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



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DNP Scholarly Project Defense

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Background and Significance

- Advances in drug therapies = more patients with cystic fibrosis are living into adulthood than ever before
- Median age of survival increasing
 - 1970 = 16
 - 2015 = 32
 - 2019 = 48 (Cystic Fibrosis Foundation, 2019; West & Mogazel, 2016)
- Impact of CFTR Modulators

Background and Significance

- 52.7% of the patient population with CF are over the age of 18 (CFF, 2019).
- Demand for disease-specific adult services:
 - family planning
 - fertility issues
 - long-term complications and age-related changes (Coyne et al., 2017)

Background and Significance

- Planned transition
 - Gradual process
 - Early in adolescence → transfer
 - A systematic approach to introducing patients to issues related to self-management, autonomy, and personal decision-making (Middour-Oxler et al., 2021)
- Goals of planned transition:
 - Improve quality of life
 - Maximize independence
 - Minimize interruption in care (Goralski et al., 2017)
- Healthcare transition program interventions (TPIs) associated with:
 - Increased knowledge
 - Increased patient satisfaction
 - Improved continuity of care (Baker et al, 2015)

Review of Literature Question

Do CF transition program interventions at a CF Care Center at an academic medical center increase transition readiness and patient satisfaction, and decrease transition-related anxiety in adolescents and young adults with CF?

Review of Literature



16 articles

Themes from the Literature

- **Transition Program Interventions**
 - Education – based (Baker et al., 2015); (Campbell et al., 2016); (Crowley et al., 2011); (Gravelle et al., 2015); (Okumura et al., 2014); (Schmidt et al., 2016)
 - Health care service delivery (Campbell et al. 2016); (Crowley et al, 2011); (Peeters et al., 2019); (Skov et al., 2018);)
 - Collaborative (Chaudry et al, 2013); (Crowley et al. 2011); (Okumura et al., 2014); (Peeters et al., 2019)
- **Structured versus non-structured transition programs** (Al-Yateem et al., 2012); (Coyne et al., 2017); (Chaudhry et al., 2013); (Middour-Oxler et al, 2021)
- **Barriers and challenges to transition**
 - Patient barriers (Gorlaski et al., 2017); (Towns & Bell. 2011); (Tuchman et al., 2010)
 - Parent barriers (Gorlaski et al., 2017); (Towns & Bell, 2011)
 - Provider barriers (Baker et al. (2015); (Gorlaski et al., 2017); (Towns & Bell. 2011); (Tuchman et al., 2010)
 - System barriers (Tuchman et al., 2010); (Gorlaski et al., 2017)

Summary of Literature



Evidence supports the use of transition program interventions to improve transitional competencies



Minimal evidence to support the use of transition programs interventions in order to directly impact patient clinical outcomes

