



Evaluation of a Multidimensional Cystic Fibrosis Transition Program: A Quality Improvement Initiative^{1,2}

Anna M. Gravelle MSN^{a,*}, Mary Paone MSN^b,
A. George F. Davidson MD^c, Mark A. Chilvers MD^d

^a*Cystic Fibrosis Clinic, British Columbia's Children's Hospital, Vancouver, BC, Canada*

^b*ON TRAC Transition Initiative, British Columbia's Children's Hospital, Vancouver, BC, Canada*

^c*Cystic Fibrosis Clinic, Department of Pediatrics, British Columbia's Children's Hospital, Vancouver, BC, Canada*

^d*Cystic Fibrosis Clinic & Division of Pediatric Respiratory Medicine, British Columbia's Children's Hospital, Vancouver, BC, Canada*

Received 8 May 2014; revised 20 June 2014; accepted 30 June 2014

Key words:

Youth health;
Adolescent transition;
Cystic fibrosis (CF);
Quality improvement (QI)
initiative

The adequate preparation of cystic fibrosis (CF) youth for the transfer from pediatric to adult-based health care services is essential to meet the needs of this changing population. This paper describes the evolution of a transition clinic for patients with CF into a multidimensional quality improvement transition initiative. Three transition interventions (a patient transition clinical pathway; collaboration with the adult clinic; and a tool to measure transfer readiness) were sequentially implemented and evaluated. Each was found to be a valuable addition to a comprehensive transition protocol and today are endorsed as part of transition best practices.

© 2015 Elsevier Inc. All rights reserved.

PEOPLE WITH CYSTIC fibrosis (CF) are living well into their adult lives. Today, nearly 50% of all people with CF in the United States are adults (nearly 60% in Canada) (Cystic Fibrosis Canada Patient Data Registry 2012; Cystic Fibrosis Foundation Patient Registry Report 2012). While the median predicted age of survival continues to rise, a greater number of adult patients are entering the adult system annually. Appropriate preparation of CF youth and their families for the transfer from pediatric to adult-based health care services is essential to meet the needs of this changing population. Transition is defined as

the planned movement of adolescents with chronic medical conditions to adult health care with the goal to maximize lifelong functioning and potential through the provision of high-quality, developmentally-appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood (American Academy of Pediatrics et al. 2011). Most importantly, transition is not a single event but rather a complex process that occurs over time during which health care is transferred from one agency to another (Culter & Brodie 2005). The process is complete once the young adult transfers to the adult system and actively participates in activities of self-management and decision making (Telfair, Alexander, & Loosier 2004).

Initial Transition Clinic

At our hospital, CF patients have benefitted from a longstanding commitment to transition commencing in 1982 when the local adult CF clinic opened. At that time the

¹ Data from this manuscript have been presented at the following meetings: North American Cystic Fibrosis Conference 2004, St. Louis Missouri, USA. European Cystic Fibrosis Society Conference 2006, Copenhagen, Denmark. North American Cystic Fibrosis Conference 2007, Anaheim, California, USA. European Cystic Fibrosis Society Conference 2008, Prague, Czech Republic.

² No extramural funding and/or commercial financial support has been received for this quality improvement project.

* Corresponding author: Anna M. Gravelle, MSN.
E-mail address: amgravelle1@gmail.com.

concept of transition was in its infancy and was interpreted as helping CF youth and their parents at a single point in time, at transfer of care in the youth's 18th year. "Transition clinics" facilitated introduction to the adult CF clinic. They consisted of a final pediatric CF clinic appointment to which adult clinic staff was invited, providing an opportunity for formal handover and an optional tour of the adult CF clinic. A retrospective study that evaluated staff, youth, and family perceptions of the transition clinic format showed them to be a valuable preparatory step towards specialized CF adult-oriented health care (O'Loane & Joy 1992). Current research demonstrates that this opportunity for a crossover visit is a significant component for successful transitions of youth across many health conditions (McCurdy et al. 2006; Peters et al. 2011). However, we know today this single event in time is not sufficient in itself to support effective transitions, rather interventions need to start earlier on in adolescence (and could culminate in a transition clinic) to address the planning, preparation and transfer needs of youth with complex health care needs (Kennedy & Sawyer 2008).

