



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.

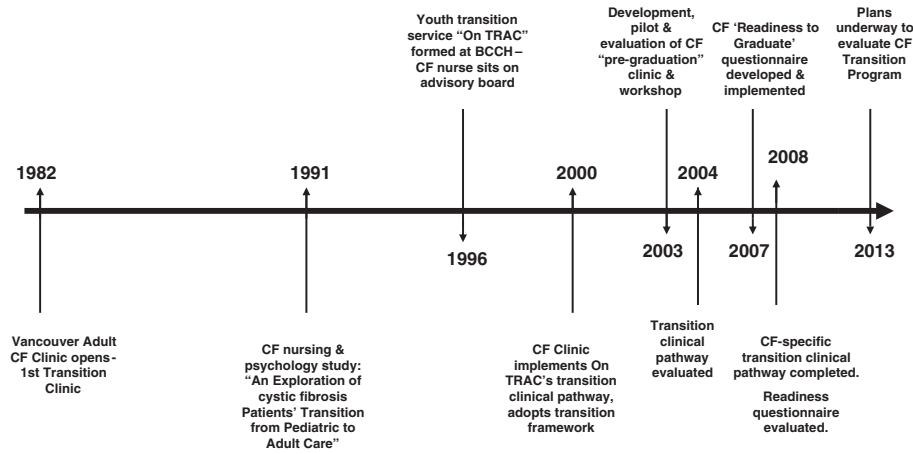


Figure 1 Timeline of transition quality improvement at BCCH cystic fibrosis clinic.

Evaluation of TCCP

A retrospective evaluation of the TCCP was undertaken after 4 ½ years of use, in which pathways were reviewed for completeness of documentation and for number of indicators met by youth. As some patients were older teens when the TCCP was first introduced into clinical care in 2000, they missed early and/or middle stages of the pathway. Completeness of documentation was therefore tallied on the basis of age group at initiation. In addition, informal feedback on the TCCP was solicited from CF allied healthcare staff.

Results and Discussion

Data from 22 TCCPs were examined post patient transfer to an adult CF clinic (Figure 2). Results indicated that 73% of TCCP indicators had been checked as addressed with the youth, reflected by either a date of completion (with nurse’s initials) or the letter “F” for “Focus” which indicated that although the indicator had been addressed, it was not yet achieved by the patient. Table 1 summarizes the indicators met by patients at various stages/components of the TCCP. For those who started the pathway in the early and/or middle stage, there were higher completion rates of indicators throughout the late stage (ie age 16-18 years) as compared to those who started late, at age 16–17 years. In other words, more indicators were met between the ages of 16-18 years by those who started the TCCP earlier, perhaps substantiating the assertion that transition care needs to be started early in order to be successful by the time the patient leaves pediatric care. However, sample size was low (especially in the “started late” group); statistical analysis was therefore not appropriate, and generalization of findings not possible. There were some inconsistencies that are difficult to explain, such as why some group indicator percentages varied a great deal from one age group to the next. Others have likely explanations: for example, the low scores across the board in “educational/vocational/financial planning”

likely reflect a lack of social work resources; while overall higher scores in “self-advocacy” and “sexual health” likely reflect the individual expertise of the nurse clinician in assisting the youth to achieve indicators in these components. It is also possible that charting of certain indicators was overlooked. As the sole documenter, the nurse may not have been able to always solicit the necessary feedback on indicator completion from the appropriate healthcare team member; inclusive multidisciplinary team charting in the TCCP is something we are still working on achieving. Irrespective of what age patients started the TCCP, nobody completed all indicators and it is unknown what percentage of indicators might be necessary to achieve an overall successful transition. Evaluation of the TCCP occurred at a time when very little evaluation of transition practices had been done. Objective outcome measures for CF-transitional care were not clearly defined. Without this type of data to guide an evaluation, and as the pathway is not designed for clinimetric or psychometric evaluation it was reasonable to