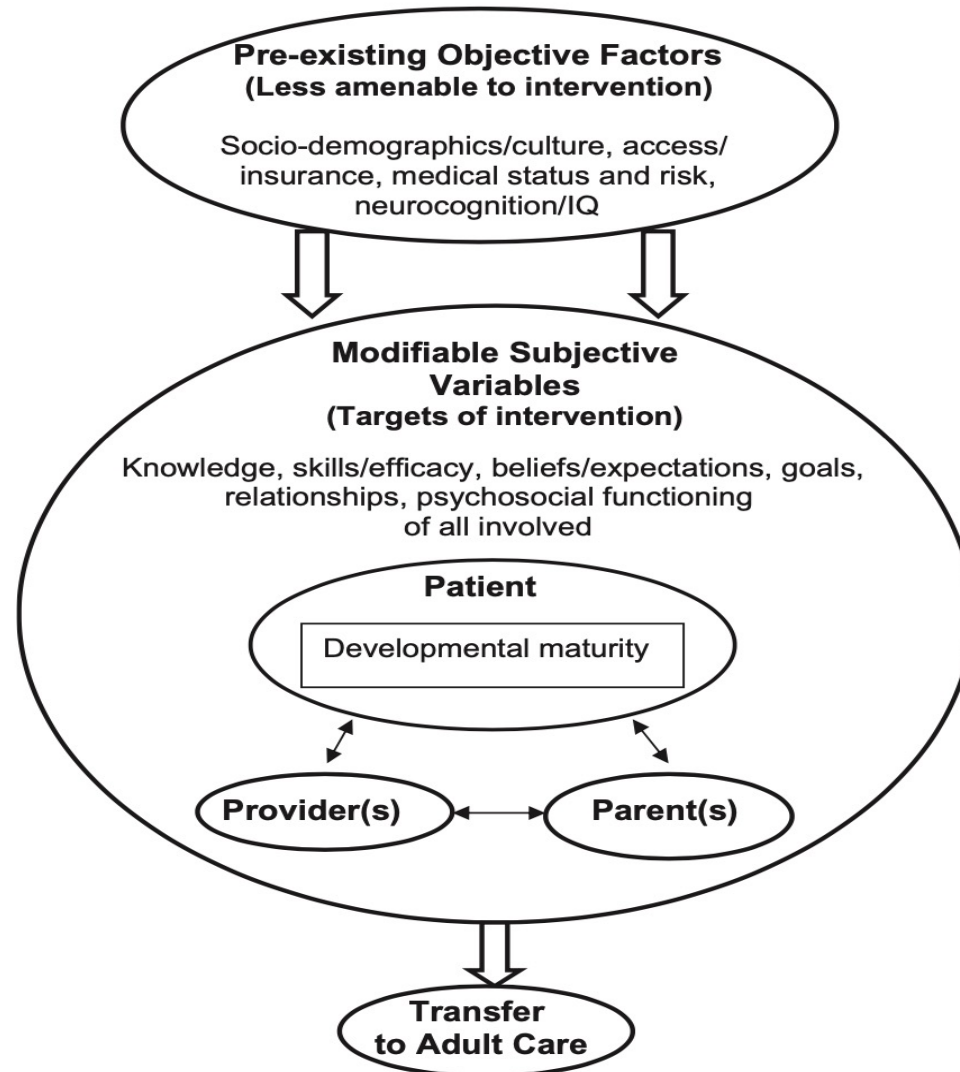


A planned, structured transition process from pediatric to adult care services for patients with CF is endorsed by:

- The American Academy of Pediatrics
- Healthy People 2020
- Cystic Fibrosis Foundation (CF Foundation, 2019; Office of Disease Prevention and Health Promotion [ODPHP], n.d.; White et al., 2018).

Theoretical Framework – SMART Model

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



Purpose

The purpose of the scholarly project was to complete a program evaluation of an Academic Medical Center's Cystic Fibrosis transition program.

Methods and Results

Implementation Framework

CDC's Framework for Program Evaluation in Public Health



1. Engage Stakeholders
2. Describe the Program
3. Focus Evaluation Design
4. Gather Credible Evidence
5. Justify Conclusions
6. Ensure Use and Share Lessons

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

Step 1: Engage the Stakeholders

- CF transition team members - APRN, RN coordinator, social worker, psychologist, pharmacist, quality improvement coordinator, and parent and family representative.
 - Team meetings
 - Needs assessment
 - Modification of survey tool and data collection metrics
 - Development of Logic Model
 - Individual meetings with team members
- Patients with CF
 - Survey

Step 2: Describe the Program

- A CF Foundation-accredited CF Care Center at an academic medical center in the mid-eastern U.S.
- Comprised of two outpatient programs:
 - Pediatric CF program – 130 patients
 - Adult CF program – 136 patients
- Partners with the Learning and Leadership Collaborative (LLC) to use the Dartmouth Institute Microsystem Approach for quality improvement

Step 2: Describe the Program

- CF Transition Program Interventions
 - CF R.I.S.E program – modules, readiness assessment
 - Ages and Stages questionnaires (ASQ)
 - “Meet and Greet” visits with adult team
 - Quarterly joint meetings of adult and pediatric staff
 - Split-visits
- Formative process of building transition program
 - Standardization of processes
 - Implementation of more evidenced based transition program interventions

Step 2: Describe the Program

Logic Model for 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	Patients participate in survey	Team makes plans for interventions based on recommendations	Transition interventions implemented	Improved transition readiness and patient satisfaction, decreased transition anxiety
	CF Transition Team Meetings	Analysis of data is completed			
	Needs Assessment by transition team	Learnings shared with CF Transition Team	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
	Survey Tool Modification	Learnings Shared with Working Group on Transition			
	IRB Approval	Recommendations for program changes are made	Increased awareness of patients' health utilization	Improved tracking of changes in health utilization	
	Communications with Working Group on Transition				
	Data Gathering (survey, EHR data collection)				

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

Step 3: Focus the Evaluation Design

Emory University's Post-Transition CF Survey

- Transition readiness
- Transition - related anxiety
- Satisfaction with the transition process
- Accuracy of new survey tool

Retrospective Chart Review

- Measured health stability before and after transfer
 - Continuity of Care
 - Health Care Utilization
 - Clinical Indicators

Step 4: Gather Credible Evidence

A convenience sample of 18 eligible patients was obtained at the CF Care Center for both the survey and chart review

Inclusion Criteria

- Patients who transitioned from the pediatric to adult CF clinic who received **continuous care** at the AMC
- Patients who transferred their care from pediatric to adult CF services between December 2017 and May 2021

Exclusion Criteria

- Patients who went through the transition process in the pediatric clinic but did not transfer to the adult clinic at the AMC
- Patients currently followed by adult clinic who went through the transition process at a different facility
- Patients lost to follow-up

