A Program Evaluation of a Cystic Fibrosis Transition Program at an Academic Medical Center

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A Scholarly Practice Project presented to the Graduate Faculty of the University of Virginia in Candidacy for the Degree of Doctor of Nursing Practice

School of Nursing

University of Virginia

May 2022

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Abstract

Objective: To conduct a program evaluation to evaluate the patient experience with transition from pediatric to adult cystic fibrosis health services and describe the health stability of patients with cystic fibrosis (CF) during the transition process.

Background: The goal of transition is to facilitate continuous and uninterrupted care and support for patients with cystic fibrosis as they transition from pediatric to adult health services. The Cystic Fibrosis Foundation (CFF) advocates for structured health care transition interventions and programs that are linked with increased patient satisfaction, decreased patient anxiety, and increased self-efficacy, all of which increase patient engagement in their own care. Despite this, considerable variability exists regarding the implementation of such interventions among CFF-accredited care centers.

Methods: The Centers for Disease Control and Prevention's (CDC) Framework for Program Evaluation in Public Health was used to conduct this program evaluation. This program evaluation employed a post-transition survey with quantitative and open-ended questions (n=3) to examine transition readiness, transition-related anxiety, and satisfaction with the transition process. A retrospective chart review was conducted in the electronic health record (n=18) to describe the health stability of patients with CF during the transition process to include number of days between the last pediatric and first adult office in the CF center, adherence to quarterly visits, non-routine office visits, hospitalizations, emergency department visits, and forced end expiratory volume (FEV_1) in the year before and after transfer of care.

Results: Due to low participation rates, there was insufficient data to make conclusions on the post-transition survey data. Of three completed surveys, there was consensus on having significant concerns regarding leaving their pediatric team behind and that meeting with their pediatric team without their parents present was very helpful, and strong agreement that patients were satisfied with their care in the pediatric CF center. Data collected from the EHR (n=18) revealed the mean number of days between the last pediatric and first adult CF center to be 68.7 (SD 44.5) and overall adherence to routine appointments was over 85%, indicating continuous, uninterrupted care. Utilization of additional health care services for CF-related illnesses for non-routine office visits, hospitalizations, and emergency department visits remained stable after transition, and FEV_1, the primary clinical indicator for CF, was also stable after transition.

Implication for Practice: This scholarly project contributes to the body of knowledge on transition processes and patient outcomes from the perspective of recently transitioned patients in an AMC. Results from this program evaluation intervention are encouraging that existing transition interventions utilized by the CF center are beneficial for patients and that health stability remains steady during the transition process. Recommendations include: administering a shorter post-transition survey that is more specific to this CF center, continuing to implement a more structured and standardized evidenced-based procedure for transition, and re-evaluating health stability measures of recently transitioned patients.

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Background and Significance

Advances in treatment regimens for cystic fibrosis (CF) have led to increased life spans for patients living with a disease in which few patients previously survived until adulthood. There are now more adult patients with CF than children who have the disease, as 57.2% of the patient population with CF are over the age of 18 (Cystic Fibrosis Foundation (CFF), 2020). This increase in survival rate necessitates the development of transition programs to facilitate transfer of care from pediatric to adult health care services. Historically, patients with CF who lived until adulthood received medical services in pediatric facilities. But this increase in longevity has created a need for disease-specific adult services inclusive of family planning, fertility issues, long-term complications, and age-related changes. Therefore, there is a need for transition services to ensure that adolescents and young adults with CF can successfully transition their medical care to adult healthcare services.

Cystic Fibrosis is the most common life-threatening autosomal recessive disease in White individuals worldwide and affects more than 30,000 patients in the United States (Bono-Neri et al., 2019). Once thought to be a disease affecting only Whites, it is now known that CF affects all races, with non-White Hispanics and Blacks making up 9.6%, and 3.5% of individuals affected in the United States respectively (CFF Patient Registry, 2020). CF is caused by the mutation of the gene that produces the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) protein, which regulates intracellular sodium, chloride, and water balance. When the CFTR protein is dysfunctional, chloride and water are prevented from crossing the cell membrane, resulting in increased mucous production and plugging, particularly in the cells of the lungs and gastrointestinal tract (Hull, 2012). Consequently, CF is manifested by chronic obstructive lung

disease, pancreatic insufficiency, diabetes, malabsorption and malnutrition, liver disease, and infertility (Bono-Neri et al., 2019).

Prior to the discovery of the CFTR gene in 1989, treatment of CF had largely focused on symptom management and infection prevention. The identification of the CFTR gene led to the research and discovery of CFTR modulators, a new class of drugs that act by improving production, intracellular processing, and the function of the defective CFTR protein (CFF Genetics, n.d.). There have been significant improvements in CF therapies over the past 40 years including inhaled therapies, antibiotics, pancreatic enzymes, and airway clearance that have improved the lifespan of CF patients (West & Mogayzel, 2016). The ability of CFTR modulators to treat the underlying disease by slowing or preventing the progression of the disease has the potential to dramatically increase the life span of individuals affected. In 2019, the CFTR modulator triple therapy drug Trikafta was approved by the U.S. Food and Drug Administration for patients over 12 years of age to treat a specific mutation that affects 90% of individuals or approximately 27,000 patients with CF (CFF, 2021). An additional 1500 children were eligible to take Trikafta with the most recent extension of this approval to patients ages 6-11 years of age in June of 2021, and researchers theorize that starting this drug in early childhood prior to rapid disease progression may prevent the most common complications of CF before they start (CFF CFTR Modulator Therapies, n.d.). Health care advances such as these are likely to further extend the lives of patients living with CF leading to the transition of more patients from the pediatric to the adult setting.

Chronic illnesses such as CF represent many challenges for adolescents, who are also undergoing substantial developmental changes during this time period. Graduating from high school, starting college, or beginning a career, and becoming legally responsible for personal

decisions are significant life events that may occur during this time. Compared to their non-affected peers, patients with chronic conditions achieve milestones later in life or not at all, including having careers and personal relationships (Goralski et al., 2017). Additionally, physical changes associated with adolescence, including lung function decline and increased treatment burden often coincide with the timing of transfer to adult CF care (West & Mogayzel, 2016). Data shows that pulmonary function as measured by forced expiratory volume in one second (FEV_1) sharply declines in adolescence between ages 13 and 21(Bishay & Sawicki, 2016).

Medication adherence and compliance with treatment regimens often decrease as adolescents take more responsibility for their own health care needs during this time. Treatments for CF can be complex, time-intensive, and onerous, consisting of multiple rounds of oral medications, chest physiotherapy, and nebulized treatments daily. Developmentally, predisposition for risk-taking behavior, the need for social acceptance, and the isolation of managing a chronic disease may negatively impact compliance with medical regimens. Adolescents may view the separation from parents as an opportunity for freedom from the ties of their CF treatment regimen. The lack of disease knowledge, self-efficacy, and negative perceptions of necessity of treatments are also factors that can lead to poor adherence in adolescents with CF (Faint et al., 2017). Inadequate preparation for adulthood and the disruption of the long-term health care relationship can impact adherence and quality of life in adolescents with CF (Faint et al., 2017). Depression and substance abuse, which are increasingly common in adolescents, are also associated with poor adherence (Bishay & Sawicki, 2016).

With more individuals affected by CF living until adulthood, there is an increased focus on the importance of the transition process from pediatric to adult services. Health care transition is a complex process wherein adolescents and young adults are prepared to take responsibility for

managing their own health and transition to adult care (Baker et al., 2015). Planned transition is a gradual process that begins early in adolescence and culminates in eventual transfer, which involves the actual movement of the patient into adult care services. It involves a systematic approach to introducing patients to issues related to self-management, autonomy, and personal decision-making. The goal of a planned transition is to improve the quality of life, maximize independence, and minimize interruption in care as a patient moves from a pediatric to an adult subspecialist (Goralski et al., 2017).

Structured healthcare transition program interventions are associated with reduced medical complications and improved patient outcomes, such as satisfaction, knowledge, health status, and quality of life, greater adherence to care, improved continuity of care, and lower health care costs (Baker et al., 2015). Despite these benefits, there is inconsistent implementation of transition services. Factors such as lack of provider knowledge on transition guidelines, failure to implement transition planning in early adolescence, and lack of structured programs all contribute to this lack of implementation (Baker et al., 2015). While no single transition process works in all health care systems, most transition programs are comprised of three main components: readiness assessment, progressive knowledge and skill education, and support structures to include collaboration with adult services (Patel et al., 2017).

The Cystic Fibrosis Foundation (CFF) advocates for a planned, structured approach to transition that allows for continuous and sustained care and support for adolescents and young adults with CF (Gorlaski et al., 2017). The CFF was started in 1955 to meet the needs of children and families affected by CF through funding, research, and advocacy and currently accredits over 130 CF centers. In 2008, in a push to expand adult services, the CFF recommended that all CF centers transfer 90% of their patients to adult providers by the age of 21. Today over 100 CF

centers in the United States have both pediatric and adult programs under the umbrella of one CF center (Gorlaski et al., 2017). Despite the recommendations of the CF Foundation, marked variability exists in the implementation of transition services from center to center.

The purpose of the scholarly project was to complete a program evaluation of an Academic Medical Center's (AMC) Cystic Fibrosis Transition program that has been gradually implemented over the past 10 years but has not been formally evaluated. The CF Transition team is in the formative stages of developing more structured transition procedures and information obtained from this program evaluation will assist the team in determining the program's current status and inform future programmatic elements. The Centers for Disease Control and Prevention (CDC) Framework for Program Evaluation in Public Health was used to guide this program evaluation.

Review of the Literature

The review of the literature centered on the following question: What factors impact the successful transition from pediatric to adult health services in adolescents and young adults with CF? An integrative literature review was conducted to investigate the present research available pertaining to transitional care interventions and programs for adolescents and young adults with CF. The review of literature was conducted to examine research relating to CF and the transition process available from January 2010 to August 2021. A master's-prepared health services librarian guided this search to ensure that search methods were accurate and reliable.

Search Strategy

Four databases were searched: Cumulative Index to Nursing and Allied Health Literature (CINAHL)**,** Web of Science**,** PubMed, and Cochrane Library. The search process for these four databases, utilizing the Preferred Reporting Items for Systematic Reviews and Meta-Analyses

(PRISMA) flow diagram, is displayed in Figure A1. CINAHL was used as the primary database for comparing duplicates as it yielded the most results of all database searches.

In the CINAHL database, an advanced search was performed using the search term *transition,* which was searched along with the MeSH headings "transition to adulthood" and "transitional care." A search using the term *cystic fibrosis* and the MeSH heading "cystic fibrosis" was combined with the previous search using the Boolean operator AND to yield 142 CINAHL results. The following search string was used in both the Web of Science and the Cochrane Library: (*"transition to adult care" OR "transitional care") AND cystic fibrosis* yielding 99 and 17 results respectively. In the PubMed database, the following search string was used: (*"transition to adult care"[MESH] OR "transitional care"[MESH]) AND ("cystic fibrosis"[MESH] OR "cystic fibrosis"[TIAB]).* This search yielded 57 results. Filters were used in all searches for dates (January 2010 – August 2021), language (English language only), and document type (articles and reviews) to yield a total of 230 articles for review.

Reference management software was employed to organize the retained articles and subsequently 175 articles remained to be reviewed after duplicates were removed. In the title and abstract review, 86 articles were excluded based on the following criteria: Adult-specific CF issues (6), focus on disease process or management (23), not nursing-focused (2), not CF-related (36), not transition-related (14), and specific to region/language (5). This resulted in a total of 89 articles retained for full-text review.

After the full-text review of 89 articles, 60 articles were excluded using the criteria that the articles did not pertain to CF, adolescence, and the transition process. Upon a final review, an additional 12 articles were removed that did not focus on factors influencing successful transition from pediatric to adult health care services and an additional 2 articles were removed as they

were used in retained systematic reviews totaling 15 articles retained for further analysis. An additional research article was added after consultation with a transition expert yielding a total of 16 articles retained for this systematic review (Middour-Oxler et al., 2021).

Levels of Evidence

The Johns Hopkins Nursing Evidence-Based Practice model (JHNEBP) was used to analyze the sixteen articles that were retained from this literature search (Dang & Dearholt, S, 2017). Levels of evidence spanned a wide range between Levels I and V. The highest levels of evidence were provided by three systematic reviews of the literature, with the highest review rated Level I evidence, and two reviews rated Level II evidence (Campbell et al., 2016; Coyne et al., 2018; Crowley et al., 2011). The systematic reviews of the literature that were included focused on an evaluation of the effectiveness of transition interventions in adolescents and young adults with any chronic diseases to include CF. However, the sources in this literature review that were not systematic reviews focused on transition interventions/programs for CF specific to CF only. Level II evidence was also provided by four quantitative studies: two mixed methods retrospective studies and two quasi-experimental studies evaluated specific transition interventions/programs for adolescents and young adults with CF (Chaudry et al., 2013; Middour-Oxler et al., 2021; Peeters et al., 2019; Schmidt et al., 2016). A mixed methods exploratory design, a prospective observational study, and a qualitative phenomenological study all provided level III evidence, evaluating the implementation of structured transition programs into outpatient CF clinics and patient experiences with transition programs (Al-Yateem et al., 2012; Baker et al., 2015; Skov et al., 2018). Two quality improvement projects that implemented and evaluated CF transition interventions provided level V evidence for this analysis (Gravelle et al., 2015; Okumura et al., 2014). Four level V narrative reviews were retained for this literature

review as they provided information regarding experts' clinical experiences with barriers and challenges to the transition process (Frederick, 2016; Gorlaski et al., 2017; Towns & Bell, 2011; Tuchman et al., 2010).

Thematic Analysis

Articles were retained for this systematic review if they cited factors that influence the transition process for adolescents and young adult with CF. A thematic analysis of the literature was performed to define commonalities and patterns amongst the retained articles. Three distinct themes emerged from this analysis: interventions, structured versus unstructured transition programs, and risks and barriers to the transition process. Interventions were divided into three subcategories: education-based interventions, or interventions that focus on providing patients with the knowledge necessary to transfer successfully, health service-delivery-based interventions, or those interventions that relate to the process of providing care, and thirdly, collaborative interventions, or those interventions that are shared between the pediatric and adult health care teams. All of these interventions measured similar outcomes, most commonly patient knowledge, self-management skills, satisfaction with care, anxiety, and to a lesser extent, health outcomes. The second main theme was structured versus unstructured transition programs. Structured transition programs have formalized processes in place, while non-structured transition programs refer to programs that have some transition interventions in place but lack formality and structure in providing overall care. The third major theme identified for this thematic analysis was risks and barriers to transition, which identifies the challenges to successful transition experienced not only by patients, but also challenges in providing adequate transition services for parents or caretakers, health care providers, and health organization. These

three themes contribute to the body of evidence for improving transition services for adolescents and young adults with CF.

Interventions

Education-based interventions. Educational transition interventions center around the unique knowledge requirements of the adolescent or young adult with CF who is transitioning from pediatric to adult medical care and include education and skills training. Of the 15 articles retained for the analysis, four original studies and two systematic reviews concerned educational transition interventions (Baker et al., 2015); (Campbell et al., 2016); (Crowley et al., 2011); (Gravelle et al., 2015); (Okumura et al., 2014); (Schmidt et al., 2016).

Baker et al. (2016) described a transition program called CF R.I.S.E. (Cystic Fibrosis Responsibility, Independence, Self-care, Education) which centers around education modules and knowledge assessments. Knowledge assessments modules include topics such as General CF Health, Lung Health and Airway Clearance, Pancreatic Insufficiency & Nutrition, Sexual Health, and College and Work with subsequent skills checklists. This study examined health care providers' perceptions of CF R.I.S.E. and findings showed providers found the program to be highly valuable and sustainable, and that the modular format provided useful tools that could be tailored to the clinics' and individual patient needs (Baker et al., 2015). Providers found that overall, CF R.I.S.E was a useful tool to assess transition readiness in the adolescent population.

In a systematic review of the literature, Campbell et al. (2016) evaluated four randomized controlled trials for the effectiveness of interventions designed to improve the transition of care for adolescents from pediatric to adult health services. Three of these interventions were education-based interventions and two were found to have a significant effect on increasing knowledge and disease self-management, though they had no effect on disease status or clinical

outcomes. This study included Huang et al.'s (2014) technology-based intervention study, which found that a web and short message service (SMS) intervention yielded improvements in transition readiness and chronic disease self-management (Campbell et al., 2016). This study also found that nurse-led, one-on-one counseling led to improvements in transition readiness and disease self-management.

In an earlier systematic review of the literature, Crowley (2011) cited five patient-focused transition interventions which included both disease-specific and generic education and skills training for adolescents and young adults with chronic illness. While four out of five of these interventions were deemed successful, the only statistically significant results pertained to patients with insulin-dependent diabetes mellitus (IDDM). It is unclear if the differences in the disease processes of IDDM and CF preclude these interventions from being successful with differing populations (Crowley et al., 2011).

Two quality improvement initiatives followed the development and implementation of educational transition interventions for adolescents and young adults with CF (Gravelle et al., 2015); (Okumura et al., 2014). The implementation of a Transitional Care Clinical Pathway (TCCP) was found to improve the number of transitional items discussed with patients through the use of clinical indicators (Gravelle et al., 2015). The TCCP used a clinical checklist or screening tool, education strategies to build knowledge and awareness of CF, and skill building exercises to manage their disease and navigate the adult health care system. Findings from this quality improvement program showed that the earlier this pathway was started the more indicators were met by the time the patient was of the age to transition, indicating that the TCCP should be started early to be successful by the time the patient's care is transferred to adult care. In a multiphasic process, Okumura (2014) developed a curriculum for the transition process

based on the Health Belief Model. Transition education materials for patients and families were developed using this framework and focused on addressing gaps in disease knowledge and health status beliefs. Results of this program showed improved rates of discussion of transition with families in the pediatric center (35% to 73%) and improved transition readiness self-advocacy scores (Okumura et al., 2014).

Schmidt et al. (2016) examined the effects of a generic transition-oriented patient education program. This study asserted that a generic patient education program can be efficient because the psychological factors associated with the adaptation to the condition are similar and mostly independent of the diagnosis (Schmidt et al., 2016). Using a framework based on empowerment, this educational intervention aimed to strengthen the preparedness of adolescents and young adults with chronic diseases to be responsible for and self-manage their own condition. Findings showed that patient-focused education provided to adolescents with chronic diseases in a group format significantly affected transition competence and self-efficacy, but did not significantly affect patient activation or engagement, quality of life, and patient satisfaction with healthcare. While Schmidt et. al (2016) reported the efficacy of generic transition interventions, Crowley et al.'s (2011) systematic review of the literature found disease -specific and generic interventions highly successful in terms of transitional competencies.

Health care service delivery interventions. Two original studies and two systematic reviews explored health care service delivery transition interventions. Health care delivery transition interventions center on the process by which care is provided to patients. In Peeters et al., (2019) a transition clinic utilized a nurse coordinator, or a designated member of the health care team who acted as a driver for the transition process by facilitating transfer of all patients to adult care, handling logistics and being accessible to patients. The transition coordinator, usually

a registered nurse or nurse practitioner, is responsible for all the logistics of transition and ensures that education relating to transition is provided early in the process. The transition coordinator may act as a spokesperson and advocate for young adults and adolescents during the transition period. Patients in this transition clinic showed higher satisfaction levels with the transition experience than those in the direct hand-off group but did not show significantly different health outcomes in their disease status (Peeters et al., 2019).