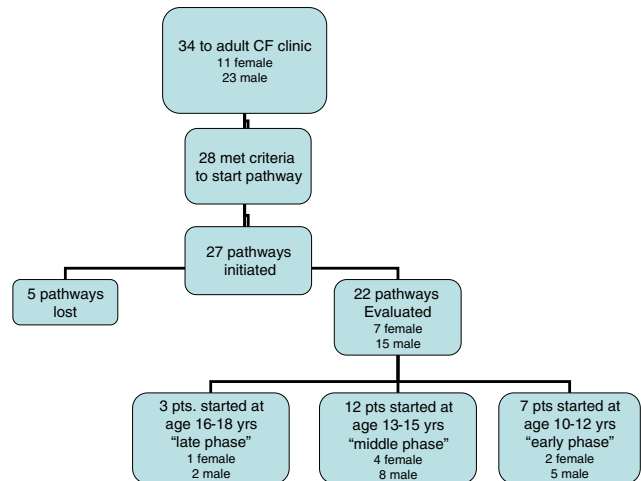


Figure 2 Evaluation of On TRAC Adolescent Transition Care Clinical Pathway in CF clinic, BCCH: number of pathways evaluated 2000–2004.

Table 1 Results of TCCP evaluation: indicators met.

Components of transition	Started “early” <i>n</i> = 7			Started “middle” <i>n</i> = 12			Started “late” <i>n</i> = 3		
	Early	Mid	Late	Early	Mid	Late	Early	Mid	Late
Self advocacy	86%	77%	83%	n/a	60%	62%	n/a	n/a	67%
Independent behaviors	71%	55%	57%	n/a	36%	61%	n/a	n/a	53%
Sexual health	39%	71%	100%	n/a	41%	73%	n/a	n/a	92%
Social supports	57%	33%	38%	n/a	23%	39%	n/a	n/a	33%
Educational/vocational/financial planning	9%	43%	55%	n/a	27%	36%	n/a	n/a	29%
Health and Lifestyle	63%	68%	71%	n/a	36%	52%	n/a	n/a	89%

Evaluation of ON TRAC Adolescent Transition Care Clinical Pathway in CF clinic 2000 to 2004: indicators that were charted by CF healthcare professional as “met by the patient” expressed as a percentage and indicated by age at initiation of pathway. “Early” = 10 to 12 years old; “middle” = 13 to 15 years old; “late” = 16 to 18 years old.

target the more fundamental measures of ‘documentation’ and ‘number of indicators met’ for formal evaluation. The TCCP was unanimously endorsed by all CF staff as providing a concrete reminder of the goals of transition care which helped the CF team to keep a stronger youth focus. Incorporating a transition care clinical pathway as a standard of care improved processes of patient care in our clinic. While step one of the QI initiative was thus deemed successful, concerns were also identified. An unrealistic amount of time was required for disease-specific charting and moreover, omission of disease-specific education was reported back by the adult CF clinic. Additionally, almost all indicator charting was done by the nurse who had to repeatedly check with staff whether indicators were being addressed and met. In order to maintain the benefits of a TCCP and address the omission of disease-specific requirements, the creation of a CF-specific TCCP was recommended.

Design of a Disease-Specific TCCP

Work thus ensued to create a disease-specific TCCP by incorporating CF-specific education and skills into the generic TCCP [Supplement 1: CF TCCP]. The progressive and multi-system nature of CF informed the revisions to the TCCP which were undertaken by CF nursing and allied health staff (who had an average of 15 years working with CF). The first draft was reviewed by a small group of youth with CF and their parents with subsequent minor revisions, following which it was formally introduced into clinical care. After several years of use, planning is underway for a formal evaluation. Subjectively, the CF TCCP is preferred for its attention to the nuances of such a complex disease, coupled with the underlying generic transition principles and strategies. The CF TCCP is handed over to the adult CF clinic at the time of transfer, providing a written transition summary and status report. More recently, adult multidisciplinary teams who have experienced the value of the intervention have asked for support in developing a CF TCCP for youth 19–24 years of age once they transfer to adult services. Although the efficacy of utilizing a generic

chronic illness versus disease-specific TCCP has not been addressed in the literature, staff clearly felt the complexities of CF were best addressed by a disease-specific tool. The CF TCCP is based on sound theory and expert practice. The adolescent chronic illness developmental framework and generic TCCP created by On TRAC have since become foundational for other transition programs globally (Royal College of Nursing, 2004).

