

CF RISE: Implementing a Clinic-Based Transition Program

Anna M. Baker, PhD,¹ Kristin A. Riekert, PhD,¹ Gregory S. Sawicki, MD, MPH,² and Michelle N. Eakin, PhD¹

During the period of healthcare transition, adolescents should increase responsibility for managing their health. Transition services are associated with improved outcomes; however, many youth with chronic conditions such as cystic fibrosis (CF) are not receiving guideline-based transition services. Individual CF centers have transition programs, yet no specific program is widely disseminated. A transition program CF: Responsibility, Independence, Self-care, Education CF RISE was recently developed and implemented at 10 CF centers. We conducted a process evaluation of CF RISE implementation based on the Consolidated Framework of Implementation Research (CFIR). CF healthcare providers (23/25 [95%]) from the 10 sites completed an online survey about their experiences 6 months after initiating the program. Open-ended survey questions were coded into central themes addressing domains of implementation. Providers reported that CF RISE facilitated communication with the family, particularly the knowledge and skills assessments. All providers rated the program as valuable with 60% finding the program very or extremely valuable. Time was the biggest implementation barrier (96%) followed by planning for the visit (61%). Ninety-five percent felt the program could become a sustainable part of the clinic, and 91% felt that it was somewhat or completely likely that they would be using the program 1 year from now. Providers also appreciated the flexibility of the program. CF healthcare providers positively evaluated CF RISE during its initial implementation period. The feedback provides insight into the sustainability and challenges that must be considered as wider implementation plans are developed. It is critical to evaluate the effectiveness of programs such as CF RISE on the outcomes during the transition period.

Introduction

HEALTHCARE TRANSITION is a two-fold process in which adolescents are prepared to (1) take responsibility for managing their health and (2) transfer to adult-focused care.¹ Transition services are associated with reduced medical complications, improved patient reported outcomes, such as satisfaction, health status, knowledge, and quality of life, greater adherence to care, improved continuity of care, and lower healthcare costs.²⁻⁶ Despite the benefit of transition services, a national survey of children with special healthcare needs showed that only 40% of children are receiving guideline-based transition services.⁷ Barriers include a lack of provider knowledge of transition guidelines, a failure to initiate transition planning in early adolescence, and lack of structured transition programs.²

For adolescents and young adults with cystic fibrosis (CF), there is also inconsistent implementation of transition services.⁸ Discussions about transition and the actual transfer process occur across a wide age range. About half of CF centers allow patients to delay or decline transition and less

than 30% consistently offer visits or specific clinics focused on transition. Importantly, less than half of centers provided a transition timeline, designated a team member to be responsible for transition, or performed any kind of readiness assessment.⁸

Some specific CF transition programs have been evaluated and have targeted collaboration with adult services and developed tools and educational curriculums for use during transition.^{4,9,10} These interventions found positive outcomes such as earlier readiness to transfer, increased patient understanding of expectations in adult care, positive feedback from patients about the process, increased transition discussions with the families, increased patient self-advocacy, decreased inhospital transfer, and better health status and independence.^{4,9,10} Unfortunately, these programs have rarely been disseminated to or implemented at other centers.

The Consolidated Framework for Implementation Research (CFIR) is a commonly used framework for understanding implementation of interventions in new settings.¹¹ CFIR identifies five domains that impact implementation: *intervention characteristics, inner setting, outer setting, individuals, and process.*

¹Division of Pulmonary and Critical Care Medicine, Johns Hopkins University, Baltimore, Maryland.

²Division of Respiratory Diseases, Harvard Medical School, Boston, Massachusetts.

The *intervention characteristics* domain reflects that an intervention must come to a particular setting with the ability to be adapted and accepted by those giving and receiving the intervention. The *inner* and *outer setting* domains reflect the differences within both the broader setting (eg, hospital) and more direct setting (eg, clinic team or hospital unit) that can influence implementation. The *individuals* domain reflects the personal agency and influence of the personnel involved in implementation. The *process* domain reflects the active change process that must take place for both individual and organizational use of the intervention being implemented.

A comprehensive transition program (CF: Responsibility, Independence, Self-care, Education; CF RISE) was recently developed and piloted at 10 CF care centers across the United States. Including multiple centers provided a unique opportunity to examine the implementation process of a single transition program across sites to identify common barriers and facilitators that may affect the uptake and sustainability of transition programs. Study of these processes will aid in our understanding of how to better implement and sustain transition programs to ensure all youth with CF receive quality transition services.