Skov et al. (2018) used a split visit consultation model to promote autonomy for patients preparing for transition. In this model, adolescents were seen alone by a provider during the first half of their consultation and together with a parent or caregiver during the remaining portion of their appointment. Used along with nurse-led consultations, findings showed that self-assessed transition readiness scores increased, and overall health related quality of life remained stable after this intervention (Skov et al., 2018).

Two systematic literature reviews evaluated health care delivery transition interventions. Campbell et al. (2016) found the use of transition coordinators led to patients taking more initiative in communicating with their health care providers. In this same review, a technology-based intervention was used not only as an educational intervention, but also acted as a mechanism by which patients could obtain direct access to their CF health care team, and findings showed this, along with the educational component of the program, enhanced communication and improved transition readiness and disease management skills. Crowley et al.'s (2011) review studied healthcare delivery service interventions that included separate young adult clinics which facilitated comfort for adult patients and convenient appointment times for working adults, off-hours phone support for patients, and enhanced follow-up via telephone for patients who missed appointments and found that the majority of interventions were successful

(Crowley et al., 2011). As with the previously mentioned educational interventions, it is important that the only difference in physical health outcomes was seen in non-CF patients in this review.

Collaborative interventions. In a quantitative, non-randomized study, Peeters et al. (2019) compared the use of a transition clinic, wherein both adult and pediatric health care providers jointly delivered outpatient care prior to transfer to direct hand-off of care, wherein no joint visits took place and patients moved to the adult center when they meet the chronological age criteria. Patients in the transition clinic showed higher satisfaction levels with the transition experience than those in the direct hand-off group but did not show significantly different health outcomes in their disease status (Peeters et al., 2019).

Crowley et al. (2011) found that the use of joint pediatric and adult provider visits along with the use of a transition coordinator improved continuity of care, ensured a structured transition process, and improved information sharing between services. Chaudry et al.'s (2013) study added joint visits to an already existing transition program. Patients and families who did not feel ready to transition after this joint visit, repeated the joint visit up to three times. Findings showed this process led to increases in patient satisfaction with care, perceived health status, and independence (Chaudry et al., 2013).

Okumura et al. (2014) stressed a culture of shared responsibility wherein both adult and pediatric CF teams jointly care for patients during the transition process. In addition to joint patient visits with the adult and pediatric teams, this quality improvement project instituted regular joint meetings between the adult and pediatric CF healthcare teams every two months which researchers viewed as an essential forum for promoting improvement in overall CF care (Okumura et al., 2014).

Structured versus unstructured transition programs

Structured versus unstructured transition programs was a common theme in the literature review of CF and the transition process. Most interventions are not singularly implemented but are part of a group of interventions designed to improve the overall transition process. A structured transition program is a process that consists of deliberate, progressive transition interventions or activities that improve disease knowledge and promote autonomy and self-management (Middour-Oxler et al., 2021). Structured transition interventions include educational interventions, health care service delivery interventions, and collaborative transition interventions. An unstructured or semi-formal transition program includes the usual pediatric care with the addition of some educational and health care service delivery activities, but little exposure to collaborative interventions. In this review of the literature, three original studies and one systematic review cited the importance of structured programs.

In a retrospective cohort study, Middour-Oxler et al. (2021) compared patient experiences in a formal transition program with a semi-formal program using participants who had transitioned to a single adult center from one of two pediatric CF centers in a metropolitan city in southeastern United States. Though part of the same health system, each of the pediatric centers offered an exclusive formal or semi-formal transition process based on location, and patients who had transitioned were included in the study if they had at least six months of care in the adult CF clinic. Findings showed that participation in a structured transition programs was associated with decreased pre-transition anxiety, increased transition readiness, and increased self-perceived healthcare independence. More than half of patients surveyed were not satisfied with the timing of their transfer to adult services, no matter which transition process they experienced, with 18% wanting to move to adult care sooner and 34% wanting more pediatric

care (Middour-Oxler et al., 2021). Overall, this study found their structured transition program to be significantly more beneficial than their semi-formal program in improving transitional competencies.

Chaudry et al. (2013) evaluated the transition experience of patients who had transferred to an adult program at a CF care center in the midwestern United States. Almost half of the participants in the study had a structured transition experience at the same health system's pediatric center or at another CF center while over half of the participants did not go through a formal transition process and had a direct transfer or hand-off of care from their pediatric program. Findings showed that there were no differences in transfer-related anxiety between the two groups, but patients who participated in structured programs had higher levels of satisfaction with both their pediatric and adult CF programs, perceived health status, and independence. Patient opinions regarding the timing of their transfer to adult care were more likely to be considered by their medical teams when they participated in a structured transition program (Chaudhry et al., 2013).

In Al-Yateem's (2012) qualitative phenomenological study, the theme of "amorphous service" was used to describe what patients felt was a disjointed and fragmented way of receiving transition services (Al-Yateem, 2012, p. 852). This study found that existing transition interventions provided in both the pediatric and adult settings lacked a comprehensive and cohesive structure, impeding the patient's development of autonomy, self-management, and decision-making skills. Recommendations from this study include a gradual, planned, and collaborative transition of care, with emphasis on an early introduction of transition interventions in the pediatric clinic, allowing patients more time to developmentally take on self-management (Al-Yateem, 2012).

In a systematic review, Coyne et al. (2017) found that structured transition programs for patients with CF led to increased satisfaction, self-care and self-advocacy skills, increased independence, lower anxiety, and increased self-management of their disease. This review sites the absence of high-quality studies relating to the CF transition process but asserts that structured transition programs appear to positively impact patients, while the benefits of singular interventions remain unclear. Recommendations for CF transition programs included utilizing a developmental approach and providing both individualized and universal information on the CF disease process, self-advocacy and self-management skills, future health care needs, and accessing and navigating the health care system (Coyne et al., 2017).

Barriers and challenges of transition

There are barriers and challenges to the transition process for adolescents and young adults with CF that may impact their overall health and quality of life. The consequences of these barriers may lead to fragmented care and result in delays in seeking care until seriously ill, poor management of chronic symptoms leading to progression of disease, and patient avoidance of preventative care services (Gorlaski et al., 2017). These barriers can be divided into four categories: patient challenges, parent and caregiver challenges, provider challenges, and systems challenges that have the potential to hinder successful transition

Patient challenges. The process of transitioning from pediatric to adult care services can be anxiety-provoking for many adolescents and young adults (Gorlaski et al., 2017); (Towns & Bell, 2011); (Tuchman et al., 2010). Such anxiety may inhibit patient engagement in adult care. Early introduction to the concept of planned transition prior to adolescence can decrease anxiety by facilitating appropriate expectations about self-management and autonomy from an early age (Gorlaski et al., 2017). Balancing health care priorities with changing life opportunities in

adolescence may also present developmental challenges to patients with CF. While life goals for patients with CF are similar to those without CF, the chronic nature of the disease creates an additional burden in developing life skills and the complex nature of CF treatments and frequent hospitalizations may add to this burden (Towns & Bell, 2011). Adolescents and young adults with CF are also at increased risk of depression and anxiety. Depression and anxiety have been shown to have negative health outcomes for patients with CF, including decreased health-related quality of life, decreased adherence to prescribed therapies, decreased pulmonary function, increased hospitalizations, and increased health care costs. Recommendations to address this barrier include routine screening, monitoring, and treatment of depression and anxiety in the CF center (Frederick, 2016).

Gorlaski et al. (2017) sites lack of knowledge as a barrier to successful transition. While CF disease process knowledge relating to pulmonary and nutrition issues is high, research shows a general lack of knowledge of reproductive health and genetic issues (Gorlaski et al., 2017). This knowledge deficit may lead to poor decision-making regarding family planning and vulnerability to sexually transmitted diseases (STDs), impacting overall health. Lack of knowledge regarding how health insurance works, basic health coverage, and how to obtain coverage beyond their parents have also been cited in the literature as barriers to transition (Frederick, 2016; Middour-Oxler et al., 2021; Tuchman et al., 2010). Patients should be encouraged to become familiar with their individual policies, keep organized records, and respond quickly to bills and deadlines which can facilitate a more efficient provision of health care services and reduce individual financial burden (Tuchman et al., 2010).

Lack of adequate peer support is another challenge facing patients with CF. Unlike most other chronic conditions, patients with CF must maintain a safe physical distance from their CF-

affected peers due to the possibility of cross-infection (Tuchman et al., 2010). While there is little opportunity for in-person peer support or group education activities, adolescents with CF can connect with their peers through various social media platforms.

Parent and caregiver challenges. Gorlaski et al. (2017) asserts that excessive parental involvement may be a barrier to transition if parents have difficulty relinquishing their caregiver role. Parental concerns regarding their limited influence on the continuity of health maintenance may result in tension between the adolescent and parent, thus necessitating a sensitive approach in handling parents of adolescents who are transitioning their care to adult services (Towns & Bell, 2011).

Provider challenges. Health care providers also face obstacles in providing transitional care services for patients who have CF. As the population of adults with CF surpasses that of the pediatric population, there is a need for more CF-trained health care providers (Gorlaski et al., 2017). Training opportunities for adult pulmonologists that specialize in CF have historically been limited, and as patients are living longer there is also a need for CF-trained subspecialists including gastroenterologists, endocrinologists, otolaryngologists, surgeons, and obstetricians and gynecologists (Towns & Bell, 2011). The Cystic Fibrosis Foundation (CFF) has attempted to address this need by creating specialized clinical fellowships for physicians, aimed at promoting comprehensive CF care and CF-related research. The CFF also mandates the establishment of separate adult CF programs for centers with over 40 patients, creating a one center, two programs model in order to share resources (Tuchman, 2010).

Some pediatric providers may delay the transfer of care to the adult team, fearing a decline in the level of care that is provided by the adult team (Gorlaski et al., 2017; Tuchman et al., 2010). A close partnership between pediatric and adult providers is necessary to prevent

delays in patient transfers, poor communication, and to ensure provider confidence in quality of care (Gorlaski et al., 2017).

Baker et al. (2015) noted time constraints and coordination with clinic staff and lack of clinic organization/planning as barriers to successful implementation in his study examining health care providers' experience with the educational program CF R.I.S.E. In addition to time constraints and planning, Peeters et al. (2019) cited lack of financial support, as transitional care is typically not reimbursed beyond a regular consultation.

System challenges. Timing of the transfer of care from pediatric to adult health services is often dictated by health systems or insurance companies. Some health systems mandate the transfer of care based on chronological age without making provisions for necessary developmental and psychosocial services (Tuchman et al., 2010). Health care coverage may also determine which provider a young adult will be able to see and may affect utilization of services; however, this coverage can also facilitate payment for high-cost treatments, which is necessary due to the burden of high health care costs associated with CF (Tuchman et al., 2010).

Lack of health outcome data is a major barrier to transition and may contribute to the perception that transition to adult care providers will result in poor outcomes (Tuchman et al., 2010). There is limited consensus on successful outcome measures regarding health outcomes such as change in pulmonary function status, mortality, and acquisition of new bacterial species (Goralaki et al., 2017). While there is evidence that transition interventions and programs lead to increases in patient satisfaction, there is no clear evidence that this translates into stability of health status after the transition process (Tuchman et al., 2010). To address this barrier, quality improvement initiatives must take place. The Learning and Leadership Collaborative (LLC) is one such measure. Sponsored by the CFF and utilizing the Dartmouth Institute's Clinical

Microsystem Academy curriculum, the LLC provides funding through grants and focuses on quality improvement activities at CF centers nationwide, which can be key for developing guidelines for transition programs (Gorlaski et al., 2017).

Publication Bias Check

A search of the gray literature was conducted in Google Scholar to assess for publication bias. The search term "transition and cystic fibrosis" was utilized, and the first 20 results were reviewed. Based on this search of the gray literature, there was no evidence of publication bias, and the results were consistent with the results of the integrative review as outlined above. A review of publications cited in the articles were consistent with the results of the integrative review and no new pertinent evidence emerged.

Limitations

Transition interventions are rarely implemented singularly, but rather as part of a multi-faceted approach to improve the transition process for adolescents and young adults with cystic fibrosis. As such, it is difficult to measure the impact of a single intervention on patient outcomes. All interventions included in this review of the literature took place as part of a "transition program" or "transition clinic" that use various multi-faceted approaches to the transition process.

Summary of Literature Review

This integrative review answered the following question: In adolescents and young adults with cystic fibrosis, do transition programs lead to successful transition from pediatric to adult healthcare services? The evidence supports the use of interventions and programs that improve the acquisition of transitional competencies in adolescents and young adults as they transfer from pediatric to adult health care services (See Table A1). There is little evidence to

support the use of transition programs to directly impact patient clinical outcomes. The American Academy of Pediatrics, the Department of Health and Human Services' Healthy People 2020, and the CFF endorse the planned, structured transition process from pediatric to adult care to facilitate continuous care (Office of Disease Prevention and Health Promotion [ODPHP], n.d. ; Tuchman et al., 2010; White et al., 2018;). These recommendations, in conjunction with the evidence in the literature, provide a sufficient basis to endorse a structured transition program at the CF center at the academic medical center (AMC).

Purpose Statements

The purpose of this scholarly project was to conduct a program evaluation of a CF Transition Program at a CFF-accredited center in an AMC in the Mideastern United States. As this transition program is in a formative phase of development, a program evaluation is necessary to determine the merits of the existing program and inform the CF center as to best steps forward to provide optimum transitional care for the CF population.

Theoretical Framework for Scholarly Project

The theoretical framework that was used for this project is the Socio-ecological Model of Adolescents and Young Adults (AYAs) Readiness for Transition (SMART Model). The SMART Model expands the conceptualization of transition beyond they typical components of age, disease knowledge, and skills by incorporating socio-demographics, culture, health care access, and patient characteristics with the inter-related components of knowledge, skills/self-efficacy, beliefs/expectations, goals, relationships, and psychosocial functioning of patients, parents and providers, (Schwartz et al., 2011). A particular emphasis is placed on variables that are amenable to intervention within the medical setting. Initially developed for childhood cancer survivors, the SMART Model is generalizable to other medically vulnerable AYAs due to the similarities in

complications of chronic disease processes. The SMART Model asserts that disease prevention and management of AYA survivors is dependent on sustained engagement in the adult healthcare system (Schwartz et al., 2011).

The SMART Model is grounded in three theoretical models: socio-ecological models of adaptation and disease management, the medical traumatic stress model, and the pediatric psychosocial preventative health model. The socio-ecological models of adaptation and disease management emphasize that the child is at the center of broader systems: the microsystem, or those areas that directly and immediately impact the child (parents, siblings, friends, teachers, medical providers), the mesosystem, or the interaction between two or more microsystems (i.e., parent-child or child-provider relationships) that directly impact the child, the exosystem, or the indirect (one-step-removed) influence on the child, and the macrosystem, or cultural and political influences that influence the child (Schwartz et al., 2011). As shown in Figure B1, the SMART Model depicts both linear and reciprocal influences on the child (Schwartz et al., 2011). The medical traumatic stress model emphasizes that psychological responses to chronic illness are highly variable and subjective and that transition itself may be perceived as another disease-related trauma with potential long-lasting effects. This model details the importance of approaching transition with positive beliefs about transition outcomes to reduce trauma. The psychosocial preventative health model purports that patients' psychosocial needs can be reliably identified using universal preventative health services so that risk for poor outcomes can be identified. These models form the basis for the SMART Model, which aims to underscore measurable components of transition readiness that can be translated to clinical assessment and guidelines to improve transition readiness (Schwartz et al., 2011). The utility of this model for this program evaluation is that it demonstrates the relationship between modifiable variables and

the parent, child, and provider; recommendations for improvements in the transition program were based on this theory to improve outcomes.

Implementation Framework

The Center for Disease Control and Prevention's Framework for Program Evaluation in Public Health guided the implementation of this scholarly project (CDC Framework, 1999). This framework summarizes the essential elements of program evaluation, provides a structure for conducting effective evaluations, clarifies steps in the program evaluation process, reviews standards for effective program evaluation, and addresses misconceptions regarding the purposes and methods of program evaluation (CDC, 1999). Typically used in the public health domain, it is a practical tool designed to summarize and organize essential elements of the program evaluation. This model is particularly beneficial for use in formative evaluations due to its non-linear design. Though the steps of this process are interdependent, they may be carried out in a non-linear sequence. Earlier steps in the sequence create a foundation for subsequent progress, but the sequence is iterative and is only finalized when previous steps have been addressed. This framework has two main components: *standards* for effective evaluation and *steps* in the evaluation process.

The four standards for evaluation in the CDC's Framework for Program Evaluation are utility, feasibility, propriety, and accuracy (CDC, 1999). These standards provide a lens to help isolate the best approach to each step of the evaluation. Utility standards refers to the need for the evaluation to serve the information needs of the intended users. Feasibility standards ensure that the evaluation will be financially prudent, realistic, diplomatic, and frugal. Propriety standards ensure that the evaluation will be carried out ethically and legally and places utmost importance

on the welfare of all involved in or affected by the evaluation. Accuracy standards ensure that technically accurate information that determine the merit of the program will be evaluated.

The CDC's Framework for Program Evaluation are composed of 6 interconnected steps that must take place in any evaluation (See Figure 1). *Engage the Stakeholders* is the first step in the process and seeks stakeholder input to delineate important elements of a program's objectives, operations, and outcomes. The next step is *Describe the Program,* wherein the researcher determines what need is being addressed by the program and explores the context in which the program operates in terms of history, geography, social constructs, etc. In this stage, a logic model is developed to illustrate how the program is supposed to work. The third step of the evaluation process is *Focus the Evaluation,* in which a systematic approach is used to determine the focus of the program through application of the evaluation standards. Step 4 is *Gather Credible Evidence* which strengthens evaluation judgements and recommendations that follow. Step 5 calls for the researcher to *Justify Conclusions* based on the gathered evidence and comparing them to values set by stakeholders, while step 6 is *Ensure Use and Share Lessons Learned* which ensures that stakeholders are made aware of the findings and that these findings are considered in decisions that affect the program.

Figure 1

CDC Framework for Program Evaluation in Public Health

Note: Centers for Disease Control and Prevention. Framework for program evaluation in public health. MMWR. 1999;48 (No. RR-11).

Project Design

For this scholarly project, an evaluation of a transition program for adolescents and young adults was conducted using the CDC Framework for Program Evaluation in Public Health (CDC, 1999). This program evaluation took place between March 2021 and January 2022.

Definition of Terms

Adolescence: Individuals who are approximately 10 – 19 years of age, generally coinciding with the onset of puberty and continuing until early adulthood.

Forced End Expiratory Volume (FEV_1): The volume of air, in liters, exhaled in the first second during forced exhalation and maximal inhalation. FEV_1 is the primary clinical outcome indicator for severity of cystic fibrosis which measures disease progression and severity.

Health Stability Measures: For this program evaluation, health stability will constitute three main components 1) Continuity of care – days between last pediatric and first adult center visit, adherence to quarterly appointments 2) health utilization – non-routine office visits, hospitalizations, emergency department visits, and 3) FEV_1 – an established clinical indicator of CF disease progression.

Transfer: The discrete point in time wherein a patient moves from pediatric to adult health care services at a single point in time.

Transition: The planned, purposeful process of moving adolescents and young adults with chronic medical conditions from pediatric to adult health care services.

Transitional Competencies: Skills that promote patient engagement and activation such as improved knowledge, self -advocacy, and self-efficacy.

Young Adults: Individuals ages 18-24 years of age, ranging from the outset of legal adulthood at age 18 until the mid-twenties.

Stakeholders: Transition team members at the CF center at the academic medical center (AMC) who are committed to improving the transition process, i.e., pediatric, and adult providers, patients with CF, and parents of patients with CF.