Integration and Evaluation of a Multidimensional Transition Program for CF: Quality Improvement Initiative

This retrospective paper describes the evolution of a transition clinic for patients with CF into a multidimensional quality improvement transition initiative. Quality improvement (QI) initiatives are defined as systematic, data-guided activities designed to bring about improvement in the process, outcome, and efficiency of complex systems of health care (Hughes 2008). Within this model, adolescent transition is considered a 'complex system of health care', and the data to guide interventions were provided by an emerging comprehensive approach to transition (Madge & Bryon 2002; Royal College of Nursing 2004) and by a novel developmental transition framework developed by the BCCH youth health transition service ON TRAC—"Taking Responsibility for Adult Care" (Whitehouse & Paone 1998).

Transition Framework: A Developmental Approach to Transition Care

The ON TRAC framework was chosen as the theoretical underpinning to guide the QI initiative of expanded CF transitional care at our hospital. The framework was developed from extensive stakeholder engagement, synthesis of the literature and clinical observation. It conceptualizes three stages of adolescence and covers an age span from pre-adolescence to early adulthood (10–18 years of age). Each stage incorporates the developmental and health challenges that affect healthy outcomes for youth: self-advocacy, independent health care behaviors, sexual health, social supports, educational/vocational planning, and health

and lifestyle decision-making. Adoption of the ON TRAC framework was the foundational step of the QI initiative and served as the basis for each transition intervention.

QI Initiative Interventions

The transition initiative for youth and families with CF was led by the CF nurse clinician, and included the integration and evaluation of three main interventions:

1. a) Implementation of a generic transition clinical pathway; b) Development of a CF-specific transition clinical pathway;
2. Collaboration with companion adult CF clinic in the creation of a "pre-graduation" workshop; and
3. Development of a "CF readiness to graduate" questionnaire.

Overall emphasis was on guiding health care staff in the provision of "transition care" defined as "the work undertaken by health care providers to prepare youth with chronic illnesses (such as CF) for the adult health care system and the management of their health condition into adulthood" (Gravelle, Davidson, & Chilvers, 2012). Most components were built sequentially over several years in a stepwise model of development, implementation, and evaluation (Figure 1).

Intervention #1: A Clinical Pathway to Guide Transitional Care

Our first transition intervention was the implementation of a *Transition Care Clinical Pathway* (TCCP) into our CF clinic program. Goals of the intervention were to introduce standardized transition care at a younger age than previous, and to document patient transition progress. The TCCP was created by ON TRAC and evolved from their transition framework (Paone, Wigle, & Saewyc 2006). It combines a clinical checklist or screening tool for health care practitioners; youth education strategies to build knowledge and awareness of their condition; and skill building exercises to manage their disease and navigate the adult health care system. Over 4½ years the pathway was gradually introduced to our CF patients between the ages 10 and 17½ years who attended our CF clinic at least biannually. Patients were started in their age-appropriate category (early; middle; or late transition) and TCCPs were stored in patients clinic charts which were accessible to all CF clinic staff. Implementation consisted of CF nursing and allied health-care members continuing their routine patient consultations at CF outpatient appointments, while incorporating developmental transition principles in helping patients to meet transition indicators on their TCCP. The CF nurse clinician, who had received training in the ON TRAC transition framework, was on hand to help guide clinic staff in general transition concepts as needed. Interpretation of whether patient indicators were successfully completed was at the discretion of clinic nursing and allied staff.

Download English Version:

<https://daneshyari.com/en/article/5870573>

Download Persian Version:

<https://daneshyari.com/article/5870573>

[Daneshyari.com](https://daneshyari.com)