Step 4: Gather Credible Evidence

Modified Emory University's Cystic Fibrosis Post-Transition Survey

- **Measures patient transition readiness, transition-related anxiety, and satisfaction**
- Validated tool/rigorous content validity analysis
- 48 – point survey - multiple choice, matrix and open-ended questions
- **Recruitment letter** through an EHR communication portal with a link to participate in the survey via online survey tool
- 2 reminders sent through the EHR communication portal during 10-week data collection period

Step 4: Gather Credible Evidence

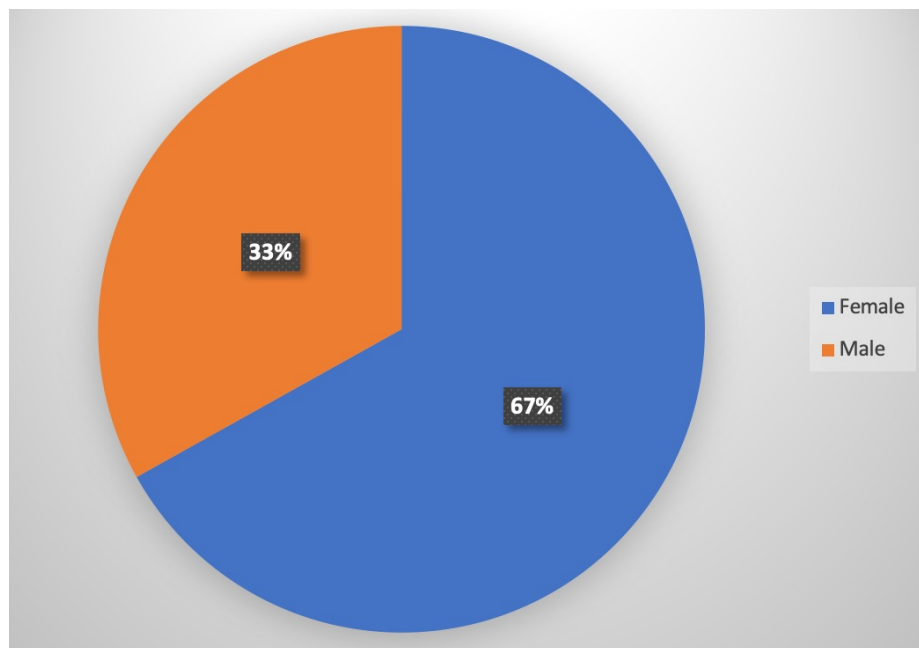
Retrospective Chart Review – “Health Stability”
Measures obtained through the Electronic Health
Record (EHR):

- Continuity of Care Measures:
 - Number of days between last pediatric and first adult center visit
 - Adherence to routine quarterly appointments
- Health Care Utilization Measures:
 - Non-routine office visits
 - Hospitalizations
 - Emergency Department Visits
- Clinical Indicators
 - Forced End Expiratory Volume (FEV₁) compared to calculated FEV₁ baseline

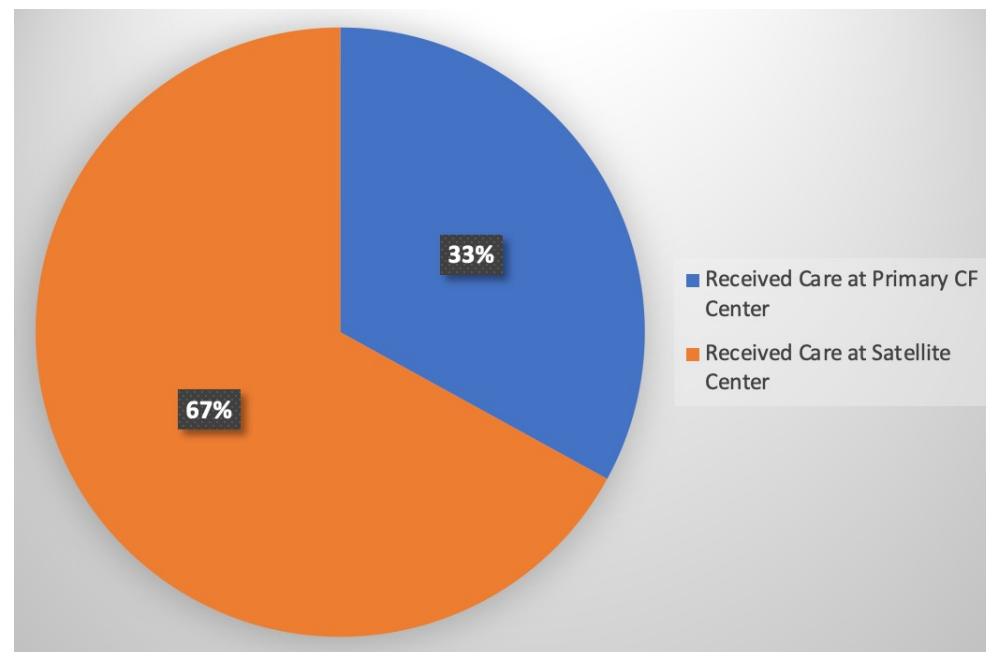
Step 4: Gather Credible Evidence- Data Management/Analysis

- Approval from the AMC's Institutional Review Board for Health Sciences Research (IRB-HSR)
- Protection of Anonymity
- Data Storage – secure online survey platform and secure online platform
- Data collected was analyzed using SPSS, Version 28.
- Descriptive Statistics reported as mean, standard deviation, and percentages as appropriate.