Therefore, the purpose of this study was to conduct a *post hoc* mixed-methods evaluation of the feasibility of implementing a program (CF RISE) at 10 CF care centers. The evaluation was conducted 6 months postinitiation of the program at a site based on CFIR to identify which program components were perceived as most helpful, the barriers for implementation, and likelihood of continued use.

Methods and Materials

The CF RISE program

The CF RISE program was developed by a national multidisciplinary group of CF care providers with clinical and research expertise in transition. CF RISE was designed for use with individuals with CF aged 16–25 years and a support person (eg, parent and spouse). The centers were trained in the delivery of the program and participated in monthly group support calls. The CF centers, not the healthcare providers, were compensated a nominal amount for their efforts to train the CF care teams on the program, enroll patients, administer the program on at least two separate sessions per patient, and provide CF care team feedback. CF RISE was delivered as part of clinical care, and patients were not financially compensated. Eight out of the 10 centers that piloted CF RISE included a provider who consulted on the development of the materials.

CF RISE consists of 11 knowledge assessment modules (General CF Health, Lung Health & Airway Clearance, Pancreatic Insufficiency & Nutrition, CF Liver Disease, CF-Related Diabetes, Screening & Prevention, Equipment Maintenance & Infection Control, Sexual Health, Lifestyle, Insurance & Financial, College & Work) and a skills checklist with six modules (Working with the CF Care Team and Other Healthcare Providers, Responsibility for CF Treatments, Living with CF, CF Transfer, Insurance & Financial Planning, Education & Career Planning). A progress report tracks assessment results and documents goals and plans related to transition readiness. An educational resource guide provides links to online resources that corresponded with knowledge assessment items.

The intent of CF RISE was to develop a modular program. As such, each center individually tailors aspects of the program based on patient needs and center resources, including which and how many modules to administer, how the materials are accessed (eg, paper or online portal), where to administer (outpatient and/or inpatient), and which staff member will administer the survey and remediate knowledge and skills gaps. While there are existing tools and information available to aid in transition, CF RISE offers a package that is more comprehensive and focused on issues specifically pertaining to CF, particularly in the skills assessment. Gilead Sciences, Inc. funded the development and ongoing maintenance of the CF RISE program. The training and materials are available at no cost to any CF center (www.cfrise.com).

Procedures

This study was approved by the Johns Hopkins University Institutional Review Board. Providers at the 10 CF care centers were contacted through e-mail and invited to complete an online survey ~6 months after initiating CF RISE. The e-mail described the study and contained a link to access a Health Insurance Portability and Accountability Act of 1996 (HIPAA) compliant web-based survey. Study data were collected and managed using REDCap¹² electronic data capture tools hosted at Johns Hopkins University. The participant provided consent by completing and submitting the survey. The survey took 10–15 min to complete. Follow-up e-mails were sent three times to providers who did not complete the survey. The providers were not compensated for survey completion. The surveys were deidentified to keep the investigators blind to the CF care center of the provider.

Participants

CF care teams routinely include a multidisciplinary team consisting of physicians, social workers, nurses, respiratory/physical therapists, and dietitians. Of the 25 eligible providers, 23 (95%) completed the survey. Participants included 7 Physicians, 3 Nurse Coordinators, 1 Nurse, 1 Nutritionist, 10 Social Workers (1 of which was also Center Coordinator), and 1 Nurse Practitioner. There were 2 male and 21 female participants. Every center had at least one team member participate (median = 2, Range = 1–4). Fifty-two percent of participants worked with pediatric patients, 26% worked with adult patients, and 22% worked with both pediatric and adult patients.

Measures

Survey. The survey consisted of 57 questions using a mixed methods approach. Items included questions about the participant's background, role with the CF care center, and the center's transition practices before the start of CF RISE. Participants were asked about the center's experiences using CF RISE, including details about how the center implemented the program, who was involved, what components were used, and barriers that arose. Questions about satisfaction, efficacy, and so on were rated on a 1–10 scale with 10 being better.

Examples of the open-ended questions included the following: "What changes to clinic, pre-clinic, or post-clinic processes did you make in order to integrate CF RISE into your center long term?" "What are the biggest challenges to implementing CF RISE at your CF Center?" Questions about the sustainability and likelihood of use were also included in a free response format.

Analyses

Descriptive statistics were used to determine the frequency, mean, and standard deviation of responses to the survey using SPSS Version 22.¹³ The open-ended questions were coded into central themes based on the CFIR domains.