Telemedicine: The means by which health care professionals communicate with and provide health care services for patients who are not physically located in the same place. These health care visits typically occur via virtual meeting in an online format.

Setting

This scholarly project took place in a CFF- accredited center at an academic medical center (AMC) in the Mideastern United States. This center offers both pediatric and adult CF programs, caring for approximately 265 patients who have CF collectively. Patients may receive health services at either the main hospital or one of two satellite centers in the state. As appointments were primarily held via telemedicine due to the ongoing COVID pandemic, patients were contacted for participation via an online platform that allows for communication between patients and their health care team. CF Transition team meetings were held utilizing CISCO WebEx, a secure online platform for virtual meetings that is regularly utilized by all team members at this AMC.

Approvals

This scholarly project was initially determined by the Institutional Review Board -Human Subject Research (IRB-HSR) of the university on September 16, 2021, to be non-human subject research. At the request of the adult CF center director, additional approval was obtained from the IRB-HSR on October 29, 2021, when this study was deemed Exempt as low-risk (Appendix C). Approval was granted by B. Middour-Oxler, the Principal Investigator for use of Emory's Post-Transition survey from her published study (Middour-Oxler et al., 2021) (Appendix D).

Procedures (CDC 6-step process)

Step1: Engage the Stakeholders (See Appendix E)

There are numerous different stakeholders for this CF transition project. A work group of multi-disciplinary team members was formed in Fall of 2019 to address concerns regarding the transition process in the CF population. Issues surrounding the onset of the COVID pandemic in March of 2020 precluded the team from meeting again until March of 2021. From March 2021

until December 2021, the student investigator participated in this work group's monthly meetings to delineate the group's priorities regarding the transition process. A preliminary needs assessment showed that the aim of the group was threefold: to evaluate the patient experience with transition, to improve the patient experience with transition, and to formalize the transition program at this CF center, all with the central aim of improving patient outcomes. A needs assessment with stakeholders determined that gauging the patient experience with transition and examining the health stability of patients who transitioned to adult services was a priority. Stakeholders participated in modifying a vetted post-transition survey evaluation tool. Stakeholders were instrumental in deciding what measures to include under the umbrella of "health stability" which included measures for continuity of care, health utilization, and clinical indicators.

Stakeholders within the health system included pediatric and adult health care providers, an advanced practice nurse, a nurse coordinator, a social worker, a psychologist, a pharmacist, and a parent and family representative. The quality improvement team leader for the CF center was also a stakeholder and provided important information regarding how this program operates within the framework of the Dartmouth Clinical Microsystem approach to health care that the CF center currently utilizes. Individual and small group communication and meetings with each of these stakeholders was conducted during the program evaluation to determine additional priorities for the evaluation process.

Step 2: Describe the Program (See Appendix F)

The CF center at this AMC is one of only 130 CF Foundation accredited programs in the United States, ensuring high quality, specialized and comprehensive CF care. It is comprised of both a pediatric and adult program, which currently provide health care services for 130 and 136

patients with CF respectively. While each program maintains separate health care providers, nursing staff, and social workers, they share several resources, including a psychologist, respiratory therapist, and registered dietician. Accredited by the CF Therapeutics Development Network (CFTDN), this CF center is focused on advancing clinical research and making new therapies available to patients with CF.

In 2015, the CF center joined the Learning and Leadership Collaborative (LLC), a joint initiative of the CF foundation and the Dartmouth Institute Microsystem Academy. The Dartmouth Institute partners with the CF center to provide training to enhance the quality improvement process, with the aim of optimizing patient care and safety in both the inpatient and outpatient settings. This partnership with the LLC has resulted in numerous quality improvement projects that are led by CF team members and utilize patient feedback to determine the content of education, counseling, and resources that are aimed at improving patient outcomes for CF.

The CF center's transition program consists of several evidence-based interventions aimed at improving the transition process. Patel et al. (2017) asserts that transition programs are comprised of three main components: readiness assessment, progressive knowledge and skill education, and support structures to include collaboration with adult services (Patel et al., 2017). Transition readiness is determined through the Ages and Stages questionnaires (ASQ) that is administered at routine appointments starting between ages 10-12. Educational modules are provided, and transition readiness is also gauged using the CF R.I.S.E. program. Support structures that are implemented by this CF center include patients meeting with their pediatric team without their parent/caregiver present by 18 years of age and attending a "Meet and Greet" visit with the adult care team which takes place at 21 years of age; initially done in person, it has been held virtually since March 2020 at the start of the COVID pandemic. Additionally,

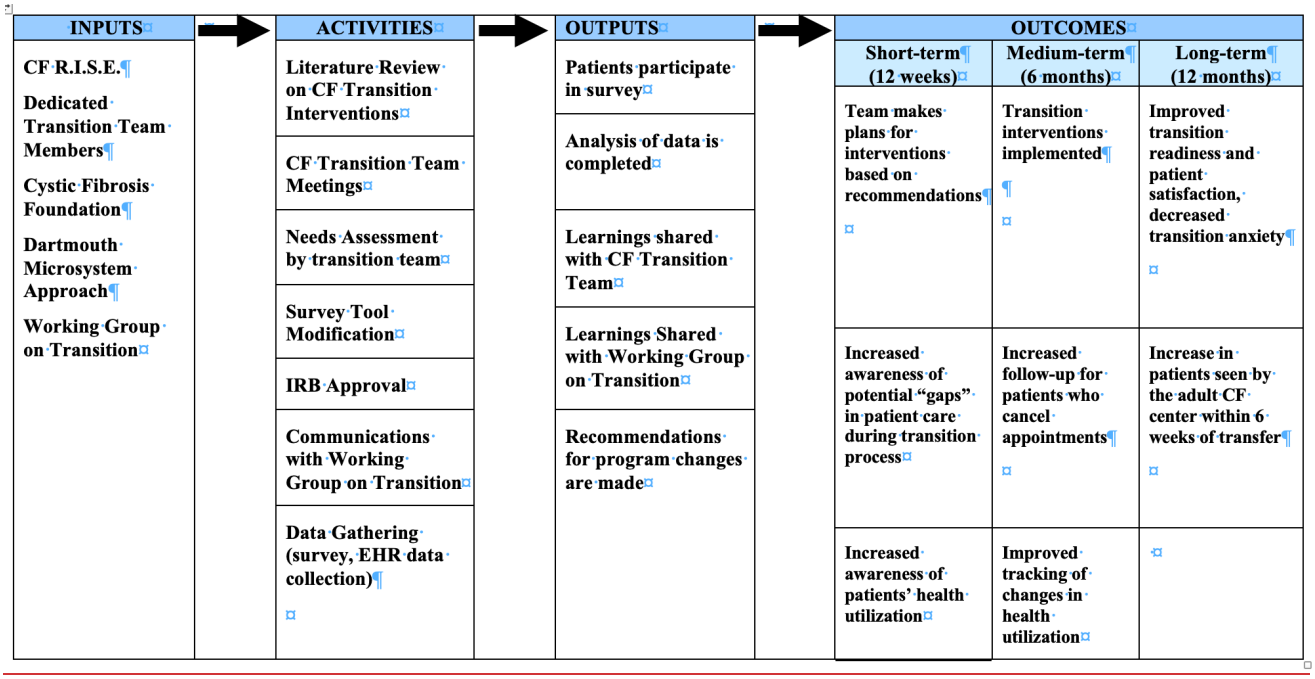
quarterly transition team meetings are held with both pediatric and adult CF care teams to present patients and plan timing of patient transfers. The CF transition team is in the process of developing and implementing additional transition program interventions to improve the transition process such as helping patients input medical identification information on smart phones and providing more guidance around health insurance information. Improvements to the EHR include the development and embedding of a CF clinical pathway for transition milestones and a shared patient list into the EHR, enabling the patient care team to ascertain where the patient is in the transition process and ensuring health team members' easy access to medical records.

This program evaluation provides a baseline to assess the needs of the program to support the implementation of new interventions, including the use of a new post-transition survey tool with the aim of improving patient outcomes. Additionally, the AMC has a Pediatric Health Care Transition Working Group that aims to improve the transition of all patients from pediatric to adult health care services. This program evaluation may benefit this group as some aspects of health care transition may be transferable from the CF population to other chronic conditions and/or the general pediatric population.

A logic model was developed to serve as the foundation for this program evaluation, with the intent of keeping goals at the forefront of this activity. This logic model illustrates the resources, activities, outputs, and outcomes for the program evaluation (See Figure 2). It depicts the relationship between the program activities and their intended effects. The Logic model was developed by student investigator with input from the stakeholders.

Figure 2

Logic Model for CF Transition Program Evaluation



INPUTS	ACTIVITIES	OUTPUTS	OUTCOMES		
			Short-term (12 weeks)	Medium-term (6 months)	Long-term (12 months)
CF R.I.S.E. Dedicated Transition Team Members Cystic Fibrosis Foundation Dartmouth Microsystem Approach Working Group on Transition	Literature Review on CF Transition Interventions CF Transition Team Meetings Needs Assessment by transition team Survey Tool Modification IRB Approval Communications with Working Group on Transition Data Gathering (survey, EHR data collection)	Patients participate in survey Analysis of data is completed Learnings shared with CF Transition Team Learnings Shared with Working Group on Transition Recommendations for program changes are made	Team makes plans for interventions based on recommendations	Transition interventions implemented	Improved transition readiness and patient satisfaction, decreased transition anxiety
			Increased awareness of potential "gaps" in patient care during transition process	Increased follow-up for patients who cancel appointments	Increase in patients seen by the adult CF center within 6 weeks of transfer
			Increased awareness of patients' health utilization	Improved tracking of changes in health utilization	

Logic model template from: https://templatelab.com/logic-model/

Step 3: Focus the Evaluation (See Appendix G)

In determining where to focus the evaluation, the CDC's framework standards of evaluation were used, most importantly the standards of utility and feasibility. Under the standard of utility, it is important to determine the purpose of the evaluation and how the evaluation outcomes will be used. Under the standard of feasibility, the researcher must determine how much money, time and effort that can be devoted to this project. As transition is a priority in the CF care center, this program evaluation has high degrees of utility and feasibility. With stakeholder input, the focus of evaluation was determined to be the following:

1. Does the CF transition program at this AMC increase transition readiness?
2. Does the CF transition program at this AMC decrease transition - related anxiety?

3. Does the CF transition program at this AMC increase satisfaction with the transition process?
4. What is the health stability of patients in the year before and after transfer?
5. Is this post-transition survey tool useful in evaluating the patient experience with CF transition at this AMC?

Stakeholders determined that this project would pilot a Post-Transition CF Survey recently developed by the CF Center at Emory University to evaluate patients' transition-readiness, transition-related anxiety, and satisfaction with the transition process at this CF center. The outcome of the survey was intended to inform transition program improvements to enhance the overall transition experience for patients with cystic fibrosis. As part of this program evaluation, baseline measures of health stability in terms of continuity of care, health utilization, and clinical indicators were collected.

Step 4: Gather Credible Evidence (See Appendix H)

As this was a formative program evaluation, a needs assessment was completed with all stakeholders to determine the priorities for this transition program. Individual interviews, small group communications, and team meetings were the main mechanism for gathering information from stakeholders within the health system. The preliminary needs assessment showed that the focus for this program evaluation was understanding, evaluating, and improving the patient experience with the transition process. A secondary objective was to determine patients' health stability in the year before and after transition by obtaining descriptive data on these measures by a retrospective chart review. This program evaluation was conducted to be the impetus to improve processes in transition in this CF center by using a newly developed post-transition

survey and retrospective chart review to gather information on patient experiences with transition and patients' health stability, with the intent of improving health for this population

Post-transition Patient Survey (See Appendix I). A modified version of Middour-Oxler et al.'s (2021) Cystic Fibrosis Post-Transition Survey was distributed to patients to obtain information regarding their experience with the transition process. This survey tool measured transition readiness, transition-related anxiety, and satisfaction with the transition process. This survey is a vetted tool that has undergone rigorous content validity analysis at a CFF-accredited CF center. Permission to use and modify this survey was given by the original researchers (See Appendix I). Stakeholders were instrumental in making modifications to this tool (with author permission) so that it best applied to practices in this CF center. While this tool was primarily quantitative, the following open-ended questions were included in the survey:

1. What was the most difficult part of your transition to the adult clinic?
2. What did you find most helpful when you transitioned to the adult clinic?
3. Were there any CF education topics that were not covered adequately in the pediatric clinic that you would have liked more information on before you transitioned to the adult clinic?
4. Is there anything you would suggest we do differently to improve transition?

This survey was distributed to patients who transferred from the pediatric to adult CF program at this CF care center from December 2017 to May 2021 who had received continuous care at this AMC. Patients met the inclusion criteria if they had a diagnosis of CF and had at least 6 months of care in the adult CF center. Demographics of age, gender, and year of transfer of care were collected. A recruitment letter was sent to eligible patients through, an online portal that allows patients to communicate with providers, access their medical records, and manage

their care at this AMC (See Appendix J). This recruitment letter contained an anonymous link to an online survey platform. An email reminder was sent at weeks 2 and 10 of the data collection period via the online portal. Submitting any portion of the survey indicated informed consent. Anonymity was maintained in the data collection and all IRB-HSR requirements were met.

Retrospective Chart Review (See Appendix K). Electronic health records (EHR) were reviewed on all 18 patients who met the above eligibility criteria. Demographics of age and gender were collected. The following "Health Stability" measures were collected:

a. Days between last pediatric visit and first adult clinic visit
b. Adherence to quarterly routine office visits with health care team
c. Number of additional or non-routine office visits
d. Hospitalizations (by occurrence) in the year prior and after transfer of care
e. Emergency Department visits (by occurrence) in the year prior and after transfer of care
f. Forced End Expiratory Volume (FEV_1) and calculated Forced End Expiratory Volume (FEV_1) baseline before and after transfer

Days between last pediatric and first adult CF center visits and adherence to quarterly routine appointments represent continuity of care data. Health utilization data measures included number of non-routine office visits, hospitalizations, and emergency department visits. Health utilization measures pertained only to utilization for CF-related issues. Utilization for pregnancy, injury, and other non-CF related illnesses were not included. FEV_1 was the only clinical indicator measured in this study and it was collected alongside the calculated baseline FEV_1, which is the baseline level for each individual patient based on previous FEV_1 measures.

Demographic and health stability data was collected in the EHR utilized at this AMC. Patient data was de-identified as it was collected and was stored using a random numeric patient identifier. Data was only accessed by the student investigator and university statistician. All individual and aggregate data was stored securely in the online survey platform and an online data management platform provided by the student investigator's research institution, throughout the duration of this project

Step 5: Justify Conclusions (See Appendix L)

Cystic Fibrosis Post-Transition Survey Data. Six participants opened and began the online survey but only 3 participants provided responses beyond demographic data. Three participants completed the survey. All participants were between 22-24 years old and 66.7% (n = 2) were female; 33% (n=1) was male. Two participants primarily received their CF care at the local institution (66.7%), while 1 participant received CF care in a satellite office (33.3%).

Patient Satisfaction with Transition Process (Table M1)). Survey items were scored so that responses with the lowest level of agreement were given a score of 1 and the items with the highest level of agreement were given a score of 5. The overall average score for patient satisfaction with the transition process was 4.52 (SD = 0.67) with a range in answers from 3 to 5. The item with the strongest rating was "I am satisfied with the care I received in the Pediatric clinic", with a score of 5.0 (SD = 0.00). The survey item with the lowest rating was "Transition and transfer to the adult clinic met or exceeded my expectations" with a score of 4.0 (SD = 1.00). However, this score was still relatively high as one participant selected "Strongly Agree", the other participants selected "Agree" or "Neither Agree or Disagree." For the all the other survey items regarding satisfaction with the transition process, the participants selected "Agree" or "Strongly Agree."

Concerns regarding Transition Process (Table M2). The survey items in this section were scored to demonstrate level of concern. The lowest level of concern was assigned a value of 1, and the highest level of concern was assigned a score of 5. The overall average score for all survey items regarding concerns with the transition process was 2.94 (SD = 1.75) with a range of 1 to 5. The participants showed the most concern for "Leaving behind my Pediatric CF Team" with a mean score of 5.0 (SD = 0.0) as all 3 participants rating this concern as "Very." For the survey item "Just prior to transfer of my care to the adult program I was anxious," 2 of the 3 participants rated this concern as "Very," with a mean score of 4.0 (SD = 1.73). The survey items that received 2 out of 3 higher than average concerns were "Having to meet new caregivers" and "Being admitted to the Adult hospital" with a mean score of 3.67 (SD = 2.31).

Aspects That Were Helpful in Making Patient Feel Prepared and Confident During Transition Process (Table M3). The survey items were scored to indicate that items were least helpful with a score of 1 or most helpful with a score of 5. The overall mean score for "Aspects that made patients feel prepared and confident during transition process" was 3.59 (SD = 1.77) with a range of 1 to 5. All survey participants selected "Meeting with the Pediatric CF Team without parents in the room" and "Completing and discussing the transition assignments with the pediatric staff" as "Very" with mean scores for both items being 5.0 (SD = 0.00). The lowest rated items were "Support with planning for insurance coverage," and "Support with planning for higher education and/or employment," with mean scores of 2.67 (SD = 2.08), though one participant selected "Very" for each of the items.

For the question, "Prior to having your first clinic visit in the UVA Adult CF clinic, did you meet the Adult CF team at one of your pediatric clinic visits?" two participants (66.7%) reported "yes," and one participant (33.3%) reported "no." Both participants who answered

"yes" agreed that "Meeting the Adult CF team prior to my transfer to the Adult CF clinic greatly reduced my anxiety about transitioning care to the adult program." The participant that did not meet the Adult CF team prior to the transition reported that it *probably* would have significantly reduced their anxiety level.

Transition Readiness. For the survey item, "At the time of my transfer to the Adult CF program, I completely understood my CF and was completely independent in my own medical care (including how to take my medications, what CF is and does to my body, different kinds of airway clearance, insurance, how to schedule appointments, how to re-order medications)." All three participants answered affirmatively. For the survey item "If there were aspects of your medical care that you did not feel completely independent about at the time of your transfer to the Adult CF center, what were they?" one participant answered, "how to schedule appointments" and "how to get in touch with CF center," while the two other participants did not select any answers. For the survey item, "Do you know where to get information regarding CF treatments and research at your center?" two participants answered "yes," and one answered "no."

Open-ended questions. Four open-ended questions were included at the end of the survey. The following three questions were answered: "What was the most difficult part of your transition to the adult clinic?", "What did you find most helpful when you transitioned to the adult clinic?", and "What did you find most helpful when you transitioned to the adult clinic?" All respondents cited feelings of loss around leaving the pediatric team. Other themes included difficulty with scheduling appointments in the adult clinic and challenges associated with change and transitions in general.

Retrospective Chart Review.

Demographics. A total of 18 patient records were extracted from the Electronic Health Record (EHR). Females comprised 55.6% of the patients, while 44.4% of patients were male. The mean age of patients at transfer was 22.4 (SD = 2.53) with a range of 21-32 years of age (See Appendix N). Race was not collected due to potential for compromise of anonymity in non-Caucasian patients due to the small number of eligible patients.

Health Stability: Continuity of Care Measures. Two continuity of care measures were obtained in this retrospective chart review. The mean number of days between the last pediatric CF center visit (transfer) and the first adult CF center visit was obtained and determined to be 68.7 days (SD = 44.5). Adherence to routine quarterly office visits was 100% in the three months before and after transition and decreased at 7-9 months after transition (69%) (See Appendix O).