Post –Transition Survey Results – Demographic Data



*Participant Gender for Post-Transition
CF Survey (n=3)*



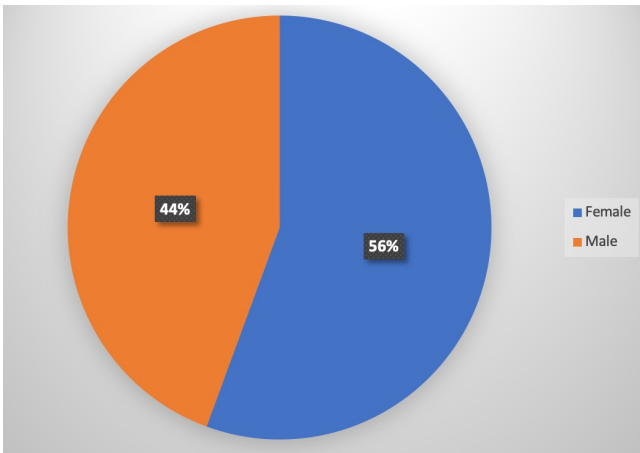
*Site Participant Received Care for Post
Transition CF Survey (n=3)*

*All respondents were between ages 22-24 years of age

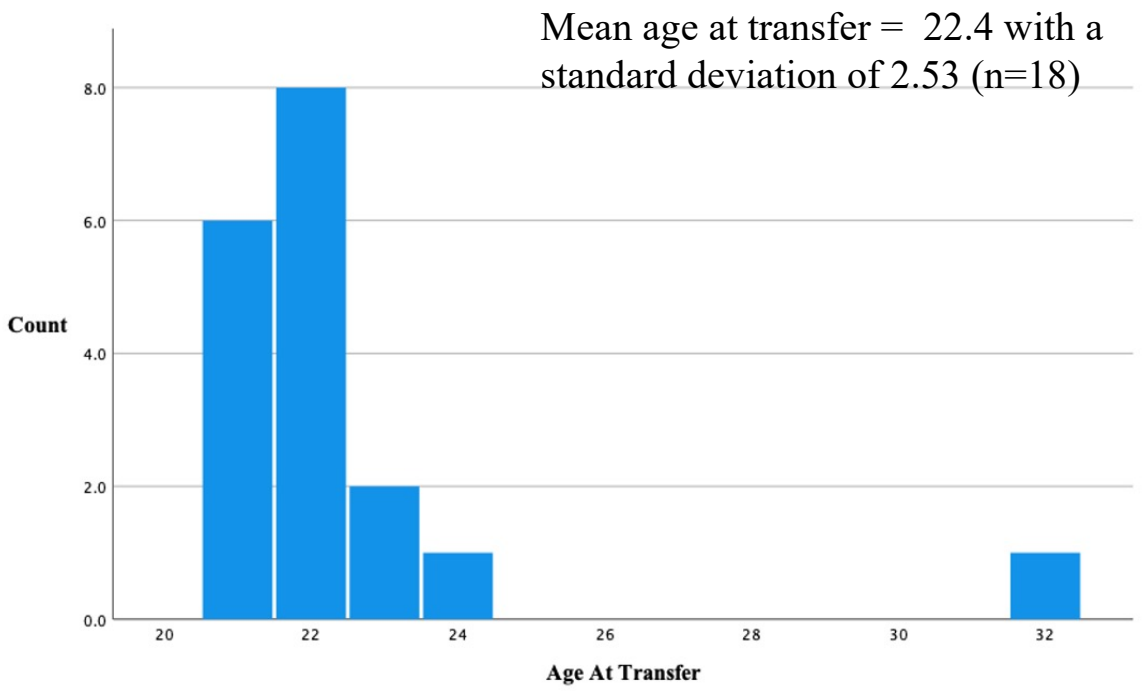
Post-Transition Survey Results

Category	Mean (SD)
Overall Patient Satisfaction Score	4.52 (SD = 0.67)
★ "I am satisfied with the care I received in the Pediatric clinic"	5.0 (SD = 0.00)
"Transition and transfer to the adult clinic met or exceeded my expectations"	4.0 (SD = 1.00)
Overall Score for Concerns Regarding Transition Process	2.94 (SD = 1.75)
★ "Leaving behind my Pediatric CF Team"	5.0 (SD = 0.00)
"Just prior to transfer of my care to the adult program I was anxious"	4.0 (SD = 1.73)
"Having to meet new caregivers"	3.67 (SD = 2.31)
"Being admitted to the Adult hospital"	3.67 (SD = 2.31)