Intervention #2: Collaboration on a Pre-Graduation Workshop

Continuity of care between pediatric and adult settings is both desirable and challenging. It requires an uninterrupted flow of clinical care, information and services across pediatric, adult and community jurisdictions (Haggerty et al. 2003). To address this, pediatric and adult CF clinical staff collaborated to develop a “CF transition pre-graduation workshop” in 2004. Its aim was to supplement existing transition care which by this time consisted of initiation of TCCP at age 10 (until 18 years), and attendance at a transition clinic before transfer to the adult setting. The workshop brought together local pediatric and adult CF healthcare teams with adolescent CF patients and their parents a year or two before transfer occurred in order for youth to gain a better understanding of the logistics and expectations of the adult system and CF clinic. The workshop included a computerized “CF medication Jeopardy” game; a visit from an adult with CF; sexuality talk from a youth health nurse; self advocacy video; and an overview by adult CF clinic staff. Evaluation of the workshop consisted of a pilot questionnaire developed to address aspects of the transition process such as expectations of the adult CF clinic and basic CF pathophysiology. It was administered to youth before and again after the workshop intervention to 6 youth (age range: 15–18 years). The youth scored better on their post-tests, and their verbal and written comments indicated they felt more knowledgeable about the expectations of adult caregivers, and that it was a worthwhile undertaking. Parents especially praised the opportunity to meet with members of the adult CF clinic. Although the number of participants was small, it was concluded that a CF pre-graduation workshop assists in addressing continuity of care between the pediatric and adult

clinic thus successfully addressing step two of our QI initiative. Six subsequent workshops were run from 2004 to 2008, at which time they were terminated due to emerging CF infection control concerns. With current technology it is planned to re-introduce this component by implementing a virtual pre-graduation workshop which would comply with CF infection control policies and undertake a formal evaluation based on results of the pilot questionnaire.

Intervention #3: A Readiness Scale for Youth With Cystic Fibrosis

A developmental approach to transition provides a sequential framework to assess the youth's and family's readiness to transfer (Betz, Redcay, & Tan 2003; Sawicki et al. 2009). Currently, the youth's readiness capabilities towards self-reliance and self-management skills have been identified as the most important predictor for successful transitions, demonstrating links between self-efficacy, health outcomes and quality of life (Binks, Barden, Burke, & Young 2007; Williams et al. 2010). Thus the final QI intervention was the creation and testing of a Cystic Fibrosis Readiness to Graduate Questionnaire [Supplement 2: "CFRGQ"]. The CFRGQ was created by the CF nurse clinician based on the recently validated ON TRAC model readiness questionnaire "Am I ON TRAC for Adult Care" (Moynihan, Saewyc, Whitehouse, Paone, & McPherson 2013). The scope of the CFRGQ reflects ON TRAC's 6 components of transition, and the knowledge/skill level reflect the "late transition stage" (16–18 years) of the CF TCCP. The first draft was reviewed by CF team members (allied health and CF specialists, who had an average of 21 years working with CF) for content validity, and by four CF youth for language comprehension. The goal of this intervention was to create a tool to measure youth perceptions of readiness to transfer to the adult CF health care setting; and in so doing to have a handover document to inform the adult CF clinic of further areas in need of attention.

Evaluation of CFRGQ

The CFRGQ was prospectively evaluated over a 1-year period by administering the questionnaire to CF patients just prior to their transfer to the adult CF clinic. A simple scoring system was developed whereby answering "yes" to a question indicated readiness to transfer; "somewhat" indicated more education intervention was required; and "no" indicated a patient is not prepared for adult healthcare in that particular area. A passing grade of 75% was arbitrarily set, and as such may shift as more research is done in this area.

Results and Discussion

All CF patients due to transfer in 2008 ($n = 12$: 5 females, 7 males; median age: 18 years) completed the CFRGQ within 2 months prior to their final pediatric visit. All had