Health Stability: Health Utilization Measures. Three health utilization measures were collected in this retrospective chart review: number of non-routine office visits, hospitalizations, and emergency department visits. The occurrence of one or more non-routine office visits was highest in the three months prior to transfer (66.7%) and lowest in the three months after transfer (16.7%) (See Table P1). Overall hospitalization rate of one or more occurrences in the year both before and after transfer was 13.9%. The rate of one or more Emergency Department visits was 5.6% in both the year before and after transfer. (See Appendix P).

Health Stability: Clinical Indicators. Forced end expiratory volume in 1 second (FEV_1) and calculated baseline FEV_1 were the only clinical indicators, or physical markers of disease progression, that were collected from the EHR. The calculated baseline FEV_1 was determined by averaging the two highest actual FEV_1 measurements in the previous year when the patient was not taking intravenous antibiotics. If a patient was started on a CF modulator in the previous year, the calculated baseline FEV_1 was determined after the patient started the CF modulator.

Pre-transfer calculated baselines were determined at the last pediatric clinic visit or at transfer. Post-transfer calculated baselines were determined at the last adult clinic visit the year after transfer. The actual $FEV_{1,}$ when compared to the calculated baseline FEV_1, remained stable through transition (2.98/3.12 L to 3.09 L/3.12 L) (See Appendix Q).

Timing of Introduction of CF Modulators. Most patients' transition was not impacted by the start of a CF modulator, as they either started the CF modulator more than a year after the transfer of their care (44.4%) or did not take a CF modulator (5.6%) (See Table 9). Patients that were taking CF modulators during the transition process but had started them more than a year prior to transfer totaled 16.7%. Patients that started a CF modulator in the year prior to transfer (16.7%) or in the year after transfer (16.7%) totaled 34.7%, indicating that the introduction of a CF modulator may have impacted the transition process for over one third of patients included in this program evaluation (See Appendix R).

. The above collected data was analyzed and interpreted, and recommendations were made based on the quantitative data in Step 4. Data collected was analyzed using SPSS, Version 28. Descriptive Statistics was reported as mean, standard deviation, and percentages as appropriate.

Discussion

The importance of a deliberate, planned transition process for patients with CF who are transitioning from pediatric to adult care is demonstrated in this program evaluation. While the low response rate for the Post-Transition Survey precludes drawing conclusions or correlations about patients' experience with transition satisfaction, transition readiness, and transition-related anxiety at this CF center, the measures of health stability from the retrospective chart review are indicative of patient stability through the transition period.

Continuity of care is an important measure of the success of a transition program. Using data from the CF Foundation Registry, Sawicki et al. (2018) examined "gaps in care", or the number of days between the last visit in a pediatric CF center and first visit in an adult CF program and found that the mean gap was 183 days. Prolonged gaps in care were considered to be 100 days or more between the last pediatric and first adult clinic visit. This gap was longer in patients who transferred at a younger age and did not adhere to routine quarterly or guidelines regarding respiratory cultures and regular pulmonary testing (Sawicki et al., 2018). The mean gap in care at this AMC's CF center was 68.7 days, indicating that the average patient had continuous, uninterrupted care. The overall percentage of adherence to quarterly visits is over 85%, a further indication of uninterrupted health care during the transition process.

Utilization of additional health care services included examining trends in non-routine office visits, hospitalizations, and emergency departments. Only visits reflecting CF as a primary diagnosis were factored into the data collection. The percentage of patients who had one or more non-routine visits to the CF center was highest in the 4- 6 months (38.9%) and up to three months (66.7%) prior to transfer of care. While this may indicate that decline in health status was an impetus for transfer of care, it may also indicate a recognition by pediatric staff of an increased need for more visits to prepare for the transfer to adult services. The highest rate of hospitalizations (22%) and emergency departments (11%) occurred at both 7-9 months before and after transfer of care but remained stable before and after transfer. The rate of overall hospitalizations (13.9%) and Emergency Department visits (5.6%) remained unchanged before and after transition. This pattern of utilization of additional health services during transition is indicative of a chronic patient population that has access to well-coordinated care (Moeenuddin et al., 2019).

Utilization of health care services may have been impacted by the COVID 19 pandemic, which occurred in last 14 months of the time frame for this data collection. This CF center quickly pivoted to the use of telemedicine at the outset of the pandemic; patient needs including technology capacities and home equipment were assessed and previously scheduled appointments were conducted remotely. This AMC's adult CF center published a study examining the impact of telemedicine on patient outcomes and found that there was no change in pulmonary function with the use of telemedicine (Somerville et al., 2021). Ninety-two percent of all clinical encounters occurred through telemedicine or a hybrid visit (with in-clinic telemedicine support) at this center during the first year of the pandemic. This rapid transition to telemedicine at this CF center contributed to the high adherence rate and well as the low utilization of additional health resources. Protective measures including wearing masks, improved hand hygiene, and social isolation as well as fear of exposure to the virus may have limited exposure to infection and discouraged use of emergency departments during this time.

Though the post-transition survey had a low response, the quantitative data in the survey illustrates the perception of transition for three participants. Patient satisfaction with the transition process was high, particularly with the care they received in the pediatric center. All respondents indicated they had a high degree of transition readiness at the time of their transfer of care and that meeting their adult team significantly reduced their transition-related anxiety or would have reduced their anxiety if they had the opportunity to do so prior to transfer.

The close bond patients had with their pediatric team is evidenced by a consensus of patients who indicated that they were most concerned with "Leaving their pediatric team behind." Further evidence of this bond was provided in the answers to the open-ended questions in the survey, where all participants described feelings of loss associated with leaving the pediatric

center. Challenges regarding the nature of change in general were adeptly addressed by one participant who expressed that change is hard in general and that despite the health care teams efforts, the transition was inevitably going to be difficult.

Low participation in this post-transition survey reflects a need for more effective transition program evaluation methods to understand patient and family perceptions. Non-participation in health surveys is multifactorial; the length of the survey, lack of incentivization, the sensitive or personal nature of the topic, and the perception of transition as not significant may have contributed to the low participation rate. All patients eligible for participation were actively using the EHR communication portal, so it is unlikely that lack of technology played a part in non-participation.

More effective evaluation tools are needed to measure the patient experience and outcome data on transition processes for patients with CF. While the post-transition survey reflected information desired by the health care team, it must also meet the needs of patients. Additional methods for evaluating the patient experience with transition include performing face to face "exit" interviews and including parent experience with the transition process in the evaluative process. Improved tools that measure both patient responses to the transition process and health stability during the transition process can lead to improved transition processes. Thus, there is potential to impact the transition procedure for the CF population and all patients with chronic conditions who transition their care from pediatric to adult health services and optimize health outcomes.

Conclusion

Though survey data are limited due to the small number of participants, the retrospective chart review data is influential in highlighting the stability of patients' health status before and after transition of care from pediatric to adult CF health care services. This program evaluation

revealed that the health stability of patients who transitioned their care from pediatric to adult CF services remained steady in terms of continuity of care, health utilization, and clinical indicators during the transition process.

Recommendations

Recommendations include administering a shorter patient survey that is ideally more specific to this institution. The adapted Emory Post-Transition survey tool was lengthy, and this may have deterred patients from participating, particularly in the online survey format. The CF Transition Team has developed a brief, 10-point survey that evaluates patients' experience with the transition process at this CF center (See Appendix S). The brevity of this survey, along with its specificity to this CF center, makes this tool preferred over the adapted Emory Tool. The Emory Post-Transition survey is vetted, and its use was recommended by the Director of Quality Improvement of the CF Foundation, K. Sabadosa, and by the Emory University CF Center Transition Coordinator and creator of this tool, B. Middour-Oxler. The Emory Tool would likely have more success if administered to patients in-person. The ongoing Covid-19 pandemic and change to telehealth visits precluded the face-to-face opportunity to administer it in person for this program evaluation.

Additionally, standardizing transition interventions will ensure that all patients are exposed to the same transition interventions which will allow for future statistical comparisons of pre and post transition stability measures. To that end, in the Fall of 2021the CF transition team developed and embedded a CF Transition Flowsheet and shared patient list into the EHR which enables all health care providers to input and view transitional interventions experienced and milestones attained. A more structured, standardized process will facilitate future research, evaluation, and improvement.

The CF transition team should continue to implement and build on evidence-based transition interventions that facilitate transfer from the pediatric to adult CF health care services. The CF team should determine which patient outcomes are most important in order to prioritize transition interventions. Health stability data measures should be collected in three years to determine impact of new interventions within the CF transition program. The three-year time frame would allow adequate time for a sufficient number for a patient sample. The health stability measures in this project should serve as a baseline for future nursing research in this CF center.

This program evaluation did not include a cost-benefit analysis for this AMC's CF transition program. Future program evaluations should consider the financial return on investment and should be completed as another aspect of the CDC Framework for Program Evaluations.

Step 6: Ensure Use and Share Lessons Learned (See Appendix F)

In this final step of the CDC's Program Evaluation, results were shared with stakeholders within the health system to include the CF transition team on February 17, 2022. As one of the goals of the CF transition team is to create a program for transition that the rest of the pediatric specialties can utilize, the results will be shared with the AMC's Pediatric Health Care Transition Working Group to ensure that lessons learned will be shared with the AMC at large.

A manuscript will be written and submitted for publication to the Journal of Pediatric Health Care. The final documents will be submitted to Libra, the university's scholarly repository.

Ethical Considerations

Approval from the AMC's Institutional Review Board for Health Sciences Research (IRB-HSR) was be obtained prior to initiating this scholarly project. Participants in the survey were informed of the purpose of the study, the risks, and benefits of participating in this study, and their right to decline to participate. This program evaluation presented minimal risk to stakeholders, participants, and the organization and unintended adverse effects are not anticipated with the survey/data collection process. All data collected was de-identified prior to storage to preserve patient anonymity and findings were reported on an aggregate level.

Strengths and Weaknesses of Design

The CDC Framework for Program Evaluation is an effective program evaluation that uses a systematic and structured approach in the evaluation process. Its strength lies in its ability to summarize and organize essential elements of program, and its use of a non-linear design allows for re-iterations of steps in the evaluation process, permitting a more thorough evaluation. Another strength of the design of this program is the enthusiasm of stakeholders to take part in the program evaluation process. Key stakeholders are committed to improving the transition process and were integral in determining the needs and scope of this project.

A weakness of this study design was the limited access to patients who had participated in the transition process at this AMC. Only patients who participated in the transition process at this AMC's CF center that had received continuous care from the pediatric to adult CF programs were included in this study. Patients who participated in the transition process in the pediatric program but who discontinued their care or were lost to follow-up at this AMC's adult CF program were not included in the study. While some of those patients had relocated for careers,

college, and other anticipated life changes, this patient group may also represent patients who were dissatisfied with their care and sought care at other CF programs.

Another limitation of this program evaluation is the timing of this project: the COVID 19 pandemic placed a significant burden on the CF center at this AMC as they transitioned to a primarily online format to provide and coordinate patient care. The planned transfer of some patients from pediatric to adult program was delayed due to these shifting priorities. Additionally, the adult program stopped all transfer of patients from the pediatric to adult clinic for a brief period in 2019 due to staffing issues. As such, the data obtained from the last three years of transition experiences may not be representative of the typical experience of patient transition.

Due to the time frame and the dynamic nature of improving processes within the health center, not all patients who participated in the transition process received the same transition interventions. While the basic transition interventions were in place for these transitions, such as the Ages and Stages Questionnaire, others, such as the physician "Meet and Greet' have been implemented more recently. As the pediatric CF program has gradually added more transition interventions into the program, it is expected that patients who transferred most recently will be exposed to the most resources and interventions.

The timing of the introduction of CF modulators is a significant factor that impacted the data collection for this project. While most patients' transition process was not impacted by the start of a CF modulator, a total of 34.7% of patients in the project started Trikafta in the year before or after transfer. Given the potential for Trikafta to significantly decrease symptoms and improve overall lung function, any improvements in FEV_1 may not be attributed to the transition processes but may provide evidence of the efficacy of the CF Modulators.

Nursing Practice Implications

This program evaluation adds to the nursing body of knowledge on the value of interventions and programs aimed at transition readiness for patients with CF as they transition from pediatric to adult health care services. Additionally, these findings may be generalizable to patients with other chronic conditions who are likewise transitioning to adult health care services. This program evaluation provides important information on the transition experience of patients with CF who are managing the complexities of their chronic conditions while becoming autonomous adults who oversee their own health care. Though a multi-disciplinary team approach is used to provide transition services, nurses are at the forefront of this process, helping to ensure smooth transitions that promote wellness while coordinating services in many CF centers. As such, nurses are in a prime position to advocate for the delivery of transition services that are most relevant and beneficial for patients to reduce gaps and improve patient outcomes.

Products of Scholarly Practice Product

The program evaluation of the CF transition program in the CF center at this AMC is the primary product of this scholarly project. The dissemination of key findings to members of the CF transition team, CF health care providers, and the Pediatric Health Care Transition Working Group at this AMC is another product of this program evaluation.

A manuscript will be prepared and submitted for publication based on the program evaluation findings to the Journal of Pediatric Health Care. The project will be completed, reviewed, and published in the University of Virginia's Libra database and submitted to the University of Virginia School of Nursing as part of the requirements for completion of the Doctor of Nursing Practice program.

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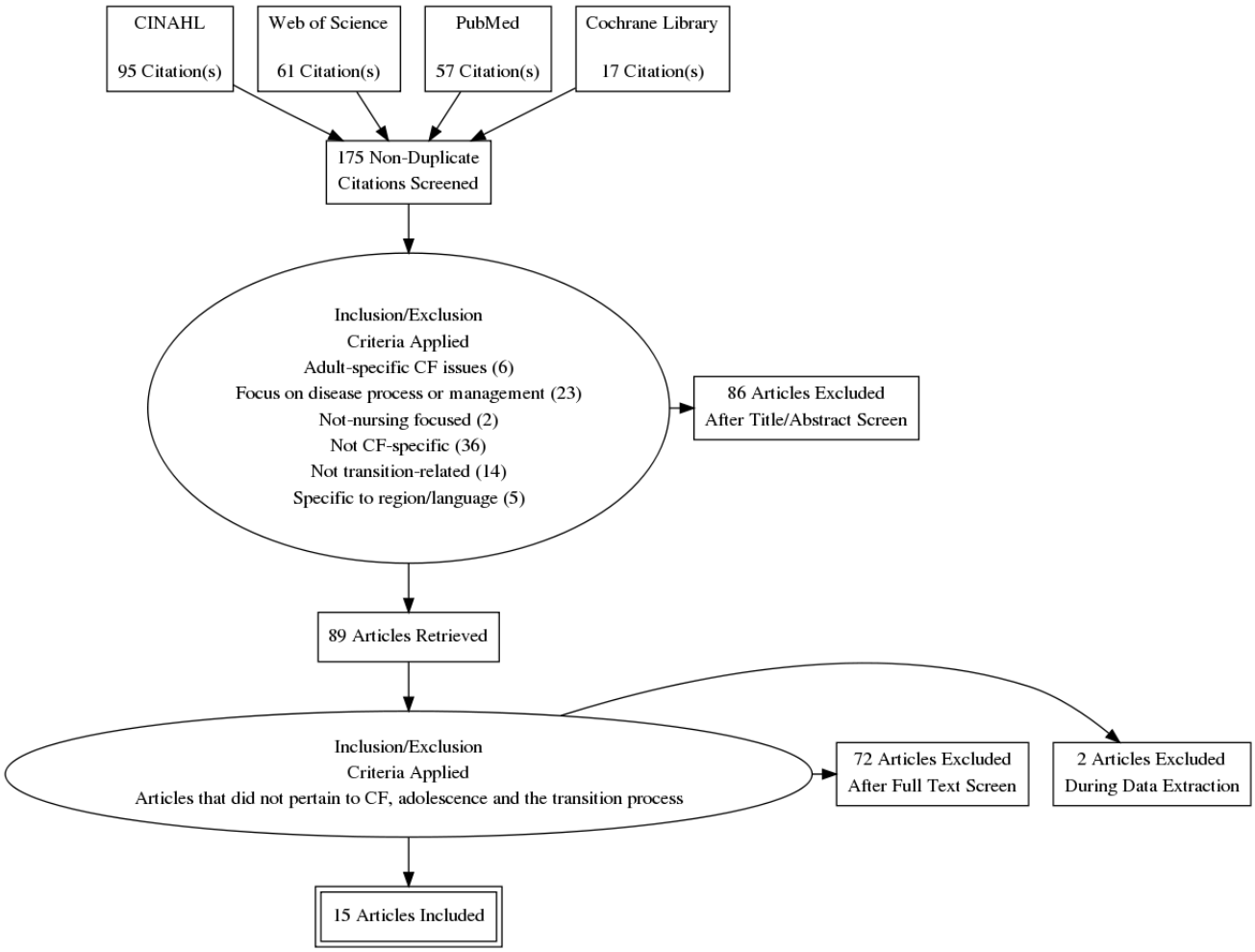
Appendix A

Review of the Literature

Figure A1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram



Note: This figure demonstrates the process by which articles were selected and eliminated from the review of the literature.

