Psychosocial Challenges/Transition to Adulthood

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KEYWORDS

- Cystic fibrosis • Transition • Adolescence • Psychosocial

KEY POINTS

- Amazing advancements in the last 20 years afford individuals with CF the opportunity to lead longer, fuller lives.
- The process of transitioning adolescents to adult CF care programs needs to be optimized.
- Adolescent and adult CF care providers need to consider the growing list of psychosocial needs that individuals with CF will encounter.

BACKGROUND

Individuals with cystic fibrosis (CF) are living longer and more active lives. Thanks to medical advances from new drugs, such as inhaled antibiotics, mucus-modifying agents, and the most recent development of CF transmembrane conductance regulator modulator therapies, the median age of survival continues to rise, reaching 39.3 years of age in 2014. Adults now comprise 50.7% of the CF population (**Figs. 1** and **2**).[1,2] There was a time when pediatric CF programs were able to provide care for adults with CF. Adults were not a large portion of their practice, they did not typically have complications outside of the pulmonary or gastrointestinal tract, and they had a long-standing trusting relationship with their pediatric providers. In the 1990s when it became increasingly apparent that transition of adults was needed, adult CF care centers were few and far between. This prompted the Cystic Fibrosis Foundation (CFF), which accredits CF care centers around the United States, to mandate that all centers with more than 40 adults establish an adult program by the year 2000. This mandate was met with some resistance but today with more than half of individuals with CF being older than the age of 18, there is a well-established network of adult programs to care for this population.

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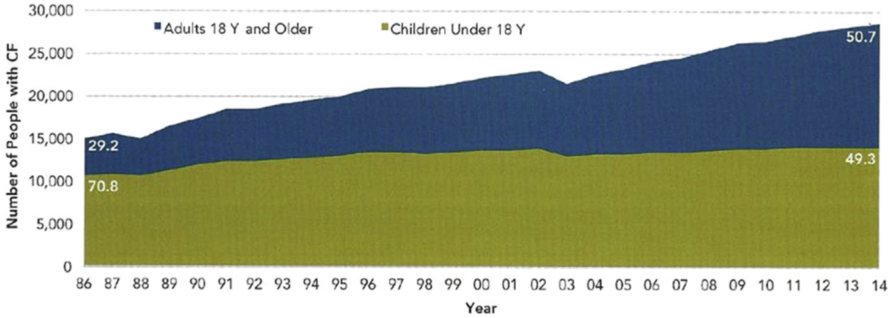

Fig. 1. Number of children and adults with CF: 1986 to 2014. (*From* Cystic Fibrosis Foundation Patient Registry. 2014 Annual Data Report. Bethesda, Maryland; ©2015 Cystic Fibrosis Foundation.)

Pediatric and adult programs are developing expertise and more enthusiastic attitudes in the area of transition.[3] The existence of adult programs and the aging of adults bring a variety of additional clinical questions and concerns to surface. When should an individual be transitioned from a pediatric to an adult program? What skills do teenagers need to care for themselves as young adults? What kind of infrastructure is necessary within a CF care center to make transition successfully happen? How will individuals with CF feel about this change? How will parents and caretakers adjust to transition? The answers to these questions are not black and white. Each CF care center has a unique population and structural set-up that demands customization of transition to best suit their needs. CF care centers across the country differ dramatically in size, geography, and socioeconomic composition. However, common components of transition include early introduction of the topic of transition; fostering skills of independence and self-management; education about CF and adult-focused issues, such as employment and fertility; introduction to adult care team members and making adult care facility tours available; and recognition of the emotional component of transition. A timeline (Fig. 3) may be helpful to conceptualize the process.

TRANSITION TO ADULTHOOD

The American Academy of Pediatrics defines transition as "the planned movement of adolescents with chronic medical conditions to adult health care with the goal to

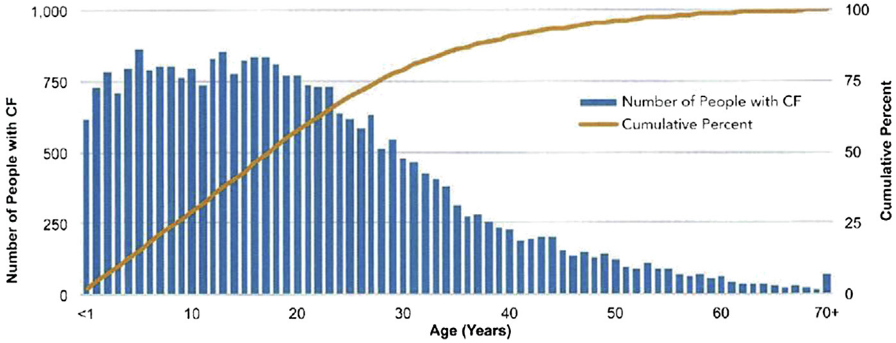

Fig. 2. Age distribution of CF population in 2014. (*From* Cystic Fibrosis Foundation Patient Registry. 2014 Annual Data Report. Bethesda, Maryland; ©2015 Cystic Fibrosis Foundation.)