59} As more adult CF care centers are established, guidelines for transition and transfer need to be developed, and best practices need to be shared. For these practices, the variability in individual providers' perspectives on transition and transfer need to be examined, and health systems, education, and training from both the pediatric and adult medicine perspective must be addressed. Through research, quality improvement, and dissemination of best practices, CF is poised to become a model for the successful transition of care for all adolescents and young adults with chronic health conditions and special health care needs.

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Happy 350th Anniversary to Modern Science: This year marks the 350th anniversary of the establishment of the Royal Society in England—founded in 1660 by followers of Sir Francis Bacon, who was the first British statesman on record to advocate for the acquisition of knowledge by testing ideas through experiments. According to an article in *The Economist* (January 9, 2010), 12 individuals gathered in that year to hear a lecture by astronomer and architect Christopher Wren, which prompted this group to then meet weekly to discuss “scientific matters” and witness experiments conducted by various members of the group. In time the Royal Society’s meetings led to scientific publishing, peer review, and made English the primary language of scientific discourse. Today there are 1300 members of the Royal Society of which 74 are Nobel laureates—all of whom will be celebrating the anniversary of the Society and in turn the “joy and vitality of science.”

Noted by JFL, MD

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