Results

Transition practices before the implementation of CF RISE

Before implementing CF RISE, CF care center providers reported transition practices similar to those found in the earlier CF transition survey study (Table 1).⁸ Social workers were most frequently noted as the primary staff member responsible for engaging the family regarding transition and transfer (52%) followed by nurse coordinators (26%). Respondents rated the center's transition efforts before starting CF RISE as 6.4/10 (SD=2.0) for meeting patient's needs.

Evaluation of CF RISE

Delivery of program. The programs enrolled a mean of 9 (SD=4; range 5–23) patients. Care team members reported that social workers (65%) and nurse coordinators (26%) were primarily responsible for implementing CF RISE, although most members of the care team were also involved. The sessions usually took between 11 and 30 min (78%). One to three knowledge modules were typically administered at each clinic visit, with 2–3 being most common (61%). At each visit, 27% of providers assigned all sections of the skills checklist,

whereas 64% assigned one or two sections ($N=22$ due to missing data for that question). Thirty-nine percent of providers indicated that they used the progress report to develop transition goals, and 57% ($N=21$) of providers used the educational resource guide with a patient.

Feedback on the implementation of CF RISE. Providers rated the average overall effectiveness of the Knowledge Assessment and Skills Checklist as 7.9/10 (SD=1.1) and 8.5/10 (SD=1.4), respectively. Care providers rated the CF RISE program as valuable (40%), very valuable (45%), or extremely valuable (15%). Almost all (95%) felt the program could become a sustainable part of the clinic with no or only minor modifications. Respondents felt that it was somewhat (43%) or completely (48%) likely that they would be using the program 1 year from now.

Implementation: CFIR domains

Intervention characteristics. Providers thought the intervention was adaptable in that they could use the modules most relevant for a particular patient at each visit and that the tools were easy to tailor for the particular participant:

"I like having a tool to use to assess knowledge gaps, identify education needs, foster communication, and better equip patients for transition and becoming responsible for their care."—social worker

"To see what areas need more work and focus on those skills."—nurse coordinator

The providers felt that the program was high quality and helped facilitate communication with the transitioning family:

"Positive-good to start communication, goals for growth, address knowledge gaps."—social worker

"Has improved dialogue on selected topics. Has had positive effect on truth telling given the verification piece of the dual [parent and adolescent completed] skills assessment"—physician

"It did show us where our patients were deficient in knowledge."—nurse coordinator

Outer setting. Providers indicated that the program helped identify and address patient needs:

"Clinical concerns around adherence and/or need for increased transition skill-building"—social worker

"...readiness for particular assessments (age and identified need); part of teen program, specific disease complication, i.e., CFRD."—nurse coordinator

Inner setting. The structural characteristics of the clinic were important to consider in implementation, and providers felt that taking this into account was imperative to the success of the program:

"Schedule longer visit, utilize weekly clinical conference to discuss CF Rise findings/goals moving forward, have administrative support to assist with flagging patients, having tablets available, etc."—social worker

"Closer review of assessments prior to clinic. Difficult because not all disciplines attend pre-clinic meeting so hard to make a plan without them present."—social worker

"Incorporate into huddle meetings"—physician

Overall, providers felt the program was compatible and easy to incorporate with existing transition practices:

"We will likely incorporate with some other tools we have used previous to using."—social worker

TABLE 1. PRACTICES BEFORE THE IMPLEMENTATION OF CF RISE

Activity	% providers reporting about their center (N=23)
Reviewed a patient's transition readiness with the care team	83
Scheduled an outpatient visit for adult team members to meet with patient/family	83
Provided educational materials about adult care to patients/families	74
Held joint pediatric–adult CF program meetings to discuss transferring patients	70
Provided follow-up on transferred patients to the pediatric program	68 ^a
Developed a transition care plan with patient/family	61
Scheduled an outpatient visit focused primarily on transfer of care	57
Obtained a written medical summary for transfer to the adult program	57
Formally assessed patient's skills for independent disease self-management	39
Provided a written transition care plan to the patient/family	22
Obtain a written medical summary for transfer from the patient/family	17

^a $N=22$ due to missing data. CF, cystic fibrosis.