Table A1

Summary of Literature Review

Study Reference (Author, Year)	Design	Subjects and Setting and Data Collection Period	Intervention, Control/Comparison	Study Outcomes	Level of Evidence and Quality Grade (Johns Hopkins)	Limitations	Thematic Analysis				
							Interventions			Structured vs. Unstructured Programs	Risks and Challenges to Transition
							Educational	Service delivery-based	Collaborative		
Al-Yateem (2012)	Qualitative, phenomenological design	**Subjects**: n=25, patients who transitioned in the previous 2 years **Setting**: 2 CF Centers in major hospitals in Ireland **Data Collection Period**: undisclosed	In-depth interviews regarding transition experience	Findings showed that transition process was fragmented and not comprehensive in nature. Patients felt inadequately prepared to transition.	III A/B	Small sample size; standard of care for current transition process not described				x	
Baker et al. (2015)	Mixed methods exploratory design	**Subjects:** n=23, health care providers (HCPs) **Setting**: 10 CF Centers in the US. **Data Collection**: after 6 months of use of CF rise	Survey of experiences with CF R.I.S.E. (Cystic Fibrosis: Responsibility, Independence, Self-Care, Education) transition program	HCPs deemed program valuable and sustainable in their practices.	III A/B	Small sample sizes resulted in clustering within a center, as there were multiple providers in a care center.	x				x

Study Reference (Author, Year)	Design	Subjects and Setting and Data Collection Period	Intervention, Control/Comparison	Study Outcomes	Level of Evidence and Quality Grade (Johns Hopkins)	Limitations	Thematic Analysis				
							Interventions			Structured vs. Unstructured Programs	Risks and Challenges to Transition
							Educational	Service delivery-based	Collaborative		
Campbell et al. (2016)	Systematic literature review	**Databases:** Cochrane Library, Medline, Embase, PsychInfo, and Web of Knowledge **Data Collection**: prior to June 19, 2015	4 RCTS reviewed, r/t transition interventions for adolescents and young adults with chronic illness	No improvement in health outcomes after implementation of interventions, but transitional competencies improved: knowledge, self-advocacy skills	I A	Difficult to isolate the effects of single interventions. Difficulties in using control groups, limited long-term evidence.	x	x			
Chaudry et al. (2013)		**Subjects**: n=91 adult patients with CF, 44 of whom participated in a structured transition program **Setting**: University of Michigan CF Center **Data Collection**: January – December 2010	Evaluated the experiences and opinions of patients in an adult CF center who went through a formal transition versus those who did not, evaluated the overall process and identified areas for improvement.	Participation in a structured transition program improved patient satisfaction, perceived health status, and independence, but did not decrease patient anxiety.	II B	Transferred on average 8.4 years prior - recall of experience unreliable in this time frame. The retrospective nature of this study is a limitation			x		
Coyne et. al (2018)	Systematic review	**Databases:** PsychInfo, CINAHL, EMBASE, and PubMed **Data collection**: January 2001 through March 2015	22 studies evaluated the outcomes and transition experiences of adolescents and young adults with CF	There is a lack of research regarding improved health outcomes and transition programs. More information is needed to construct well-informed transition programs.	II A					x	

Study Reference (Author, Year)	Design	Subjects and Setting and Data Collection Period	Intervention, Control/Comparison	Study Outcomes	Level of Evidence and Quality Grade (Johns Hopkins)	Limitations	Thematic Analysis				
							Interventions			Structured vs. Unstructured Programs	Risks and Challenges to Transition
							Educational	Service delivery-based	Collaborative		
Crowley et al. (2011)	Systematic review	**Databases**: MEDLINE, HMIC, PsychInfo, and EMBASE **Data Collection**: prior to January 2010	10 studies evaluated health outcomes for interventions for the transition between pediatric and adult care	Only 6 interventions resulted in improvements in health outcomes, and all were related to IDDM (HbA1c)	IIA	No randomization, difficult to isolate which interventions most effective. Widely differing definitions and durations of interventions, no longitudinal studies.	x	x	x		
Frederick (2016)	Narrative			Described the psychosocial challenges associated with transition based on increased longevity including social and economic effects, career choices, and family planning	V B						x
Gorlaski et al. (2017)	Narrative review			Described the barriers to transition on the patient, caregiver, and provider levels and provided examples of successful programs.	V B						x

Study Reference (Author, Year)	Design	Subjects and Setting and Data Collection Period	Intervention, Control/Comparison	Study Outcomes	Level of Evidence and Quality Grade (Johns Hopkins)	Limitations	Thematic Analysis				
							Interventions			Structured vs. Unstructured Programs	Risks and Challenges to Transition
							Educational	Service delivery-based	Collaborative		
Gravelle et al. (2015)	Quality improvement, retrospective design	Review of transition program from its inception in 1982	Transition clinical pathways, pre-graduation workshop, collaboration with adult clinic	TCCP worthwhile component of program, workshops = higher score on transition readiness post-tests,	V B	Small number of patients did not allow for this QI to be outcomes based	x				
Middour-Oxler et al. (2021)	Quantitative, retrospective cohort design	**Subjects**: n=56, patients had at least 6 months of adult care and had transitioned between 2009 and 2016. **Setting**: CF center at academic medical center in the southeast **Data Collection**: 3/2015-9/2016	Formal versus informal or semi-structured transition program	Participants significantly more satisfied with process and had less anxiety with structured program. No difference in groups for satisfaction of timing, 48% happy with timing, 18% wanted earlier transition and 34% wanted more pediatric care.	II A	Retrospective nature of study/subject memory recall.				x	x
Okumura (2014)	Quality improvement initiative	Data from transition clinic starting in 2005	Transition initiative	Shared responsibility - successful, work groups formed. For the survey, families reported an increase in discussion about transition post-	V B	Surveys based on self-report, small sample size	x		x		

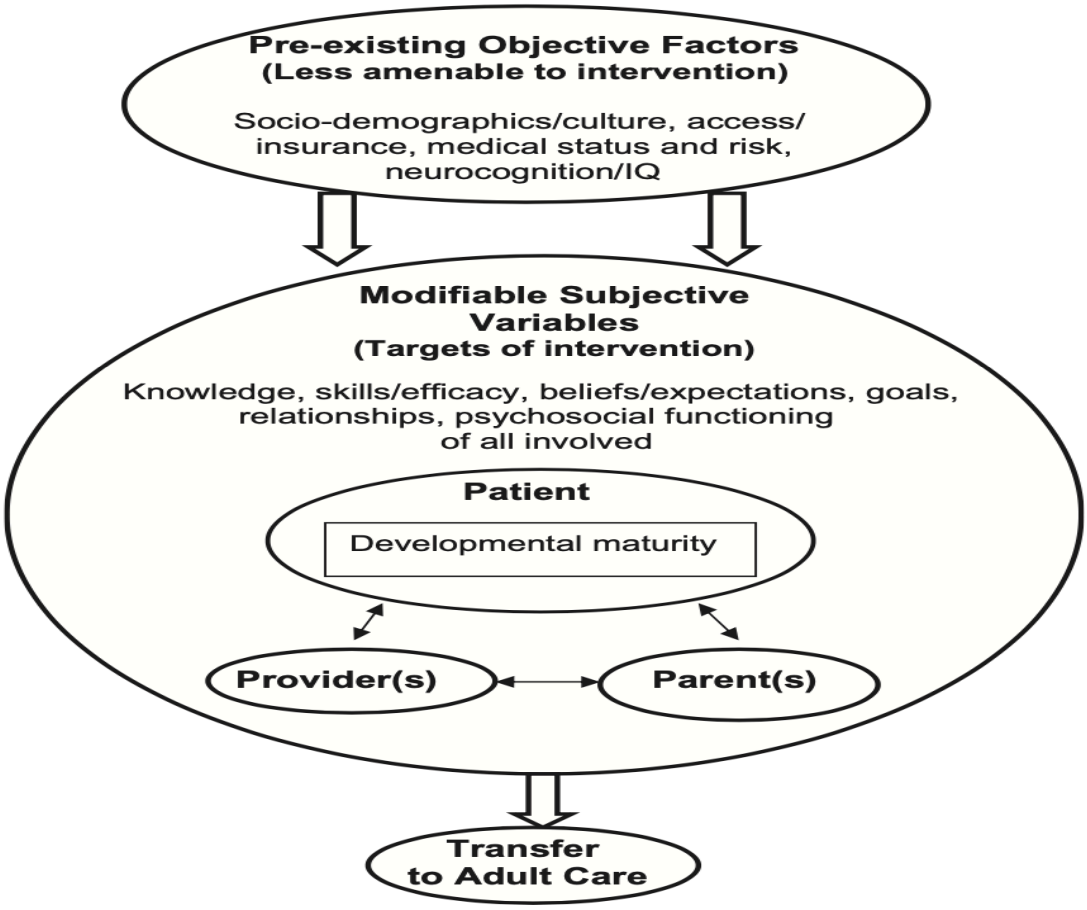
Study Reference (Author, Year)	Design	Subjects and Setting and Data Collection Period	Intervention, Control/Comparison	Study Outcomes	Level of Evidence and Quality Grade (Johns Hopkins)	Limitations	Thematic Analysis				
							Interventions			Structured vs. Unstructured Programs	Risks and Challenges to Transition
							Educational	Service delivery-based	Collaborative		
				intervention, from 35-73%. TRAQ - improved scores,							
Peeters et al. (2019)	Mixed methods retrospective controlled design	**Subjects:** Health care professionals (n = 28) and young adults who transferred to adult clinic (n=46) **Setting:** 2 CF Centers at university hospitals in the Netherlands. **Data Collection**: between 2012-2017	Direct handover versus Transition clinic	HCPs had positive experiences of TCs: process of joint adult and peds clinics made transition process more holistic transition coordinator, the TC was the preferred method of transition. No significant health outcomes for patients utilizing transition clinic.	II A	Small number of participants may have negatively impacted statistical power. Use of different EHRs at both facilities = lack of systematic data recording of missed consultations, data on missed appointments not available. .		x	x		
Schmidt et al. (2016)	Quasi-experimental, non-equivalent group design	Adolescents with chronic diseases from 12 clinical centers in Germany, data collection period not specified	Generic transition-oriented patient education group setting versus standard care	Highly significant improvement in transition competence, a significant improvement in self-efficacy and satisfaction with school/educational services. No significant differences reported for patient activation,	II A	Researchers acknowledged the CF group was underpowered, unable to find differences in QOL, but measurement tool may have been too broad.	x				

Study Reference (Author, Year)	Design	Subjects and Setting and Data Collection Period	Intervention, Control/Comparison	Study Outcomes	Level of Evidence and Quality Grade (Johns Hopkins)	Limitations	Thematic Analysis				
							Interventions			Structured vs. Unstructured Programs	Risks and Challenges to Transition
							Educational	Service delivery-based	Collaborative		
				general satisfaction with care, and QOL.							
Skov et al. (2018)	Prospective, observational study	Subjects: Setting: Data Collection: Patients with CF between 12-15 in a CF center at an outpatient clinic in Denmark were evaluated at baseline and then 12 months later between 2010-2011	Structured transition program, use of split-visits	Split visit rates improved from a baseline of 50% to 83 % at highest level, self- assessed transition readiness scores improved from a mean of 64 at baseline to a mean of 76 points. Health related QoL did not change, nor did lung function or BMI scores.	III A/B	Small sample from a single center, non-randomized, non-controlled, observational over only 1 year. No single person was assigned the task of data collection, so some forms were incomplete.	x	x			
Towns & Bell (2011)	Narrative review			Described challenges to effective transition and offered solutions to overcome such challenges.	V B						x
Tuckman et al. (2010)	Narrative review			Described evolution of transition programs and the barriers and challenges to successful transition	V B						x

Appendix B

Figure B1

Socio-ecological Model for Adolescents and Young Adults Readiness for Transition



Appendix C

Institutional Review Board Documentation

ASSURANCE FORM
University of Virginia
Institutional Review Board for Health Sciences
Research HIPAA Privacy Board

<table>
<tr><td colspan="3">UVA Study Tracking # HSR210440</td></tr>
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Determination of Exempt Research - Exempt</td><td rowspan="2">Type:
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Sponsor Protocol #:</td></tr>
<tr><td>Principal Investigator: Regina DeGennaro, RN-C, MSN, AOCN, CNL</td></tr>
<tr><td colspan="3">Title: A Program Evaluation of a Cystic Fibrosis Transition Program at an Academic Medical Center</td></tr>
<tr><td colspan="3">Assurance: Federal Wide Assurance (FWA)#: 00006183
UVa IRB #1 Registration IRB#00000447
UVA IRB #3 Registration IRB#00010459</td></tr>
<tr><td colspan="3">Certification of IRB Review:
The IRB-HSR/HIPAA Privacy Board abides by 21CFR50, 21CFR56, 45CFR46, 45CFR160, 45CFR164, 32CFR219 and ICH guidelines as compatible with FDA and DHHS regulations. This activity has been reviewed in accordance with these regulations.</td></tr>
<tr><td colspan="3">Event Date: 10/29/21
Protocol Expiration Date: 10/28/22</td></tr>
<tr><td colspan="3">Current Status: Open to Enrollment</td></tr>
<tr><td colspan="3">Consent Version Dates:</td></tr>
<tr><td colspan="3">UVA Site Only
Number of Subjects Approved to Enroll:</td></tr>
<tr><td colspan="3">Committee Members (did not vote):</td></tr>
</table>

Comments: The purpose of this study is to evaluate the patient experience with the process of transition from pediatric to adult health care in patients with cystic fibrosis.
The study will involve collection of information from medical records and a survey
There is no outside sponsor for this study.

The following documents were submitted with this application: --
Modified Emory Survey

Approved with this protocol is the following recruitment letter. --
Recruitment letter 10-25-21

This study is now open to enrollment.

REGULATORY INFORMATION:

Protocol Exempt by CATEGORY # 2(i)
This study met the criteria for an exempt determination per 45CFR46.104(d)2(i).
Research that includes only interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) and (i) the information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects.
Protocol Exempt by CATEGORY # 4(iii)
This study met the criteria for an exempt determination per 45CFR46.104(d)4(iii).
Secondary research for which consent is not required: Secondary research uses of identifiable private information or identifiable biospecimens, and (iii) The research involves only information collection and analysis involving the investigator's use of identifiable health information when that use is regulated under 45CFRparts 160 and 164, subparts A and E, for the purposes of 'health care operations' or 'research' as those terms are defined at 45CFR164.501 or for 'public health activities and purposes' as described under 45CFR164.512 (b).
HIPAA REGULATIONS
The IRB-HSR has granted a waiver of HIPAA Authorization via expedited review procedures via 45CFR 164.512(i)(2) to contact subjects by direct contact by a person who is not their health care provider. Direct contact may include phone, letter, direct email or approaching potential subjects while at UVA. Phone, letter or emails will be approved by the IRB-HSR prior to use. The following HIPAA identifiers may be collected: Name, medical record number, date of birth and contact information. The minimum necessary PHI to be collected includes only those items related to the inclusion/ exclusion.
--The study includes only collection of de-identified health information.
----Any health information shared outside of UVA will be de-identified.

RECEIVING FROM OR SENDING DATA/SPECIMENS EXTERNAL TO UVA
You are required to consult with your office of grants and contracts to determine if an agreement is required to receive data/specimens from outside UVA or to send data/specimens outside of UVA.

DATA PROTECTION
You are required to protect the data according to the enclosed Privacy Plan and the Data Security Plan.
PERSONNEL CHANGES
You must notify the IRB of any new personnel working on the study PRIOR to them beginning work.
MODIFICATIONS
If you need to modify the procedures in this study, you must submit an email to IRBHSR@virginia.edu describing the changes before they are implemented. If changes will affect the Exempt application, send the changes with tracked changes to the document.
The IRB-HSR will determine if the project continues to meet the criteria for exempt research.
CLOSURE
Send an email to IRBHSRadmin@virginia.edu within 30 days of closing this study. Include the IRB-HSR# or UVA Study Tracking # of this study in the email. An IRB-HSR Closure Form is not required.
ADDITIONAL INFORMATION
See educational resources for research http://www.virginia.edu/vpr/irb/hsr/education.html

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PLEASE REMEMBER:
* If an outside sponsor is providing funding or supplies, you must contact the SOM Grants and ContractsOffice/ OSP regarding the need for a contract and letter of indemnification. If it is determined that either of these documents is required, participants cannot be enrolled until these documents are complete.
* You must notify the IRB of any new personnel working on the protocol PRIOR to them beginning work.* You must obtain IRB approval prior to implementing any changes to the approved protocol or consent form except in an emergency, if necessary to safeguard the well-being of currently enrolled subjects.
* If you are obtaining consent from subjects, prisoners are not allowed to be enrolled in this study unless theIRB-HSR previously approved the enrollment of prisoners. If one of your subjects becomes a prisoner after they are enrolled in the protocol you must notify the IRB immediately.
* You must notify the IRB-HSR office within 30 days of the closure of this study.
* You are required to submit either an IRB Status Report or an IRB Update Form to the IRB-HSR at leastonce a year.

The IRB-HSR official noted below certifies that the information provided above is correct and that, as required, future reviews will be performed and certification will be provided.

Name: Susie R. Hoffman, RN BSN Title: Member, Institutional Review Board for Health Sciences Research 434.924.2620 Fax: 434-924-2932	Name and Address of Institution: IRB for Health Sciences Research University of Virginia, PO Box 800483 Charlottesville, VA 22908 **OR** IRB for Health Sciences Research One Morton Drive, Suite 400 Charlottesville, VA 22903

Determination made by: Susie R. Hoffman, RN BSN From IP Address: 128.143.229.234	Date: 10/29/21 at 10:45 AM

Appendix D

Permission to use Post-Transition Survey from Emory University

July 9th, 2021

Dear Kristine Young-O'Keefe,

Thank you for writing to request permission to use the *Post-Transition Questionnaire* from my recent publication "Formal vs. informal transition in adolescents with cystic fibrosis: a retrospective comparison of outcomes" in the Journal of Pediatric Nursing. I am pleased that you have asked to use this tool and grant my permission. In any publications, please reference the original work appropriately.

You may require modifications to the tool, to remove our center name and replace yours. You have my approval for this change, as well. Best of luck with your DNP project! I am happy to be a resource as you move forward with your implementation.

Sincerely,

Brandi Middour-Oxler, DNP-CPNP, ARNP

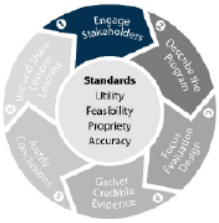
Cystic Fibrosis Transition Program Coordinator & Nurse Practitioner
Emory University School of Medicine
Department of Pediatrics
bmiddou@emory.edu

Appendix E

Step 1

CDC Program Evaluation Framework Checklist for Step 1

Engage Stakeholders



The first step in the CDC Framework approach to program evaluation is to engage the stakeholders. Stakeholders are people or organizations that are invested in the program, are interested in the results of the evaluation, and/or have a stake in what will be done with the results of the evaluation. Representing their needs and interests throughout the process is fundamental to good program evaluation. A program may have just a few or many stakeholders, and each of those stakeholders may seek to be involved in some steps or all six steps. This checklist helps identify stakeholders and understand their involvement in the evaluation.

Although "Engaging Stakeholders" is the first of the 6 steps, the first three steps of the CDC Framework are iterative and can happen in any sequence. For instance, identifying the right stakeholders may make more sense to do for your evaluation after drafting the purpose, user, and use of the evaluation that happens in Step 3. That said, this checklist will help you think through the key points in identifying and engaging stakeholders throughout your evaluation.

☐ Brainstorm potential stakeholders. These may include, among others:
- ☐ People affected by your program
- ☐ People involved in implementing the program or conducting the evaluation
- ☐ People who will use the results of the evaluation. These may include internal staff, partners, program participants, community members, and other organizations, among others

In brainstorming the list be sure to think broadly, including in your list:
- ☐ People in the above categories who share your priorities, and people who don't
- ☐ People in the above categories who are critics as well as supporters

☐ Especially if the list is very long, try to extract the subset of most important stakeholders. Some helpful criteria for identifying whether a person or organization is a key stakeholder include that they:
- ☐ Increase the credibility of your program or your evaluation
- ☐ Are responsible for day-to-day implementation of the program activities that are being evaluated and will need to implement any changes
- ☐ Can advocate for the changes to the program that the evaluation may recommend, OR actively oppose the recommended changes
- ☐ Fund or authorize the continuation or expansion of the program

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☐ Discuss with key stakeholders individually the best way to engage them—in person, phone, email etc. Regardless of chosen medium, in the engagement discussions get clarity on the following questions: [NOTE: If a preliminary logic model for the program has been completed, then use it to help frame and target the questions.]

- ☐ What do you see as the main outcomes of the program?
- ☐ What do you see as the main activities of the program?
- ☐ Which of the activities and outcomes are most important to you? That is, to retain your involvement and support, which activities must be effectively implemented and/or which outcomes achieved?
- ☐ What do you see as the most important evaluation questions at this time?
- ☐ [If outcomes are included] How rigorous must the design be?
- ☐ Do you have preferences regarding the types of data that are collected (e.g., quantitative, qualitative)?
- ☐ What resources (e.g., time, funds, evaluation expertise, access to respondents, and access to policymakers) might you contribute to this evaluation effort?
- ☐ In what parts or steps of this evaluation would you want to be involved? All or just some specific ones?
- ☐ How would you like to be kept apprised of this evaluation? How best to engage you in the steps in which you want to be involved?
- ☐ (How) will **you** use the results of this evaluation?

☐ Examine the results of the stakeholder discussion for insights related to development/refinement of the program description and logic model. Also examine for a starter set of important evaluation questions, which will be elaborated during Step 3.

☐ Especially if there are many stakeholders, summarize the results of the engagement discussions with a [simple or detailed as you prefer] plan for stakeholder involvement, including which stakeholders will participate/provide input during the major stages of the project and what their roles and responsibilities will be for each step.

Appendix F

Step 2

CDC Program Evaluation Framework Checklist for Step 2

Describe the Program

A **logic model** is a graphic depiction (road map) that presents the shared relationships among the resources, activities, outputs, and outcomes/impacts for your program. It depicts the relationship between your program's activities and its intended effects, in an implicit 'if-then' relationship among the program elements — if I do this activity, then I expect this outcome. Among other things, a logic model helps clarify the boundary between 'what' the program is doing and 'so what'—the changes that are intended to result from strong implementation of the "what."