Overall score for Aspects that Made Patients feel Prepared and Confident During Transition Process	3.59 (SD = 1.77)
★ "Meeting with the Pediatric CF Team without parents in the room"	5.0 (SD = 0.00)
★ "Completing and discussing the transition assignments with the pediatric staff"	5.0 (SD = 0.00)
"Support with planning for insurance coverage,"	2.67 (SD = 2.08)
"Support with planning for higher education and/or employment," with mean scores of 2.67 (SD = 2.08)	2.67 (SD = 2.08)

Demographics of Patients in EHR Chart Review (n=18)

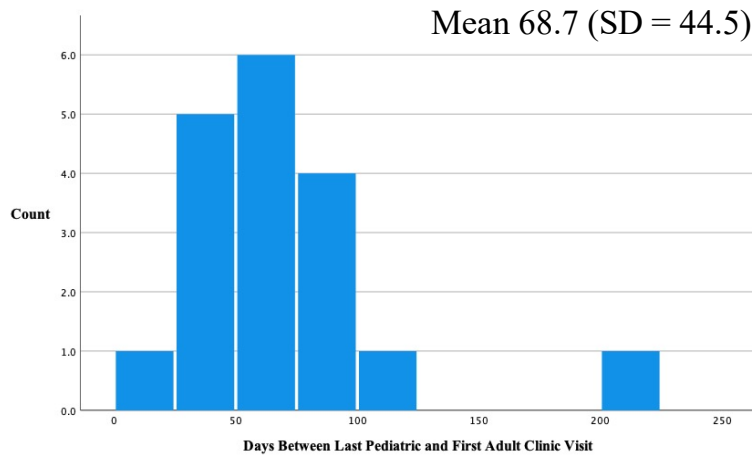


Patient Gender for Data Collection from Electronic Health Record for Program Evaluation of Cystic Fibrosis Transition Program (n=18)



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

Health Stability: Continuity of Care



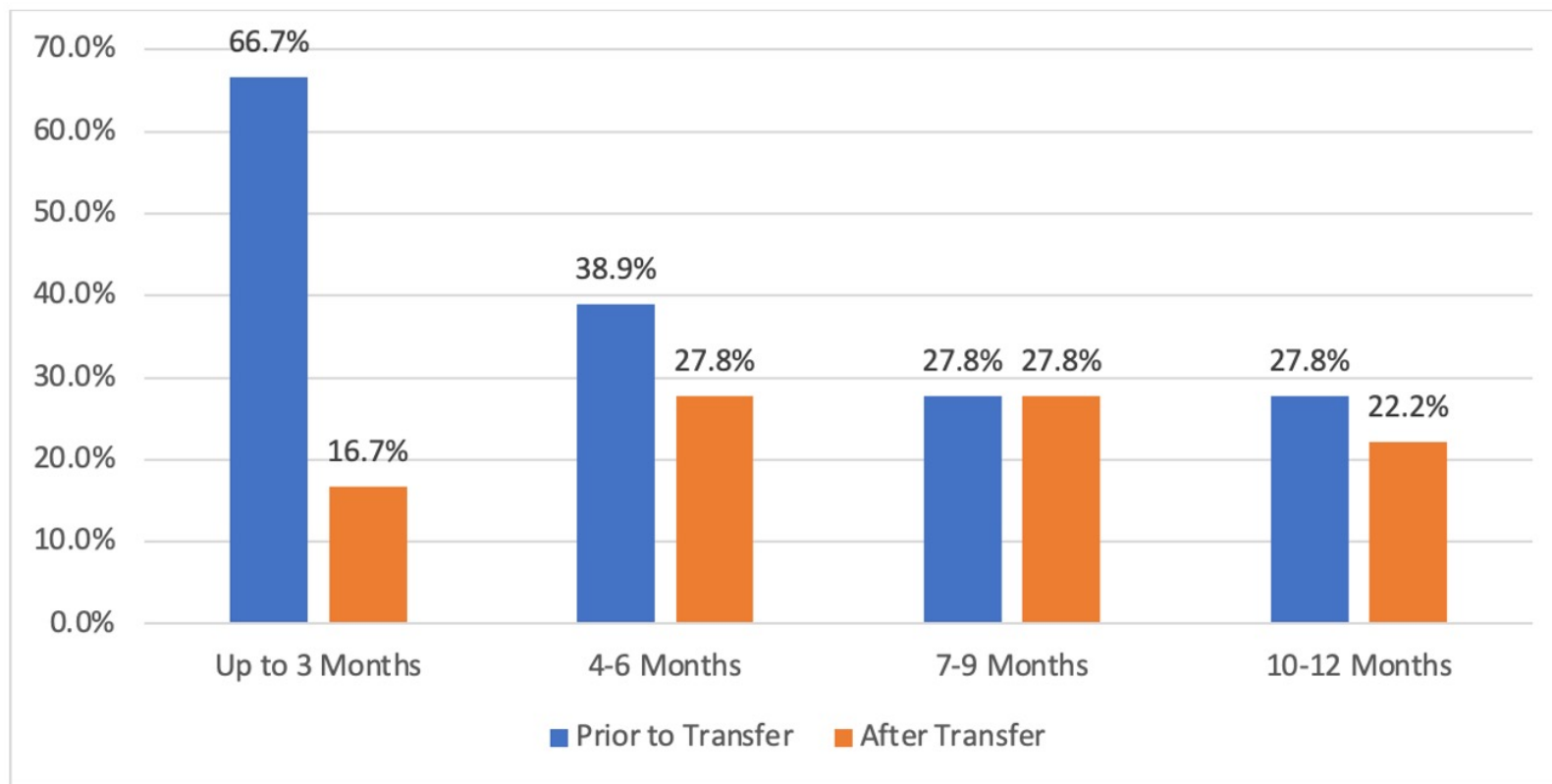
Number of Days Between Last Pediatric and First Adult Center Visit in Cystic Fibrosis Center (n=18)