“We hope to streamline the materials that CF RISE provides into our current practice.”—physician

Engagement of the full care team in the program was seen as critical and providers felt that higher engagement would lead to better implementation:

“Need buy-in and more info sharing between adults and peds to make it work”—social worker

“More team involvement is needed to make the program successful.”—social worker

“It will take time and continued effort on the coordinator’s part, and continued buy in from more team members, and understanding of roles.”—nurse coordinator

Resources were important to consider, and providers felt certain resources, like tablets, helped facilitate successful implementation:

“We purchased tablets for [CF RISE] to deal with infection and computer tie up issue and portability not to tie up office space where desk top computers are used.”—physician

Characteristics of individuals. Overall, providers believed that the intervention could be used effectively and were confident in their ability to implement the program:

“I am dedicated to using the tool set and incorporating CF RISE to our Center Adult and Ped’s.”—nurse coordinator

“As the adult team social worker I am invested in having our patients better prepared when transitioning..., as it makes for a better patient experience. I value having a more formal, objective way to track patients’ knowledge, resulting in being better able to clearly identify education needs and when and how these needs are being met.”—social worker

Process. They also felt the program was ready for implementation at their centers:

“We will be integrating CF Rise into our work developing a more rigorous transition program...”—social worker

“Plan to use it as part of the tools for transition and moving toward independence for patients.”—social worker

Providers commented on the planning necessary to execute the program, including workflow needs and increased time before the visit to plan:

“We will need to spend more time during pre-conference to set process up for each patient”—physician

“I feel strongly that we can make this happen if we can organize its administration and discuss findings/plan of care and delegate which team member will work on identified knowledge and skill deficits”—social worker

In general, time was most commonly listed as the biggest barrier to implementing the program. Providers also noted coordination with clinic staff and clinic organization/planning as barriers.

Overall, in reflecting and evaluating the process, providers indicated that the program would be a sustainable and useful part of their practice and were excited about the program:

“We believe it is a useful tool for assessment and education of patients.”—social worker

“We are very very excited to use a measureable tool and provide concrete education for CF patients who are transitioning to adult program.”—social worker

“There are likely to be edits suggested with time, but it seems to work well with the current setup”—physician

Discussion

Before the use of CF RISE, only 39% of participants said their center formally assessed transition readiness skills. Most programs did not prepare a medical summary before transfer, and there was a failure to deliver specific services consistently to all patients, which was similar to previous research.⁸ CF RISE provided a structured transition program in a modular format that could be tailored to the clinic and patients and has the potential to assist centers in overcoming this deficiency.

CFIR was used to examine the feedback of the providers. The providers appreciated the quality of the intervention materials and felt the modular format provided useful tools that could be selected based on patient needs for both the assessment of knowledge and building of skills. Participants particularly liked that the tools could be used to measure transition readiness. Providers also thought the intervention was compatible with clinic procedures overall as well as other tools the clinics had been using. The materials were reportedly easy to use with minimal additional resources required, and providers were confident they could use the tool sets and program. Overall, providers liked the modular format that allowed for tailoring and felt CF RISE was a high quality, useful program that they wanted to continue in some capacity in the future.

Previous studies¹⁴ that used CFIR to evaluate implementation found factors that facilitated implementation, including designating a person responsible for the program, ensuring clear communication with the team, and enthusiasm for achieving targeted outcomes. This is similar to our findings that one person (often the social worker) was primarily responsible for the program, participants felt communication/teamwork was important for sustained implementation and participants felt enthusiastic about the program’s ability to aid in transition. Previous transition interventions¹⁵ increased patient knowledge, increased awareness, and improved attitudes toward the program, which is similar to our finding that the participants perceived that CF RISE increased patient knowledge and targeted patients who would benefit from the program. Although programs and settings used in implementation research are quite diverse, CFIR is unique in its ability to organize valuable information that will guide implementation in the future as well as allow for comparisons of similar programs and settings to determine best practice.

While CF providers appreciated the flexibility and ease of use of the program, they noted that structural changes to the clinic, including increased resources, team buy-in, and better organization of the team, would lead to more sustainable implementation. The care team members had overall favorable views of the program and felt it was sustainable in the future. Particular focus on the structural components such as resources and logistics might help facilitate better implementation. In addition, planning and better communication between providers might lead to more systematic use of program components. CF centers may benefit from an aide or manual that could help with the implementation of the program focusing on fostering buy-in from the team, efficiency in implementing modules, and planning as a team for the program components.