A logic model can focus on any level of an enterprise or program: the entire organization, one of its component departments or programs, or just specific parts of that department or a program. Of course, the boundary between "what" and "so what" will vary accordingly.

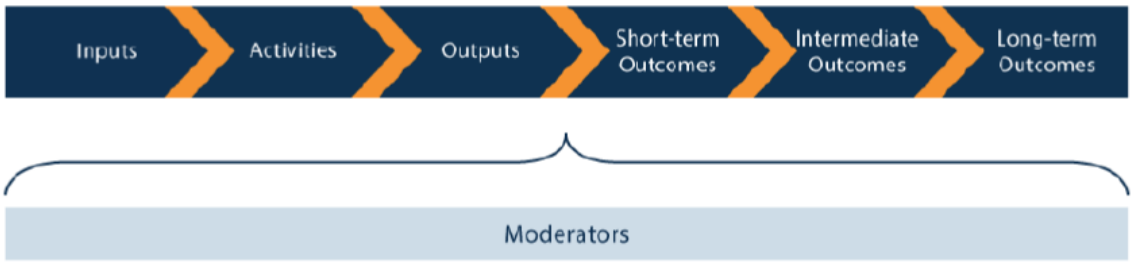
Related Terms

Logic models are the most common, but not the only, name applied to a visual depiction of a program. Here are some names of others approaches that either replicate or closely resemble logic models in their format and intent. There are occasions where one approach/format is a better fit than another, but often any of these will work equally well:

- Program Roadmaps
- Theory of Change
- Theory of Cause
- Theory of Action
- Concept(ual) Maps
- Outcome Maps
- Logical Frameworks (LogFrames)

Logic models differ widely in format and level of detail. Here are some key terms used in logic models, although not all are employed in any given model:

- Inputs: The resources needed to implement the activities
- Activities: What the program and its staff do with those resources
- Outputs: Tangible products, capacities, or deliverables that result from the activities
- Outcomes: Changes that occur in other people or conditions because of the activities and outputs
- Impacts: [Sometimes] The most distal/long-term outcomes
- Moderators: Contextual factors that are out of control of the program but may help or hinder achievement of the outcomes



Let's get started. Here are the key steps to developing a useful logic model:

- ☐ Gather information available on the program, including but not limited to:
  - ☐ Mission and vision
  - ☐ Goals and objectives
  - ☐ Current program descriptions such as websites, program descriptions, fact sheets
  - ☐ Strategic plans
  - ☐ Business, communication, and marketing plans
  - ☐ Existing/previous logic models
  - ☐ Existing performance measures and/or program reviews

- ☐ Review the information and extract from it to create a two-column table including:
  - ☐ Column 1: Activities: What the program and its staff do.
  - ☐ Column 2: Outcomes: Who or what beyond the program and its staff needs to change and how. In generating outcomes, it helps to Identify the target audiences for program activities and the action they must take in order for the activities to be successful.
  - ☐ Within the list in column 2, identify the most distal outcome: What is the big public health problem you aim to address with your program?

- ☐ Clarify the activities and outcomes with stakeholders* to ensure:
  - ☐ Appropriate classification; no activities are actually outcomes and no outcomes listed are actually activities
  - ☐ No major redundancy in list of activities or list of outcomes
  - ☐ No major missing activities or outcomes

☐ Decide whether the activities should be ordered sequentially. If so:
- ☐ Think about the "logical" relationship among the activities—which may or may not be the same as how they unfold over time— and determine if some activities need to occur before others can be implemented
- ☐ Order the activities within the columns into earlier or later activities to reflect the sequential relationships

☐ Decide whether the outcomes should be ordered sequentially
- ☐ Think about the "logical" relationship among the outcomes-- will some outcomes logically need to occur before others can be achieved?
- ☐ Move the outcomes into columns to reflect the sequence in which the outcomes should occur. Label the columns as needed (i.e., short-, mid, long-term; or [proximal, intermediate, distal)

☐ Check in with your stakeholders
- ☐ To ensure the activities and outcomes reflect their understanding of the program to ensure:
  - There are no major missing activities or outcomes
  - The logical progression of activities
  - The logical progression of the outcomes
- ☐ To (re)affirm the intended uses of the logic model (i.e., assess implementation, assess effectiveness, performance measurement, strategic planning)

The intended uses of the logic model, will determine which, if any, of the elaborations below would make the logic model more useful.

☐ If **depicting the program logic** in a roadmap format is desirable, then:
- ☐ Write each of the existing activities and outcomes on a sticky note, or equivalent
- ☐ Move the notes around to allow for drawing of lines to depict logical relationships
- ☐ Draw in lines remembering that lines may go from:
  - One or more activities to a subsequent activity
  - One or more activities to an outcome
  - One or more proximal outcomes to a more distal outcome

☐ If **outputs** are desired because stakeholders would like clarification of the direct result of the activities, then using the logic model table or (better) the roadmap:
- ☐ Identify the activities for which outputs are desired
- ☐ Identify the link between those activities and their successor activities or outcomes
- ☐ Thinking about that logical link, what are the key attributes of the activity that must be present for it to produce its successor activity or outcome
- ☐ Place the outputs in the appropriate place in the logic model table or roadmap

☐ If **inputs** are desired because stakeholders would like clarification of necessary resources to implement the program, then:
- ☐ Identify the key inputs without which the program cannot be implemented. Think about broad categories such as staff, equipment, data, funds, and partnerships.
- ☐ Place the inputs into a column to the left of the activities in the logic model.
- ☐ If it is important to see the link between each input and the activity it affects, then draw arrows from each input to the related activity

☐ If **moderators** are desired because—in the view of stakeholders and users—clarification of potential facilitators or barriers in the larger environment is necessary:
- ☐ Identify the key moderators, thinking of broad categories such as political, economic, social, and technological
- ☐ Identify what links in the program logic will be facilitated or impeded by the presence or absence of sufficient levels of the moderator. Remember moderators can facilitate or impede the ability of one activity/output to generate a successor activity/output, one activity/output to generate an outcome, a proximal outcome to generate a more distal outcome
- ☐ Be especially conscious of key moderators without which the program cannot be implemented
- ☐ Place the moderators into the appropriate place in the logic model table or roadmap.
- ☐ If using a roadmap, decide whether to leave the moderators in one block at the bottom of the logic model or draw lines from each moderator to the logical link it will facilitate or hinder
- ☐ Review and affirm or further refine with stakeholders, especially those who will use the logic model

☐ Review and affirm the elaborations of the logic model with stakeholders to ensure it accurately represents the program and the relationships among the components

☐ Create a narrative to go with the logic model. A one-page logic model will not be able to capture all the nuances of the program. The narrative will help explain the components of the logic model and how they work together to accomplish the outcomes. The narrative should include the following:
- ☐ An expanded description of the activities, outcomes, and other components of the logic model
- ☐ Any key linkages between activities, between activities and outcomes, and between different outcomes
- ☐ Attribution v. contribution to outcomes, etc.
- ☐ Stakeholder expectations for what will be accomplished, etc.

*Stakeholders are people or organizations that are invested in the program, are interested in the results of the evaluation, and/or have a stake in what will be done with the results of the evaluation. This definition is found in *Checklist for Step 1: Engage Stakeholders*.

Appendix G

Step 3

CDC Program Evaluation Framework Checklist for Step 3

Focus the Evaluation

In Step 2 you described the entire program, but usually the entire program is not the focus of a given evaluation. Step 3 is a systematic approach to determining where to focus this evaluation, this time. Where the focus lies in the logic model is determined, in conjunction with stakeholders, through application of some of the evaluation standards. While there are more than 30 standards, the most important ones fall into the following four clusters:

- **Utility:** Who needs the information from this evaluation and how will they use it?
- **Feasibility:** How much money, time, skill, and effort can be devoted to this evaluation?
- **Propriety:** Who needs to be involved in the evaluation to be ethical?
- **Accuracy:** What design will lead to accurate information?

☐ The standards help you assess and choose among options at every step of the framework, but some standards are more influential for some steps than others. The two standards most important in setting the focus are "utility" and "feasibility." Ensure that all stakeholders have common understandings of the phases (formative/summative) and types of evaluations (needs assessment/process/outcome/impact).

☐ Using the logic model, think through where you want to focus your evaluation, using the principles in the "utility" standard:

- ☐ Purpose(s) of the evaluation: implementation assessment, accountability, continuous program improvement, generate new knowledge, or some other purpose
- ☐ User(s): the individuals or organizations that will employ the evaluation findings
- ☐ Use(s): how will users employ the results of the evaluation, e.g., make modifications as needed, monitor progress toward program goals, make decisions about continuing/refunding
- ☐ Review and refine the purpose, user, and use with stakeholders, especially those who will use the evaluation findings

☐ Identify the program components that should be part of the focus of the evaluation, based on the utility discussion:

- ☐ Specific activities that should be examined
- ☐ Specific outcomes that should be examined
- ☐ Specific pathways from activities to specific outcomes or outcomes to more distal outcomes
- ☐ Specific inputs or moderating factors that may or may not have played a role in success or failure of the program

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☐ Refine/expand the focus to include additional areas of interest, if any, identified in Steps 1 and 2
- ☐ Does the focus address key issues of interest to important stakeholders?
- ☐ Did the program description discussion identify issues in the program logic that may influence the program logic?
- ☐ Are issues of cost, efficiency, and/or cost-effectiveness important to some or all stakeholders?

☐ Refine/expand the focus to include additional areas of interest based on the propriety and accuracy evaluation standards
- ☐ Are there components of the program—activities, outcomes, pathways, or inputs/moderators that must be included for reasons of "ethics" or propriety?
- ☐ Are there components of the program—activities, outcomes, pathways, or inputs/moderators that must be included to ensure that the resulting focus is "accurate"?

☐ "Reality check" the expanded focus using the principles embedded in the "feasibility" evaluation standard
- ☐ The program's stage of development: Is the focus appropriate given how long the program has been in existence?
- ☐ Program intensity: Is the focus appropriate given the size and scope of the program, even at maturity?
- ☐ Resources: Has a realistic assessment of necessary resources been done? If so, are there sufficient resources devoted to the evaluation to address the most desired items in the evaluation focus?

☐ At this point the focus may still be expressed in very general terms—this activity, this outcome, this pathway. Now, convert those into more specific evaluation questions. Some examples of evaluation questions are:
- ☐ Was [specific] activity implemented as planned?
- ☐ Did [specific] outcomes occur and at an acceptable level?
- ☐ Were the changes in [specific] outcomes due to activities as opposed to something else?
- ☐ What factors prevented the activities in the focus from being implemented as planned? Were [specific inputs and moderating factors] responsible?
- ☐ What factors prevented (more) progress on the outcomes in the focus? Were [specific moderating factors] responsible?
- ☐ What was the cost for implementing the activities?
- ☐ What was the cost-benefit or cost-effectiveness of the outcomes that were achieved?

☐ Consider the most appropriate evaluation design, using the four evaluation standards—especially utility and feasibility—to decide on the most appropriate design. The three most common designs are:

- ☐ Experimental: Participants are randomly assigned to either the experimental or control group. Only the experimental group gets the intervention. Measures of the outcomes of interest are (usually) taken before and after the intervention in both groups.
- ☐ Quasi-experimental: Same specifications as an experimental design, except the participants are not randomly assigned to a "comparison" group.
- ☐ Non-experimental: Because the assignment of subjects cannot be manipulated by the experimenter, there is no comparison or control group. Hence, other routes must be used to draw conclusions, such as correlation, survey or case study.

Some factors to consider in selecting the most appropriate design include:

- ☐ With what level of rigor must decisions about "causal attribution" be made?
- ☐ How important is ability to translate the program to other settings?
- ☐ How much money and skill are available to devote to implementing the evaluation?
- ☐ Are there naturally occurring control or comparison groups? If not, will selection of these be very costly and/or disruptive to the programs being studied?

☐ Start the draft of the evaluation plan. You will complete the plan in Step 4. But at this point begin to populate the measurement table (see example below) with:

- ☐ Program component from logic model (activity, outcome, pathway)
- ☐ Evaluation question(s) for each component

Evaluation Questions	Indicators	Data Source(s)	Data Collection Methods

Figure 1: Evaluation Plan Measurement Table

☐ Review and refine the evaluation focus and the starter elements of the evaluation plan with stakeholders, especially those who will use the evaluation results.

Appendix H

Step 4

Gathering credible evidence

Definition☐	Compiling information that stakeholders perceive as trustworthy and relevant for answering their questions. Such evidence can be experimental or observational, qualitative or quantitative, or it can include a mixture of methods. Adequate data might be available and easily accessed, or it might need to be defined and new data collected. Whether a body of evidence is credible to stakeholders might depend on such factors as how the questions were posed, sources of information, conditions of data collection, reliability of measurement, validity of interpretations, and quality control procedures.
Role☐	Enhances the evaluation's utility and accuracy; guides the scope and selection of information and gives priority to the most defensible information sources; promotes the collection of valid, reliable, and systematic information that is the foundation of any effective evaluation.
Activities☐	• Choosing indicators that meaningfully address evaluation questions; ☐ Describing fully the attributes of information sources and the rationale for their selection; ☐ Establishing clear procedures and training staff to collect high-quality information; ☐ Monitoring periodically the quality of information obtained and taking practical steps to improve quality; ☐ Estimating in advance the amount of information required or establishing criteria for deciding when to stop collecting data in situations where an iterative or evolving process is used; and ☐ Safeguarding the confidentiality of information and information sources.

Adapted from Joint Committee on Standards for Educational Evaluation. Program evaluation standards: how to assess evaluations of educational programs. 2nd ed. Thousand Oaks, CA: Sage Publications, 1994.

Appendix I

Modified Emory Post-Transition Survey

Questionnaire Instructions: Please mark the best answer to each of the following questions by placing an X in the box which best describes your response. You may elect not to respond to any questions which you do not feel comfortable answering.

1. Which CF pediatric clinic did you primarily attend? Charlottesville □ Roanoke □ Wytheville □

Thinking back to before you transitioned to the adult clinic, how **concerned** were you in the following areas:						
	Very	Somewhat	Neutral	Minimal	Not at all	N/A
1. Meeting with my CF Team without my parents in the exam room.	□	□	□	□	□	□
2. Leaving behind my Pediatric CF Team.	□	□	□	□	□	□
3. Having to meet new caregivers.	□	□	□	□	□	□
4. Your perception of how care in the Adult CF clinic might be different.	□	□	□	□	□	□
5. Adult caregivers not being as caring or friendly.	□	□	□	□	□	□
6. Adult clinic running on time.	□	□	□	□	□	□
7. Being exposed to infection in the Adult clinic.	□	□	□	□	□	□
8. Location of the Adult Clinic.	□	□	□	□	□	□
9. Being admitted to the Adult hospital.	□	□	□	□	□	□
10. Making my own clinic appointments.	□	□	□	□	□	□
11. Just prior to transfer of my care to the Adult program I was anxious:	□	□	□	□	□	□

As you were going through the transition process, how **helpful** were the following areas in making you feel **prepared** and **confident**:						
	Very	Somewhat	Neutral	Minimal	Not at all	N/A
1. Meeting with the Pediatric CF Team without your parents in the room.	□	□	□	□	□	□
2. Completing and discussing the transition assignments with the pediatric staff.	□	□	□	□	□	□
3. Receiving written materials about the adult clinic and staff .	□	□	□	□	□	□
4. Support with planning for insurance coverage.	□	□	□	□	□	□
5. Support with planning for higher education and/or employment.	□	□	□	□	□	□
6. Education to help me be able to care for my CF independently.	□	□	□	□	□	□
7. Prior to having your first clinic visit in the UVA Adult CF clinic, did you meet the Adult CF team at one of your pediatric clinic visits?	□Yes – Answer question number 8a		□No – Answer question number 8b		□Not sure – Answer question number 8b	
8a. Meeting the Adult CF team prior to my transfer to the Adult CF clinic greatly reduced my anxiety about transitioning care to the adult program.	□Strongly Agree	□Agree	□Neither Agee or Disagree	□Disagree	□Strongly Disagree	

8b. If you could have met the adult CF team prior to your transition to the Adult CF program, would your anxiety level have been significantly reduced.	□Absolutely	□Probably	□Not Sure	□Probably Not	□Absolutely Not

The following questions are meant to gauge your **satisfaction** with the transition process:						
	Strongly Agree	Agree	Neither Agee or Disagree	Disagree	Strongly Disagree	Did Not Occur
1. The time spent in my Pediatric CF clinic discussing transition to the Adult CF Clinic prepared me well for my first Adult clinic visit.	□	□	□	□	□	□
2. I feel I was provided enough information about transitioning to the Adult clinic in the year leading up to the transfer of care.	□	□	□	□	□	□
3. I was given the opportunity to ask questions about transitioning to the Adult CF clinic.	□	□	□	□	□	□
4. I am satisfied with the care I received in the Pediatric clinic.	□	□	□	□	□	□
5. I was given the chance to discuss when during the year transfer to the Adult services would occur.	□	□	□	□	□	□
6. I knew who/where to call for CF related concerns between my last pediatric appointment and my first adult appointment.	□	□	□	□	□	□
	Strongly Agree	Agree	Neither Agee or Disagree	Disagree	Strongly Disagree	Did Not Occur
7. I am satisfied with the care I have received in the Adult clinic.	□	□	□	□	□	□
8. Transition and transfer to the adult clinic met or exceeded my expectations.	□	□	□	□	□	□
9. I feel like my Adult team was well-informed about my medical history from my Pediatric team.	□	□	□	□	□	□
10. I feel I had control over how much my parents/guardians were involved in the transition process.	□	□	□	□	□	□
11. The age and timing in which I transition into the Adult program was just right for me.	□	□	□	□	□	□
12. In regards to my transition time, if I could do it over again I would have:	□Stayed in my Pediatric clinic longer.		□Transitioned to the Adult clinic sooner if I could have.		□No change. My transition timing to the Adult CF clinic was just right.	
13. Do you think the transition program made changing from Pediatric to Adult care easier, more difficult, or no difference?	□Made the change easier	□Made the change more difficult	□I was not affected by the program	□I do not remember going through a transition program	□I did not go through a transition program.	

The following questions are meant to gauge your **readiness** at the time to transition
1. At the time of my transfer to the Adult CF program, I completely understood my cystic fibrosis and was completely independent in my own medical care (including how to take my medications, what cystic fibrosis is and does to my body, different kinds of airway clearance, insurance, how to schedule appointments, how to re-order medications). a. Yes b. No c. Not sure

2. If there were aspects of your medical care that you did not feel completely independent about at the time of your transfer to the Adult CF center, what were they? (Please circle all that apply)
   a. The medications that I took and what they were for
   b. What cystic fibrosis is and does to my body
   c. Different kinds of airway clearance
   d. My insurance
   e. How to schedule appointments
   f. How to re-order my medications
   g. How to get in touch with the CF center
   h. Other:
      _____

3. Do you know where to get information regarding CF treatments and research at your center?
   a. Yes
   b. No
   c. Not sure

Overall satisfaction with the transition from pediatric to adult CF care here at University of Virginia:

□Very Satisfied	□Satisfied	□Neither Satisfied or Dissatisfied	□Dissatisfied	□Very Dissatisfied

What was the most difficult part of your transition to the Adult clinic?
What did you find most helpful when you transitioned to the Adult clinic?
Were there any CF education topics that were not covered adequately in the Pediatric clinic that you would have liked more information on before you transitioned to the Adult clinic?
Is there anything you would suggest we do differently to improve transition?