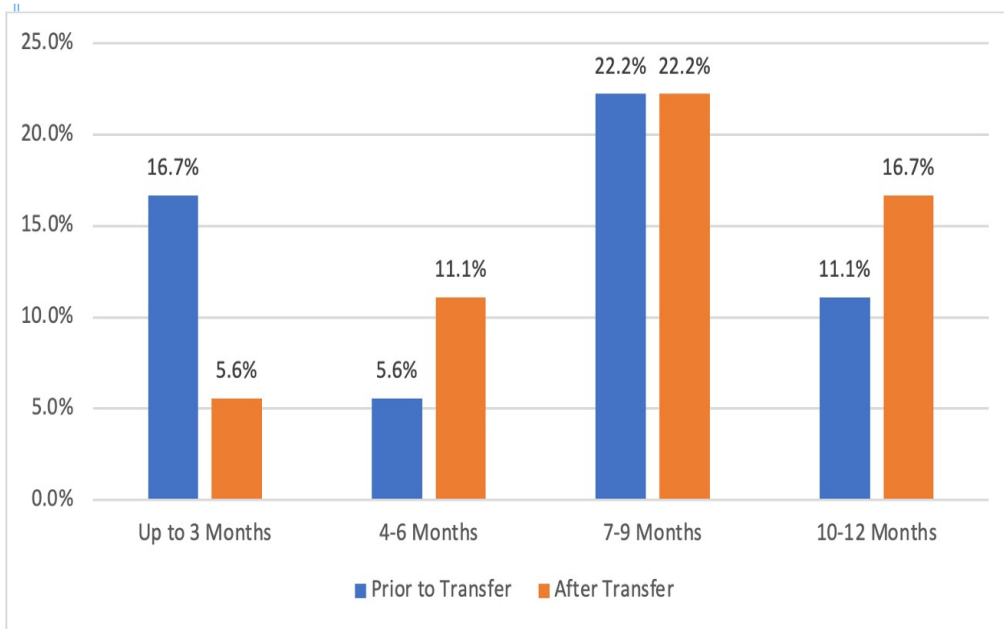
Percentage of Adherence to Quarterly Visits Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services for (n=18)

Health Stability: Healthcare Utilization

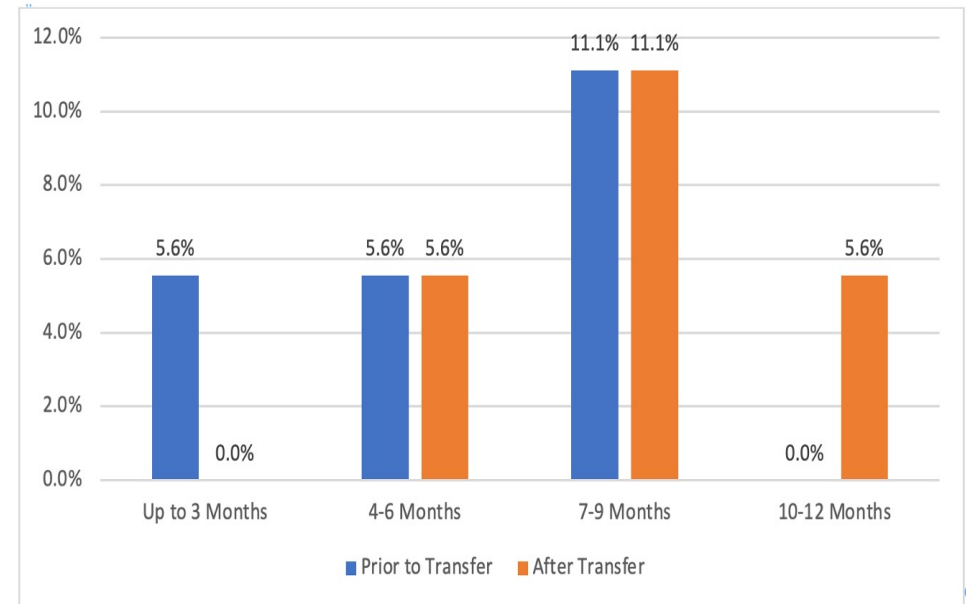
All Non-Routine and Other Office Visits Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (N=18)