There are some limitations that need to be considered: this was a *post hoc* investigation and the open-ended questions were not geared toward addressing the specific CFIR

domains. Future research should use CFIR to help guide the scaled up implementation of transition programs to more centers and subsequent analysis to determine whether this process was successful and what areas need further improvement. In addition, we had multiple providers report on their perception of transition practices within their care center. Due to the small sample size, we did not account for this clustering within center since many providers worked with both the adult and pediatric teams and we wanted to represent individual provider's perceptions of transition practices within their center, even if there was duplication or discordance within the center. The centers did not systematically provide this program to all patients, and centers individually decided which patients and how many to approach about participating. Future research should examine the feasibility of scaling the program to include all transitioning adolescents. Families and patient feedback was also not available, and future research should examine the materials, acceptability, and barriers from the patient perspective. The participants represent early adopters; indeed, many helped develop the program. Later, adaptors may have a different perspective on the usefulness of the program or encounter different or more barriers to its use. Finally, we did not evaluate the efficacy of the CF RISE program. The evaluation focused on the feasibility of using this program across multiple centers. Longitudinal randomized trials should examine whether CF RISE or other transition programs result in better patient outcomes during transition and, more importantly, after transfer to adult clinics.

Conclusion

Early adopter CF care centers reported positive attitudes about CF RISE, found it a useful tool, and planned to continue using the program. The implementation of CF RISE at 10 centers has shown that CF RISE has the potential to address the deficits in transition, although future work is needed to determine whether the program could be used on a broader scale with all transitioning adolescents at CF centers. As this program is adopted at more CF care centers, future research on efficacy will be critical. The feedback provides insight into the ongoing sustainability and challenges, such as team buy-in, time, space, and resources that must be considered as programs are developed. It is critical to evaluate these programs further as they are scaled up and modified to fit more centers. An important area of future study will be the impact that transition programs have on CF outcomes.

Author Disclosure Statement

Dr. Baker and Dr. Eakin have no personal and financial support or commercial associations that might create a conflict of interest in connection with this article. Dr. Sawicki and Dr. Riekert have served on advisory boards for Gilead Sciences, Inc. for the purpose of development of the CF RISE program. Gilead Sciences, Inc. was not involved in the design, collection of data, or analysis or interpretation of results for this study.

References

- American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 2002; 110:1304–1306.
- American Academy of Pediatrics, Department of Research. Survey: transition services lacking for teens with special needs. *AAP News* 2009; 30:12.
- Cadario F, Prodam F, Bellone S, Trada M, Allochis G, Baldelli R, Esposito S, Bona G, Aimaretti G. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach. *Clin Endocrinol (Oxf)* 2009; 71:346–350.
- Chaudhry SR, Keaton M, Nasr SZ. Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatr Pulmonol* 2013; 48:658–665.
- McDonagh JE, Southwood TR, Shaw KL; British Society of Paediatric and Adolescent Rheumatology. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford)* 2007; 46:161–168.
- Wojciechowski EA, Hurtig A, Dorn L. A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: a need for case management services. *J Pediatr Nurs* 2002; 17:18–27.
- Park MJ, Mulye TP, Adams SH, Brindis CD, Irwin CE. The health status of young adults in the United States. *J Adolesc Health* 2006; 39:305–317.
- McLaughlin SE, Diener-West M, Indurkha A, Rubin HR, Heckmann R, Boyle MP. Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices. *Pediatrics* 2008; 121:1160–1166.
- Gravelle A, Davidson G, Chilvers M. Evaluation of a multidimensional cystic fibrosis transition program: a quality improvement initiative. *J Pediatr Nurs* 2015; 30:236–243.
- Okumura MJ, Ong T, Dawson D, Nielson D, Lewis N, Richards M, Brindis CD, Kleinhenz ME. Improving transition from paediatric to adult cystic fibrosis care: programme implementation and evaluation. *BMJ Qual Saf* 2014; 23:64–72.
- Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings in to practice: a consolidated framework for advancing implementation science. *Implement Sci* 2009; 4:50.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009; 42:377–381.
- IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.
- Nouwens E, van Lieshout J, Wensing M. Determinants of impact of a practice accreditation program in primary care: a qualitative study. *BMC Fam Pract* 2015; 16:78.
- Breimaier HE, Halfens RJG, Lohrmann C. Effectiveness of multifaceted and tailored strategies to implement a fall-prevention guideline into acute care nursing practice: a before-and-after, mixed-method study using participatory action research approach. *BMC Nurs* 2015; 14:18.

Address correspondence to:
Michelle N. Eakin, PhD
Johns Hopkins University
5501 Hopkins Bayview Circle
Baltimore, MD 21224

E-mail: meakin1@jhmi.edu

Received for publication October 7, 2015; accepted after revision November 20, 2015.