APPENDIX J

Patient Recruitment Letter

Dear Patient,

The UVA School of Nursing is planning a research study to look at patients' experiences with the transition from pediatric to adult health care services at the University of Virginia's Cystic Fibrosis Center. It is a goal in our department to keep our patients informed of research in which they may be interested while carefully protecting your confidentiality. To do both we follow federal regulation called HIPAA. We would like to invite you to take part in this study.

If you agree to be in this study, it will involve completing an online survey regarding your personal experience with the transition process. This survey may be completed anonymously using Qualtrics, a secure online software program, in the link below. We will also access information from your medical record.

The study will not help you directly but has the potential to impact future patients with CF and other chronic illnesses who will undergo the transition process.

The only risk of being in this research is a potential loss of confidentiality. However, the survey will not be linked with your name, email, or any identifying information. Only the investigator, who is not a part of your health care team, will have access to your answers. Your medical information will be recorded without identifying information to decrease the risk of loss of your confidentiality.

You will not be paid for taking part in this study.

You do not have to be in this study if you do not want to be. Your care at UVA will not be changed by your decision about being in this study. Your relationship with your doctor will not be affected by your decision to be in this study or not.

If you have any questions or concerns, please email the investigator, Kristine O'Keefe-Young at ko8z@hscmail.mcc.virginia.edu.

Complete survey here: https://virginiahsd.co1.qualtrics.com/jfe/form/SV_6Gv6sXmGzAXkCtE

Thank you in advance for considering this request.

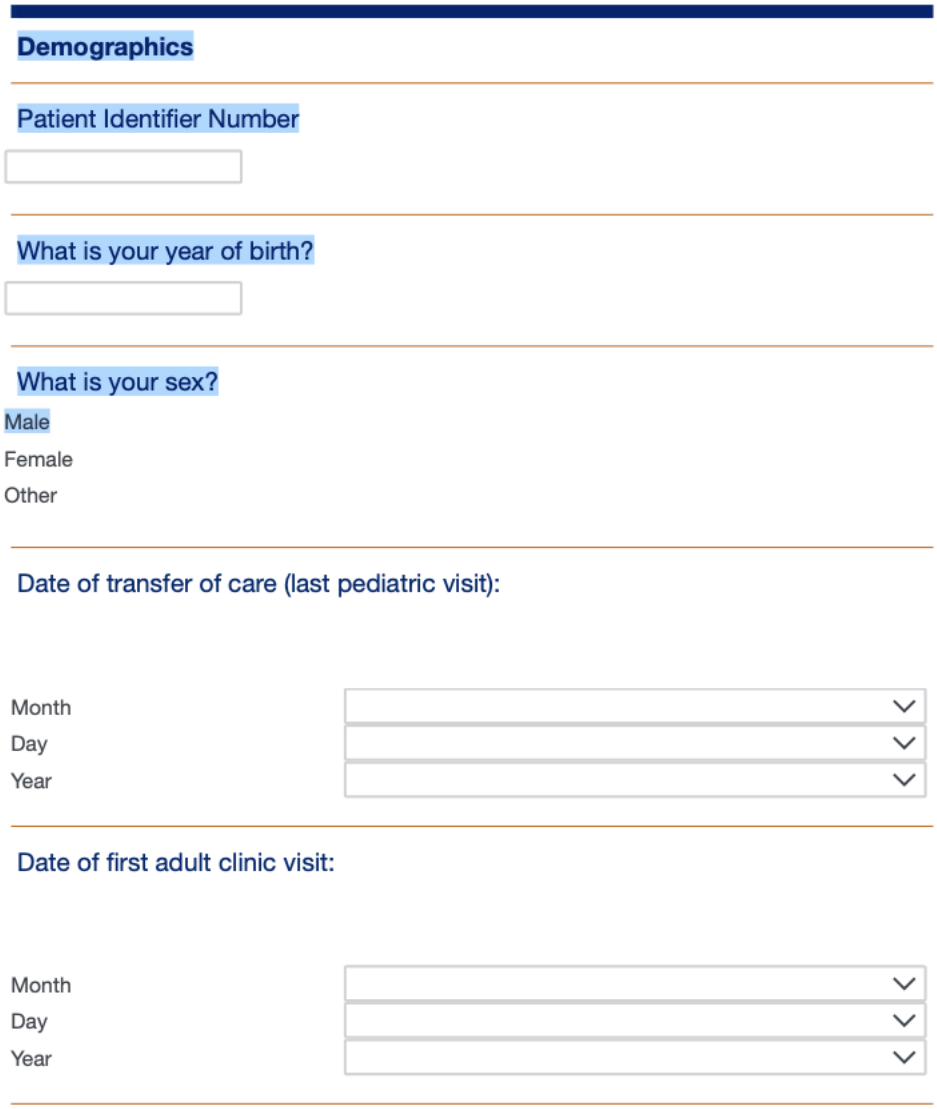
Sincerely,

Dana Albon, MD
Medical Director, Adult Cystic Fibrosis Clinic
Associate Professor of Medicine, University of Virginia School of Medicine
University of Virginia Health System, Pulmonary and Critical Care Medicine

Kristine O'Keefe-Young, RN, MSN, CPNP-PC
Doctor of Nursing Practice Student
University of Virginia School of Nursing

Appendix K

Data Collection Tool in Qualtrics



Demographics

Patient Identifier Number

What is your year of birth?

What is your sex?

Male

Female

Other

Date of transfer of care (last pediatric visit):

Month

Day

Year

Date of first adult clinic visit:

Month

Day

Year

Adherence to quarterly visits in the 12 months before and answer transfer

Adherence to quarterly visits PRIOR TO transfer (yes or no)

	Yes	No
Up to 3 month prior to transfer (Q4)	○	○
4-6 months prior to transfer (Q3)	○	○
7-9 months prior to transfer (Q2)	○	○
10-12 months prior to transfer (Q1)	○	○

Adherence to quarterly visits AFTER transfer (yes or no)

	Yes	No	Too early for appointment
Up to 3 months after transfer (Q1)	○	○	○
4-6 months after transfer (Q2)	○	○	○
7-9 months after transfer (Q3)	○	○	○
10-12 months after transfer (Q4)	○	○	○

All other office visits

All non-routine or other office visits Prior to transfer of care (by occurrence)

	Number
Up to 3 months prior to transfer (Q4)	
4-6 months prior to transfer (Q3)	
7-9 months prior to transfer (Q2)	
10-12 months prior to transfer Q1	

All non-routine or other office visits AFTER transfer of care (by occurrence)

Number

	Number
Up to 3 months after transfer (Q1)	
4-6 months after transfer (Q2)	
7-9 months after transfer (Q3)	
10-12 months after transfer (Q4)	

Hospitalizations in the year before and after transfer

Hospitalizations PRIOR to transfer (by occurrence)

	Number
Up to 3 Months PRIOR to transfer (Q4)	
4-6 months prior to transfer (Q3)	
7-9 months prior to transfer (Q2)	
10-12 months prior to transfer (Q1)	

Hospitalizations AFTER transfer (by occurrence)

	Number
Up to 3 Months AFTER transfer (Q1)	
4-6 months AFTER transfer (Q2)	
7-9 months AFTER transfer (Q3)	
10-12 months AFTER transfer (Q4)	

Emergency Department visits in the years before and after transfer (by occur)

Emergency Department visits PRIOR to transfer (by occurrence)

Number

Up to 3 Months PRIOR to transfer (Q4)	
4-6 months prior to transfer (Q3)	
7-9 months prior to transfer (Q2)	
10-12 months prior to transfer (Q1)	

Emergency Department visits AFTER transfer (by occurrence)

	Number
Up to 3 Months AFTER transfer (Q1)	
4-6 months AFTER transfer (Q2)	
7-9 months AFTER transfer (Q3)	
10-12 months AFTER transfer (Q4)	

Forced End Expiratory Volume (FEV1) in the year before and after transfer

FEV1 at last pediatric appointment PRIOR to transfer (in liters)

	Actual FEV1 in Liters	Calculated Baseline FEV1	Quarter Prior to transtion
FEV1 at last pediatric appointment			

FEV1 at adult center AFTER transfer (in liters)

	Actual FEV1 in Liters	Calculated Baseline FEV1	Quarter after transtion
FEV1 at adult center after transition			

CF Modulators

CF Modulator Start Date

	Month	Year
Please Select:		

Up to 3 Months PRIOR to transfer (Q4)	
4-6 months prior to transfer (Q3)	
7-9 months prior to transfer (Q2)	
10-12 months prior to transfer (Q1)	

Emergency Department visits AFTER transfer (by occurrence)

	Number
Up to 3 Months AFTER transfer (Q1)	
4-6 months AFTER transfer (Q2)	
7-9 months AFTER transfer (Q3)	
10-12 months AFTER transfer (Q4)	

Forced End Expiratory Volume (FEV1) in the year before and after transfer

FEV1 at last pediatric appointment PRIOR to transfer (in liters)

	Actual FEV1 in Liters	Calculated Baseline FEV1	Quarter Prior to transtion
FEV1 at last pediatric appointment			

FEV1 at adult center AFTER transfer (in liters)

	Actual FEV1 in Liters	Calculated Baseline FEV1	Quarter after transtion
FEV1 at adult center after transition			

CF Modulators

CF Modulator Start Date

	Month	Year
Please Select:		

CF modulator use/timing:

started > 1 year prior to transfer of care

started in the year prior to transfer of care

started in the year after transfer of care

started > year after transfer of care

not taking CF modulator

Appendix L

Step 5

Justifying conclusions

Definition☐	Making claims regarding the program that are warranted on the basis of data that have been compared against pertinent and defensible ideas of merit, value, or significance (i.e., against standards of values); conclusions are justified when they are linked to the evidence gathered and consistent with the agreed on values or standards of stakeholders.
Role☐	Reinforces conclusions central to the evaluation's utility and accuracy; involves values clarification, qualitative and quantitative data analysis and synthesis, systematic interpretation, and appropriate comparison against relevant standards for judgment.
Activities☐	• Using appropriate methods of analysis and synthesis to summarize findings; ☐ Interpreting the significance of results for deciding what the findings mean; ☐ Making judgments according to clearly stated values that classify a result (e.g., as positive or negative and high or low); ☐ Considering alternative ways to compare results (e.g., compared with program objectives, a comparison group, national norms, past performance, or needs); ☐ Generating alternative explanations for findings and indicating why these explanations should be discounted; ☐ Recommending actions or decisions that are consistent with the conclusions; and ☐ Limiting conclusions to situations, time periods, persons, contexts, and purposes for which the findings are applicable.

Adapted from Joint Committee on Standards for Educational Evaluation. Program evaluation standards: how to assess evaluations of educational programs. 2nd ed. Thousand Oaks, CA: Sage Publications, 1994.

Appendix M

Post-Transition Survey Data

Table M1

Satisfaction with the Transition Process (n=3)

The following questions are meant to gauge your satisfaction with the transition process:	Mean (SD)	Min-Max
Overall	4.52 (0.67)	3 - 5
The time spent in my Pediatric CF clinic discussing transition to the Adult CF Clinic prepared me well for my first adult clinic visit.	4.33 (0.58)	4 - 5
I feel I was provided enough information about transitioning to the adult clinic in the year leading up to the transfer of care.	4.33 (0.58)	4 - 5
I was given the opportunity to ask questions about transitioning to the Adult CF clinic.	4.67 (0.58)	4 - 5
I am satisfied with the care I received in the Pediatric clinic.	5 (0)	5 - 5
I was given the chance to discuss when during the year transfer to the adult services would occur.	4.67 (0.58)	4 - 5
I knew who/where to call for CF related concerns between my last pediatric appointment and my first adult appointment.	4.67 (0.58)	4 - 5
I am satisfied with the care I have received in the adult clinic.	4.67 (0.58)	4 - 5
Transition and transfer to the adult clinic met or exceeded my expectations.	4 (1)	3 - 5
I feel like my adult team was well-informed about my medical history from my Pediatric team.	4.67 (0.58)	4 - 5
I feel I had control over how much my parents/guardians were involved in the transition process.	4.33 (1.15)	3 - 5
The age and timing in which I transition into the adult program was just right for me.	4.33 (1.15)	3 - 5

Table M2

Concerns with Transition to Adult Clinic (n=3)

Thinking back to before you transitioned to the adult clinic, how concerned were you in the following areas	Mean (SD)	Min-Max
Overall Scores	2.94 (1.75)	1 – 5
Leaving behind my Pediatric CF Team.	2.00 (1.00)	1 – 3
Just prior to transfer of my care to the Adult program I was anxious:	5.00 (0.00)	5 – 5
Having to meet new caregivers.	3.67 (2.31)	1 – 5
Being admitted to the adult hospital.	3.00 (2.00)	1 – 5
Your perception of how care in the Adult CF clinic might be different.	3.00 (1.73)	1 – 4
Adult caregivers not being as caring or friendly.	1.50 (0.71)	1 – 2
Being exposed to infection in the Adult clinic.	2.67 (2.08)	1 – 5
Meeting with my CF Team without my parents in the exam room.	1.33 (0.58)	1 – 2
Adult clinic running on time.	3.67 (2.31)	1 – 5
Making my own clinic appointments.	1.50 (0.71)	1 – 2
Location of the Adult Clinic.	4.00 (1.73)	2 – 5

Table M3

Aspects That Were Helpful in Making Patient Feel Prepared and Confident During Transition Process (n=3)

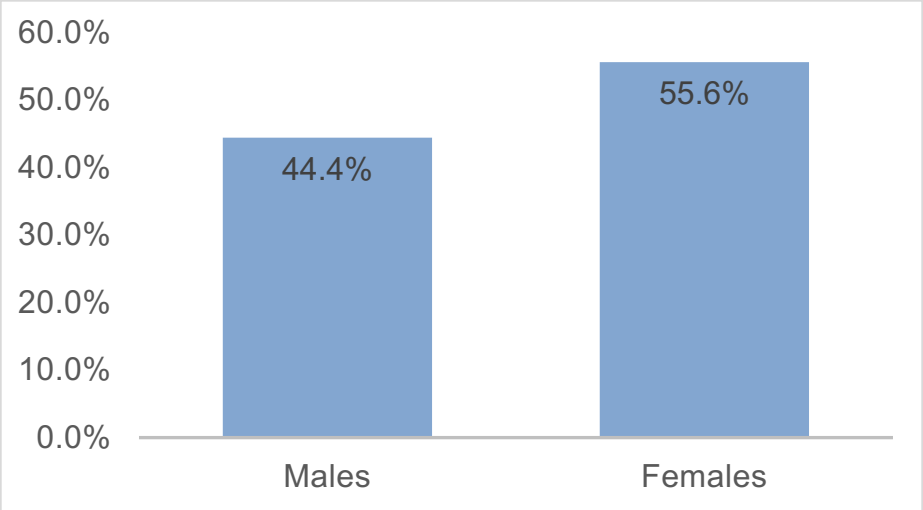
As you were going through the transition process, how helpful were the following areas in making you feel prepared and confident.	Mean (SD)	Min-Max
Overall Scores	3.59 (1.77)	1 - 5
Meeting with the Pediatric CF Team without your parents in the room.	5.00 (0.00)	5 - 5
Completing and discussing the transition assignments with the pediatric staff.	5.00 (0.00)	5 - 5
Receiving written materials about the adult clinic and staff.	3.33 (2.08)	1 - 5
Education to help me be able to care for my CF independently.	3.33 (2.08)	1 - 5
Support with planning for insurance coverage.	2.67 (2.08)	1 - 5
Support with planning for higher education and/or employment.	2.67 (2.08)	1 - 5

Appendix N

Retrospective Chart Review Demographics

Figure N1

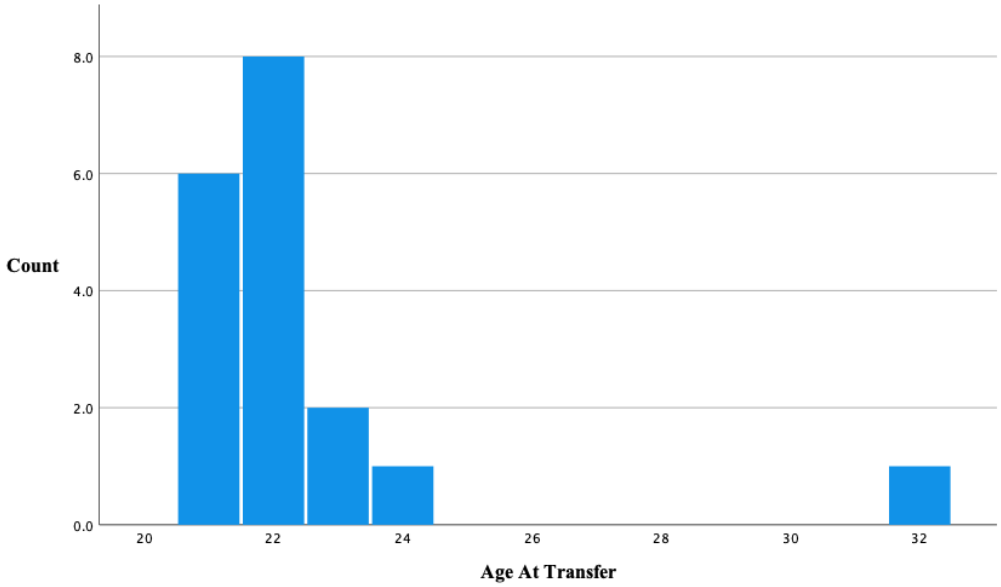
Participant Gender for Data Collection from Electronic Health Record for Program Evaluation of Cystic Fibrosis Transition Program (n=18)



Note: A total of 18 participant records were extracted from the EPIC Electronic Health Record (EHR). Figure 1 displays the gender distribution of the sample.

Figure N2

Participant Age for Data Collection from Electronic Health Record for Program Evaluation of Cystic Fibrosis Transition Program (n=18)



Note: This figure represents the average age of participants at their last pediatric visit (transfer). The mean age at transfer for patients at this Cystic Fibrosis Center was 22.4 with a standard deviation of 2.53 (n=18).