Health Stability: Healthcare Utilization

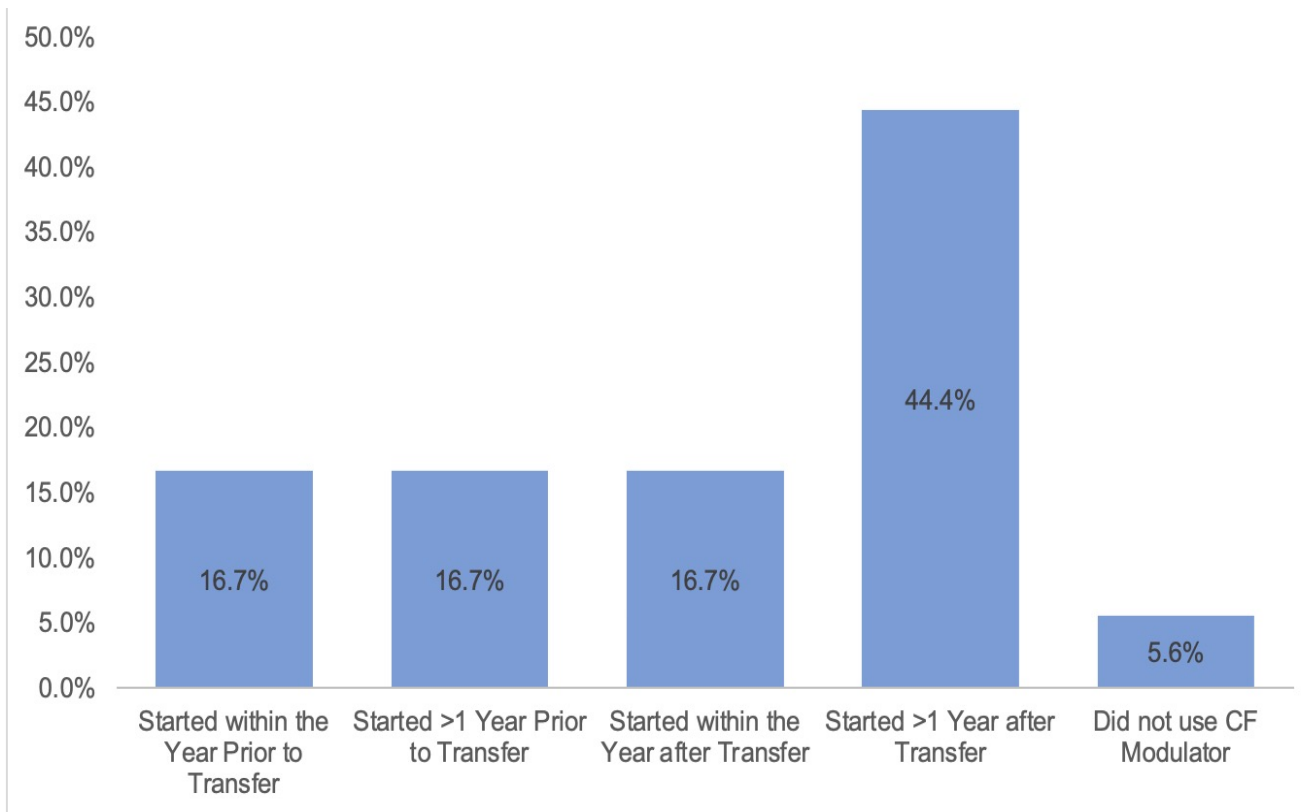


Hospitalizations Prior to and After Transition from Pediatric to Adult Cystic Fibrosis Health Care Services (n=18)



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

Health Stability: Clinical Indicators and CF Modulator Timing



Forced End Expiratory
Volume/calculated
baseline FEV₁

Prior to transfer:
FEV₁: 2.98/3.12 L

After Transfer
FEV₁: 3.09/3.12 L

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

Step 5: Justify Conclusions



Health stability



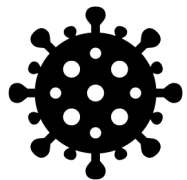
“Gaps in care” (Sawicki et al., 2018)



Adherence to routine visits



Hospitalizations and ED visits



Impact of COVID 19 pandemic on utilization

Step 5: Justify Conclusions

- Low response rate for survey
- Need for more effective evaluation tool
- **All Participants had a high degree of transition readiness at the time of their transfer of care**
- Patient satisfaction with the transition was high, particularly with the care they received in the pediatric clinic
- Bond with pediatric team

Step 5: Justify Conclusions

Recommendations

- Shorter patient survey, particular to AMC
- Administer survey in person, perform “exit interview” with open ended questions in the year after transfer
- Continue to standardize processes and implement evidence-based TPis
- Re-evaluate health stability measures in 3 years time to determine impact of evolving program.