followed the CF-TCCP since age 11–12 years. Responses were collected, quantified as per the scoring system, and analyzed. Nine out of twelve youth scored $\geq 75\%$ on the questionnaire, demonstrating a strong sense of perceived transfer readiness. Common 'problem areas' flagged for further education included: filling prescriptions, medical insurance and in-depth medication knowledge. Verbal feedback from CF youth indicated that the questionnaire was quick and easy to complete; that it was a useful concrete indicator of the upcoming transfer; and it helped to raise their confidence in feeling "ready" to move on to the adult CF clinic. Staff feedback indicated they valued having a concrete measure of readiness. It was also suggested that the scoring system be amended to a Likert scale which was subsequently done. It was concluded that the CFRGQ was a useful indicator of patient's perception of transition readiness, as well as trends in the youth's knowledge gaps and required areas for skill building. There are limitations to the CFRGQ, the most notable being that it has not been validated. Further, it does not necessarily capture different stages on a continuum of readiness such as the more recently validated transition readiness assessment questionnaire ("TRAQ") by Sawicki et al. (2009). Finally, the tool cannot be generalized beyond the adolescent's perception of readiness since evaluation did not include any objective measures of whether the patients had actually acquired the stated knowledge or skills. This was partially addressed by having the CFRGQ administered and analyzed by the CF nurse clinician who at that time had 15 years experience in her role, and had worked with these patients to achieve transition competencies (on the TCCP and CF-TCCP) since age 12 years. The nurse subjectively concurred with patients' responses as being an accurate reflection of their degree of readiness. More recently, it has been postulated that transition readiness should be assessed on multiple occasions using more than one tool in order to evaluate multiple factors (beyond patient age, knowledge and skills) that may facilitate or hinder successful transition (Kreindler & Miller 2013).

Summary

From 2000 to 2008, 40 youth (25 males, 15 females) were involved in this CF Transition QI initiative: 22 patients whose CF transition pathways were reviewed retrospectively (intervention #1); 6 patients who took part in the pilot pre-graduation workshop (intervention #2); and 12 patients who prospectively completed the CFRGQ (intervention #3). Evaluation results are summarized in Table 2.

Overall Discussion

With increasing life expectancy of CF patients, transition planning and preparation prior to transfer have become important in achieving high standards of care for the cystic fibrosis population. This is the first multidimensional *quality*

Table 2 Summary of transition interventions in CF Clinic: transition pathway; CF pre-graduation workshop; and CF Readiness to Graduate Questionnaire.

Intervention	Method of evaluation	Results	Conclusions
Adolescent Transition Care Clinical Pathway© (generic ON TRAC pathway)	Retrospective review of 4 years of pathway usage in CF clinic ($n = 22$ pathways): completion of indicators by youth; staff feedback.	<ul style="list-style-type: none"> • 73% indicators charted. • Highest % indicators met by youth were in sexual health (88%) and self advocacy (70%). • Lowest % indicators met in social supports (37%) and ed/voc/finan planning (40%). • Disease-specific education missed by staff; too much time needed for charting. 	<ul style="list-style-type: none"> • Its utilization led to earlier standardized transition care in CF clinic. • Worthwhile component of comprehensive transition program. • Disease-specific TCCP recommended.
CF “pre-graduation” workshop	Pre/post workshop questionnaire about the transition process; the adult CF clinic; and basic CF education administered to 6 youth who took part in pilot workshop.	<ul style="list-style-type: none"> • Youth scored higher on post tests. • Youth expressed better understanding re expectations of adult care. • Enjoyed the workshop. 	<ul style="list-style-type: none"> • It addresses continuity of care between the pediatric and adult CF clinics. • Worthwhile component of transition program. • Now requires reworking to comply with CF infection control policy
CF “Readiness to Graduate” Questionnaire	Questionnaire administered to 12 CF youth, ages 17 ½–18 years, about to graduate to adult CF clinic.	<ul style="list-style-type: none"> • 9/12 youth scored $\geq 75\%$. • Educational areas needing attention: names and dosages of medications, filling prescriptions, and medical insurance. • Positive feedback from youth. 	<ul style="list-style-type: none"> • Useful indicator of patient’s perception of transition readiness. • Worthwhile component of comprehensive transition program.

improvement approach to CF transitional care, which is an approach recently advocated by Tuchman, Schwartz, Sawicki, and Britto (2010). They point out that QI collaboration and methodology have successfully improved CF nutrition and respiratory care, and that a similar approach to transition may bring us closer to the ultimate goal of evidence-based guidelines. Our initiative also supports the assertion that pediatric nurses are well positioned to develop, implement and evaluate transition service models (Betz 2012) and to assume greater leadership roles in the area of adolescent transition (Betz 2013).

Looking back on the QI process, each intervention that was developed and evaluated addressed an important component of transition however the most significant change in practice was the introduction of a transition clinical pathway with subsequent adaptation to be condition-specific. Prior to this intervention, transition was generally introduced informally at around 15 years of age whereas today the CF TCCP is initiated with all CF patients at a much earlier age, in agreement with current transition policy statements (Canadian Pediatric Society 2007; Reaffirmed 2014). To utilize the CF TCCP ideally calls for an initial orientation to the underlying developmental transition framework as well as professional expertise to assist CF youth to meet various indicators. However, a strength of the pathway is that even CF staff members who lack experience with transition can, with a brief orientation, integrate transition teaching within their discipline-specific care. Still, introducing a transition

pathway was a major undertaking, taking several years to fully immerse the tool as a routine standard of care.