Appendix O

Health Stability Measures – Continuity of Care

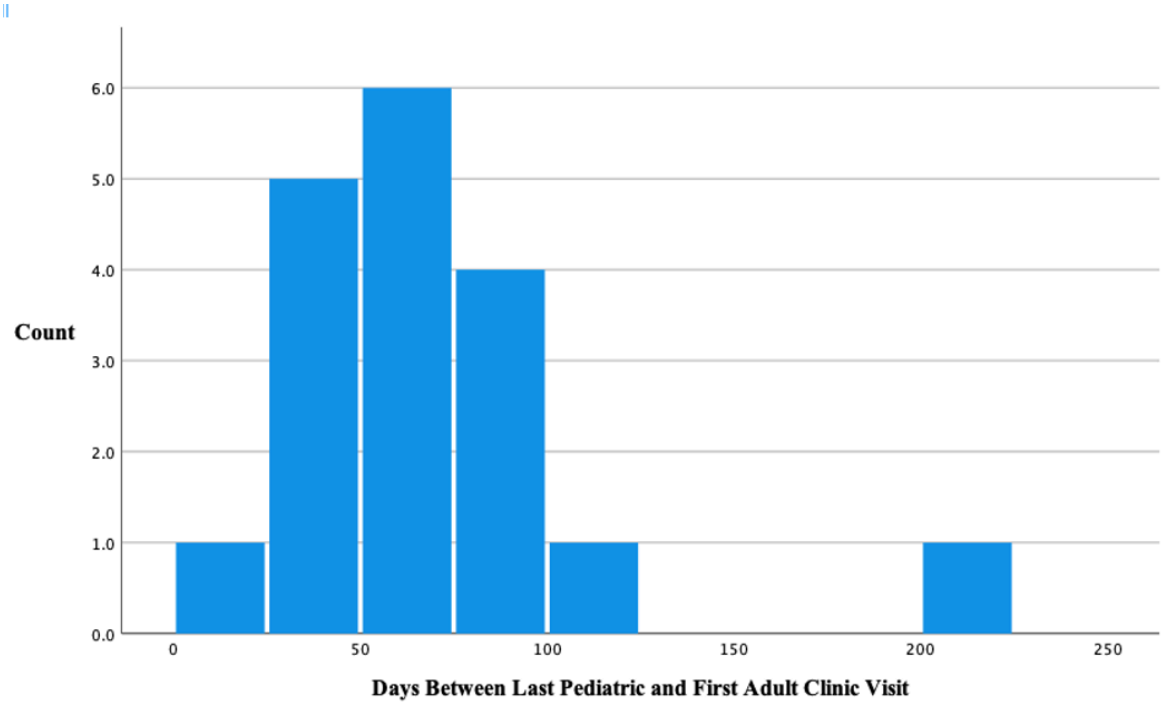
Table O1

Adherence to Quarterly Visits in the Year Prior to and After Transfer from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)

	Pre-transfer		Post-transfer	
Item	Yes N (%)	No N (%)	Yes N (%)	No N (%)
Adherence to quarterly visits up to 3 months prior to and after transfer	18 (100%)	0 (0%)	18 (100%)	0 (0%)
Adherence to quarterly visits 4-6 months prior to and after transfer	16 (89%)	2 (11%)	15 (83%)	3 (17%)
Adherence to quarterly visits 7-9 months prior to and after transfer	15 (83%)	3 (17%)	12 (67%)	6 (33%)
Adherence to quarterly visits 10-12 months prior to and after transfer	15 (83%)	3 (17%)	12 (75%)	2 (25%)

Figure O1

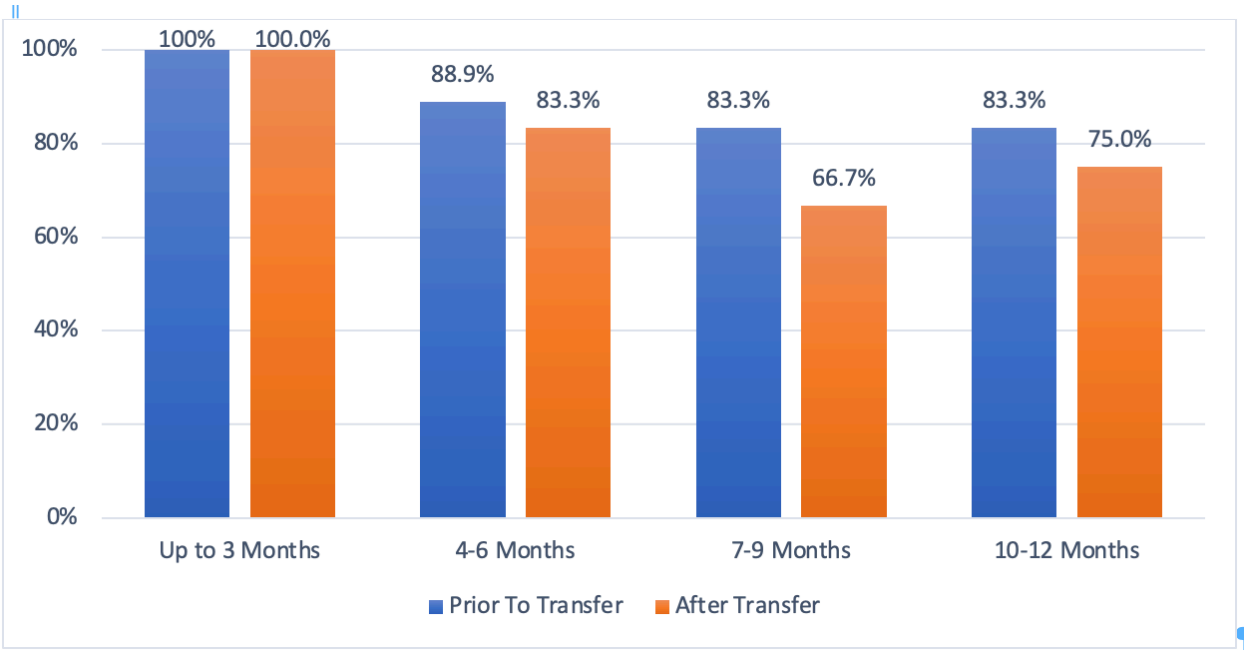
Number of Days Between Last Pediatric and First Adult Center Visit in Cystic Fibrosis Center (n=18)



Note: This figure represents the number of days between the last pediatric visit (transfer) and the first adult visit at this CF center. The mean number of days between patients' last pediatric center visit and first adult visit was 68.7 days with a standard deviation of 44.5 days.

Figure O2

Percentage of Adherence to Quarterly Visits Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services for (n=18)



Note: This figure represents the percentage of patients who were adherent to routine quarterly visits in the year prior and after transfer. The blue bars denote the time frame of the year prior to transfer, while the orange bar represents the time frame of the year after transfer.

Appendix P

Health Stability Measures – Health Care Utilization

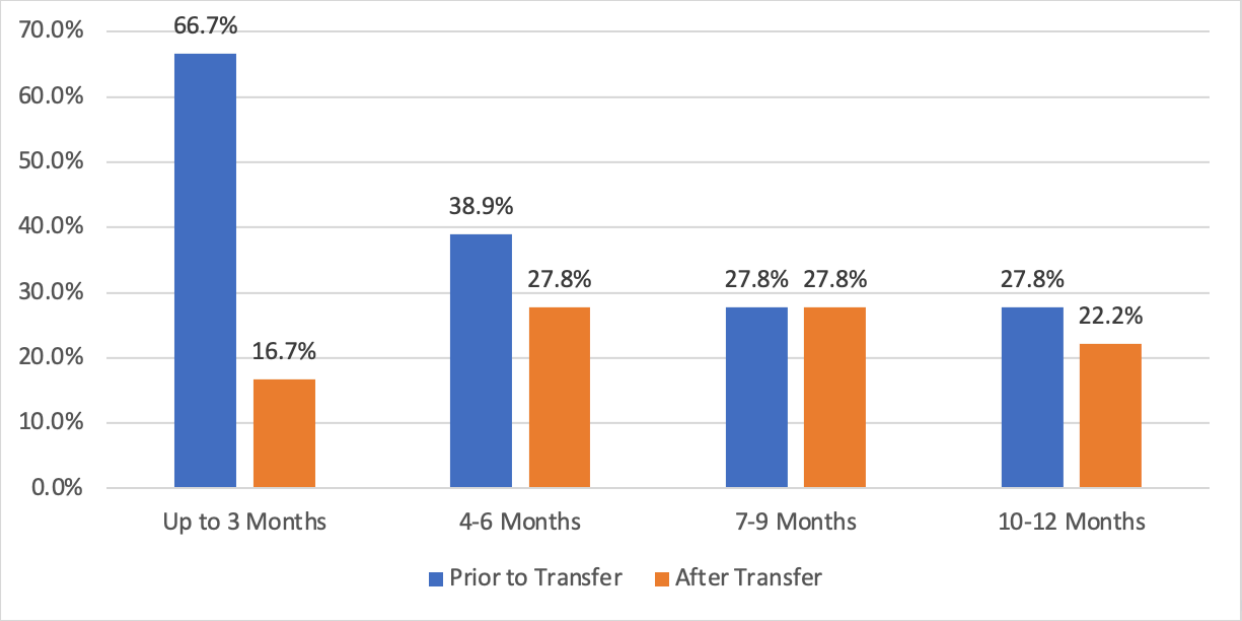
Table P1

All Non-Routine and Other Office Visits Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)

Item	Pre-transfer Mean (SD)	Post-transfer Mean (SD)
All non-routine or other office visits up to 3 months prior to and after transfer	0.56 (0.922)	0.22 (0.548)
All non-routine or other office visits 4 - 6 months prior to and after transfer	0.67 (1.138)	0.44 (0.856)
All non-routine or other office visits 7 - 9 months prior to and after transfer	0.89 (1.711)	0.44 (0.856)
All non-routine or other office visits 10 - 12 months prior to and after transfer	0.44 (0.856)	0.50 (1.043)

Figure P1

All Non-Routine and Other Office Visits Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)



Note: This figure represents the utilization of non-routine or other office visits outside of routine quarterly office visits in the year prior to and after transfer. The blue bar denotes the percentage of patients who had one or more office visits outside of quarterly visits prior to transfer while the orange bar denotes the percentage of patients who had one or more office visits outside of quarterly visits after transfer.

Table P2

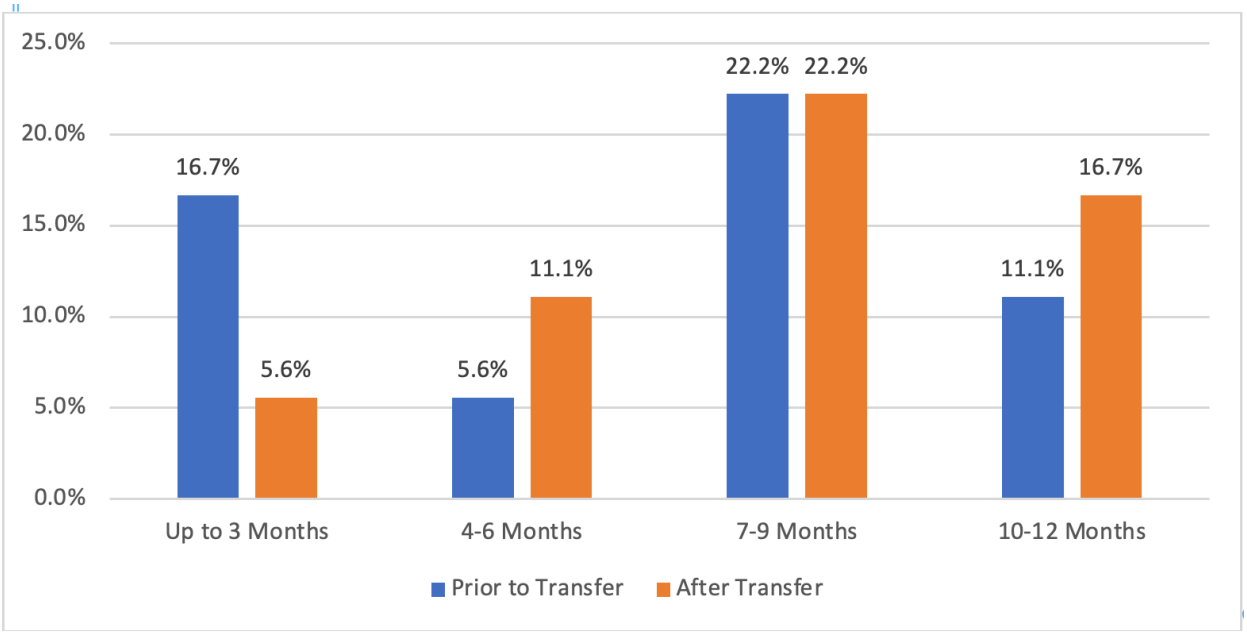
Hospitalizations Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)

Item	Pre-transfer Mean (SD)	Post-transfer Mean (SD)
Hospitalizations up to 3 months prior to and after transfer	0.17 (0.383)	0.06 (0.236)
Hospitalizations visits 4 to 6 months prior to and after transfer	0.06 (0.236)	0.22 (0.732)
Hospitalization 7-9 months prior to and after transfer	0.28 (0.575)	0.22 (0.428)
Hospitalizations 10-12 months prior to and after transfer	0.11 (0.323)	0.33 (0.840)

Note: This table represents the means and standard deviations by quarters for the number of hospitalizations for patients with cystic fibrosis in the year before and after transfer to adult cystic fibrosis services.

Figure P2

Hospitalizations Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)



Note: This figure represents the percentage of patients who had 1 or more occurrences of CF-related hospitalizations in the year prior to and after transfer to adult cystic fibrosis services. The blue bar denotes the percentage of patients who had 1 or more hospitalizations in the year prior to transfer to adult CF service. The orange bar denotes the percentage of patients who had 1 or more hospitalizations after their transfer to adult CF services.

Table P3

Emergency Department Visits Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)

Item	Pre-transfer Mean (SD)	Post-Transfer Mean (SD)
Emergency Department visits up to 3 months prior to transfer	0.11 (0.471)	0 (0.000)
Emergency Department visits 4 to 6 months prior to transfer	0.06 (0.236)	0.11 (0.471)
Emergency Department visits 7-9 months prior to transfer	0.11 (0.323)	0.11 (0.323)
Emergency Department visits 10-12 months prior to transfer	0 (0.000)	0.11 (0.471)

Note: This table represents the means and standard deviations by quarters for the number of emergency department visits for patients with cystic fibrosis in the year before and after transfer to adult cystic fibrosis health services (n=18).

Figure P3

Emergency Department Visits Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)

Note: This figure represents the percentage of patients who had 1 or more occurrences of CF-related emergency department visits in the year prior to and after transfer to adult CF services. The blue bar denotes the percentage of patients who had 1 or more emergency department visits in the year prior to transfer to adult CF service. The orange bar denotes the percentage of patients who had 1 or more emergency department visits after their transfer to adult CF services.

Appendix Q

Table Q1

Forced End Expiratory Volume (FEV_1) in Liters and Calculated Baseline FEV_1 in Liters Before and After Transition (n=18)

Variable	*Pre-Transfer Mean (SD)*	Post-Transfer Mean (SD)
Actual FEV_1	2.98 (0.79)	3.09 (0.90)
Calculated Baseline FEV_1	3.12 (0.93)	3.12 (0.88)
Quarter when FEV_1 was measured	4.00 (0.00)	3.17 (1.20)

Note: This table represents the means and standard deviations for the actual forced end expiratory volume (FEV_1) in liters and the calculated baseline FEV_1 both prior to and after transfer to adult CF services Quarters were annotated because not all patients had FEV_1 measures at 1-year post-transition, though all patients had FEV_1 measures in Quarter 4 prior to transfer. The values noted demonstrate the mean time when these values were recorded.

Appendix R

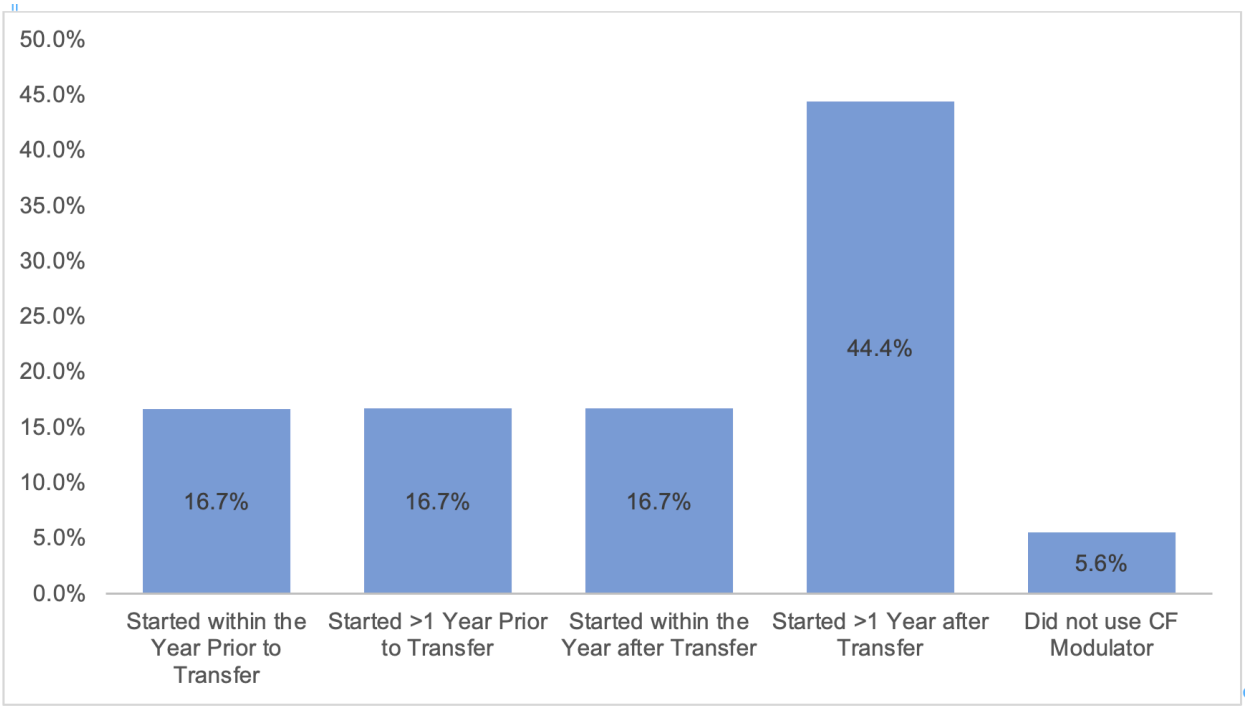
Table R1

Timing of Introduction of Cystic Fibrosis Modulator in Relation to Transition Timing (n=18)

CF Modulator Timing	N (%)
Started > 1 year prior to transfer of care	3 (16.7%)
Started in the year prior to transfer of care	3 (16.7%)
Started in the year after transfer of care	3 (16.7%)
Started > year after transfer of care	8 (44.4%)
Not taking CF modulator	1 (5.6%)

Figure R1

Timing of Introduction of Cystic Fibrosis Modulator in Relation to Transition (n=18)



Appendix S

UVA Cystic Fibrosis Center Transition Survey

This survey asks about the transition process from the pediatric cystic fibrosis care to adult cystic fibrosis care. Transition is the purposeful planned movement from child-centered to adult-centered health care systems. Please answer the questions below to the best of your recollection.

1. Are you aware of a transition process from pediatric care to adult care at the University of Virginia Health System?
   a. Yes b. No c. Unsure

2. If you have transitioned or are transitioning, is/was the timing of the of the transition process appropriate?
   a. Yes b. No (too early or too late) c. Not applicable

3. What do you think is the ideal age to initiate the transition process from pediatric to adult care?
   a. **14** b. **15** c. **16** d. **17** e. **18** f. **19**
   g. **20** h. **21** i. **22** j. **Other**_____

4. If you have transitioned or are transitioning, is/was the length of the transition process:
   a. too long b. appropriate c. too short

5. Did the transition process prepare you (or is it preparing you) to deal with the following issues:
   a. Self-care Yes No Unsure
   b. Insurance issues Yes No Unsure
   c. Being independent Yes No Unsure
   d. Relationships/sexuality Yes No Unsure

6. Is or was the transition process smooth and did you feel prepared to move from pediatric care to adult care?
   a. Yes b. No

7. Has the transition process helped with:
   a. Making an appointment with the adult clinic? Y N Unsure
   b. Finding the location of the adult clinic? Y N Unsure
   c. Independence to talk with CF health care providers? Y N Unsure
   d. Ability to care for CF independently? Y N Unsure
   e. Learning differences between pediatric and adult care approaches? Y N Unsure
   f. Following CF medications/treatment schedule? Y N Unsure

8. An ideal time for transfer of care from the pediatric care to adult care is:
   a. End of high school
   b. During college (undergraduate)
   c. After college graduation

9. If you have been transitioned, did you wish you had transferred care earlier?
   a. Yes b. No c. Not applicable

10. What is your age?_____