Strengths & Limitations

- Strengths
 - CDC Program Evaluation Framework
 - Enthusiasm of stakeholders
- Limitations
 - CF Modulators/Timing of Transition
 - Access to patients
 - Impact of COVID 19 Pandemic
 - Variability in exposure to transitions
 - Dependent on patient recall

Step 6: Ensure Use and Share Lessons

- Presentation to CF transition team
- Presentation to Pediatric Transition Working Group at AMC
- Submission to academic LIBRA repository
- Manuscript submission to the Journal of Pediatric Health Care

Nursing Practice Implications

- Adds to the nursing body of knowledge on the value of transition program interventions for patients with CF
- Findings can be generalized to other patients with chronic medical conditions who are transitioning to adult care
- Nurses are at the forefront of the transition process, taking responsibility for the provision of health care as well as the coordination of services in many CF Centers.
- Nurses are in a prime position to advocate for the delivery of transition services that are most beneficial and relevant for patients in order to reduce gaps in care and improve patient outcomes

Thank you for your attention.
Questions?

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University of Virginia's Cystic Fibrosis Clinic
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. Age: 21 and under 22-24 25 and over
 2. Gender: Male Female Other Prefer not to say
 3. Year of Transition (last pediatric appointment): 2018 2019 2020 2021
 4. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Leaving behind my Pediatric CF Team.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Having to meet new caregivers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Your perception of how care in the Adult CF clinic might be different.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Adult caregivers not being as caring or friendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Adult clinic running on time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Being exposed to infection in the Adult clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Location of the Adult Clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Being admitted to the Adult hospital.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Making my own clinic appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Just prior to transfer of my care to the Adult program I was anxious:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Completing and discussing the transition assignments with the pediatric staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Receiving written materials about the adult clinic and staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Support with planning for insurance coverage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Support with planning for higher education and/or employment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Education to help me be able to care for my CF independently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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?	<input type="checkbox"/> Yes – Answer question number 8a		<input type="checkbox"/> No – Answer question number 8b		<input type="checkbox"/> 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.	<input type="checkbox"/> Strongly Agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Neither Agree <u>or</u> Disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> 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.	<input type="checkbox"/> Absolutely	<input type="checkbox"/> Probably	<input type="checkbox"/> Not Sure	<input type="checkbox"/> Probably Not	<input type="checkbox"/> Absolutely Not	

The following questions are meant to gauge your satisfaction with the transition process:						
	Strongly Agree	Agree	Neither Agree <u>or</u> 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I feel I was provided enough information about transitioning to the Adult clinic in the year leading up to the transfer of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I was given the opportunity to ask questions about transitioning to the Adult CF clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I am satisfied with the care I received in the Pediatric clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. I was given the chance to discuss when during the year transfer to the Adult services would occur.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I knew who/where to call for CF related concerns between my last pediatric appointment and my first adult appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Strongly Agree	Agree	Neither Agree <u>or</u> Disagree	Disagree	Strongly Disagree	Did Not Occur
7. I am satisfied with the care I have received in the Adult clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Transition and transfer to the adult clinic met or exceeded my expectations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I feel like my <u>Adult</u> team was well-informed about my medical history from my Pediatric team.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I feel I had control over how much my parents/guardians were involved in the transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The age and timing in which I transition into the Adult program was just right for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. <u>In regards to</u> my transition time, if I could do it over again I would have:	<input type="checkbox"/> Stayed in my Pediatric clinic longer.		<input type="checkbox"/> Transitioned to the Adult clinic sooner if I could have.		<input type="checkbox"/> 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?	<input type="checkbox"/> Made the change easier	<input type="checkbox"/> Made the change more difficult	<input type="checkbox"/> I was not affected by the program	<input type="checkbox"/> I do not remember going through a transition program	<input type="checkbox"/> 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:

<input type="checkbox"/> Very Satisfied	<input type="checkbox"/> Satisfied	<input type="checkbox"/> Neither Satisfied <u>or</u> Dissatisfied	<input type="checkbox"/> Dissatisfied	<input type="checkbox"/> Very Dissatisfied
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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?

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

UVA Cystic Fibrosis Center Transition Survey

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:
- End of high school
 - During college (undergraduate)
 - 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? _____