QI is not a static but a dynamic process, illustrated by the many years over which this transition project evolved. We have shown that it is possible to incorporate program development & evaluation into a busy workload through stepwise increments which progressively build upon each accomplishment. Utilizing the extensive work done by On TRAC and others has allowed us to achieve our goal of an interdisciplinary transition program for youth and young adults with cystic fibrosis.

There were limitations with this project: the small number of patients did not allow the design of a hypothesis-driven, outcomes based research study and therefore findings cannot be generalized. Our intent however was to emphasize the processes undertaken to implement and evaluate components of our CF transition program, which was the first to sequentially evaluate and develop multiple transition interventions. Further, the value of the QI process was affirmed in that our transition QI outcomes ally with current transition best practices described by Chaudhry, Keaton, & Nasr (2012) and McLaughlin et al. (2008). These authors advocate for a comprehensive approach to transition and in retrospect, our QI initiative addressed most transition components, including: *utilization of a transition timeline/checklist to aid in patient preparation; readiness assessment; strategies to address communication with adult care providers and coordination of services; and*

transition program self evaluation (via this QI process). Further, our pre-existing “transition clinic” format addresses *information transfer*. Areas remaining to be addressed by our transition protocol are: *primary and preventive health care; coordination of benefits; and patient follow-up*. These outstanding components identify further work to be done by our clinic, and serve as a reminder that effective transition programs require a comprehensive and high quality infrastructure.

Conclusions

In order to meet the needs of cystic fibrosis youth navigating the complex process of transition, care provided must be multi-dimensional (Craig, Pty, Towns, & Bibby 2007; Towns & Bell 2011). Our CF clinic first identified CF transition as a quality initiative with the establishment of the adult CF clinic. Since then, a multidimensional CF transition program has evolved with individual components built upon sequential improvements and evaluation. The cornerstones of this project include a CF transition care clinical pathway; collaboration with the adult CF clinic to improve continuity of care; and a CF Readiness to Graduate Questionnaire. Transition process, outcomes and efficiency have all improved as a result, fulfilling the goals of this CF transition QI initiative. The role of transition continues to evolve and will remain a key priority for our CF clinic.

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.pedn.2014.06.011>.

Acknowledgments

The authors wish to acknowledge Maggie McIlwaine; and the pediatric and adult CF teams at BCCH and St. Paul’s Hospital, Vancouver, BC.

References

- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Colley, W. C., & Sagerman, P. J. (2011). Clinical report—Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *128*, 182–200. <http://dx.doi.org/10.1542/peds.2011-0969>.
- Betz, C. L. (2012). Health care transitions: A peek into the future. *Journal of Pediatric Nursing*, *27*, 1–2.
- Betz, C. L. (2013). Health care transition for adolescents with special healthcare needs: Where is nursing? *Nursing Outlook*, *61*, 258–265.
- Betz, C. L., Redcay, G., & Tan, S. (2003). Self-reported health care self-care needs of transition-age youth. A pilot study. *Issues in Comprehensive Pediatric Nursing*, *26*, 159–181.
- Binks, J., Barden, W., Burke, T., & Young, N. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation*, *88*, 1064–1073.
- Canadian Pediatric Society (2007). Transition to adult care for youth with special health care needs: Position statement. Reaffirmed 2014. *Paediatrics and child health*, *12*, 785–788.
- Chaudhry, S. R., Keaton, M., & Nasr, S. Z. (2012). Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatric Pulmonology*, *48*, 658–665.
- Craig, S. L., Pty, B., Towns, S., & Bibby, H. (2007). Moving on from paediatric to adult health care: An initial evaluation of a transition program for young people with cystic fibrosis. *International Journal of Adolescent Medicine and Health*, *19*, 333–343.
- Culter, A., & Brodie, L. (2005). Transition care for young people—What should we be doing? *The Australian Health Consumer*, *3*, 16–17.
- Cystic Fibrosis Canada Patient Data Registry (2012). [Online]. Retrieved from. <http://www.cysticfibrosis.ca/wp-content/uploads/2014/03/Canadian-CF-Registry-English-FINAL-FOR-WEB1.pdf> [Accessed on April 17, 2014].
- Cystic Fibrosis Foundation Patient Registry Report (2012). [online]. Retrieved from. <http://www.cff.org/UploadedFiles/research/ClinicalResearch/PatientRegistryReport/2012-CFF-Patient-Registry.pdf> Accessed on April 17, 2014.
- Gravelle, A., Davidson, G., & Chilvers, M. (2012). Cystic fibrosis adolescent transition care in Canada: A snapshot of current practice. *Paediatrics and Child Health*, *17*, 553–556.
- Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: A multidisciplinary review. *British Medical Journal*, *327*, 1219–1221.
- Hughes, R. G. (2008). Tools and strategies for quality improvement and patient safety. In R. G. Hughes (Ed.), *Patient safety and quality: An evidence-based handbook for nurses* (pp. 1–25). Rockville (MD): Agency for Healthcare Research and Quality (US).
- Kennedy, A., & Sawyer, S. (2008). Transition from pediatric to adult services: Are we getting it right? *Current Opinion in Pediatrics*, *20*, 403–409.
- Kreindler, J. L., & Miller, V. A. (2013). Cystic fibrosis: Addressing the transition from pediatric to adult-oriented health care. *Patient Preference and Adherence*, *7*, 1221–1226.
- Madge, S., & Bryon, M. (2002). A model for transition from pediatric to adult care in cystic fibrosis. *Journal of Pediatric Nursing*, *17*, 283–288.
- McCurdy, C., DiCenso, A., Boblin, S., Ludwin, D., Bryant-Lukosius, D., & Bosompra, K. (2006). There is here: Young adult patients’ perceptions of the process of transition from pediatric to adult transplant care. *Progress in Transplantation*, *16*, 309–316.
- McLaughlin, S. E., Diener-West, M., Indurkha, A., Rubin, H., Heckmann, R., & Boyle, M. P. (2008). Improving transition from pediatric to adult cystic fibrosis care: Lessons from a national survey of current practices. *Pediatrics*, *121*, 1160–1166.
- Moynihan, M., Saewyc, E., Whitehouse, S., Paone, M., & McPherson, G. (2013). *Am I ON TRAC for adult care? Assessing adolescents’ readiness to transition*. Poster Session: Annual International Association of Adolescent Health (IAAH), Istanbul, Turkey.
- O’Loane, M., & Joy, L. (1992). The impact of cystic fibrosis patients’ transition from pediatric to adult care. *11th International Cystic Fibrosis Congress Abstracts; Dublin, Ireland*.
- Paone, M., Wigle, M., & Saewyc, E. (2006). The ON TRAC model for the transitional care of adolescents. *Progress in Transplantation*, *16*, 291–302.
- Peters, A., Laffel, L., Allbright, A., Bloomgarden, Z., Childs, B., Ehlinger, E., et al. (2011). Diabetes care for emerging adults: Recommendations for transition from pediatric to adult diabetes care systems. Position Statement of the Diabetes Association. *Diabetes Care*, *34*, 2477–2485.
- Royal College of Nursing (2004). *Adolescent transition care: Guidelines for nursing staff*. London: Royal College of Nursing.
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I. C., Livingood, W., et al. (2009). Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire. *Journal of Pediatric Psychology*, *36*, 161–171.

- Telfair, J., Alexander, L. R., & Loosier, P. S. (2004). Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *Journal of Health Care for the Poor and Underserved, 14*, 443–461.
- Towns, S., & Bell, S. (2011). Transition of adolescents with cystic fibrosis from paediatric to adult care. *Clinical Respiratory Journal, 5*, 64–75.
- Tuchman, L., Schwartz, L., Sawicki, G., & Britto, M. (2010). Cystic fibrosis and transition to medical care. *Pediatrics, 125*, 566–573.
- Whitehouse, S., & Paone, M. (1998). Patients in transition: Bridging the gap from youth to adulthood. *Contemporary Pediatrics, 13*, 15–16.
- Williams, T. S., Sherman, E., Dunseith, C., Mah, J. K., Blackman, M., Latter, J., et al. (2010). Measurement of medical self-management and transition readiness among Canadian adolescents with special health care needs. *International Journal of Child and Adolescent Health, 3*, 1–9.