Transition Timeline:

One Team's Approach to Preparing Patients for the Future Using CF Rise

Kecia Nelson MSW LCSW, Hannah Holzum RD LD, Natalie Harris BHS RRT, Connie Fenton RN BSN, Haley Hill RN BSN, Kristen Medley RN BSN, James Acton, MD

Global Aim Statement

To be the best at preparing patients and families for and ushering them through a positive and seamless transition and transfer of their care from the Pediatric CF program to the Adult CF program at the University of Missouri.

Background

- In 2016, 53% of patients in the U.S. were ≥18 yrs, and the average life expectancy for individuals with CF born between 2012-2016 is 43 years.
- Within the MU CF Center, ~50% of all patients were ≥18 yrs.
- The Cystic Fibrosis Foundation has established evidence-based consensus guidelines mandating that adult CF patients should receive care from providers trained in adult medicine and in settings appropriate for adults.
- We have defined Transition as the process of preparing patients and families for and facilitating the necessary changes in their roles and the shift in responsibility for their CF care from the parent to the patient.
- The combined adult and peds CF teams assessed the existing process by which patients move from the peds to the adult CF clinic at MU and found it was inconsistent, unplanned, and ill-defined.
- In 2014 the MU CF Center was selected to participate in the CFF-sponsored OneCF Collaborative with the goals of improving the transition process and related outcomes. This summarizes the continuing work from that project.

Specific Aim Statement

We will design, test, and implement practices and tools that result in a highly reliable and standardized process for successfully transitioning pediatric CF patients to the adult clinic. Specific goals included:

- Further develop and refine our formal transition program using the CF Rise™ platform
- Patients will be actively involved in our transition program by the age of 13 years **(Fig. 1)**
- Patients will engage in a portion of their clinic visits with the care team independent of parent/caregiver participation. **(Fig. 2)**
- Patients will personally initiate communication with the care team by phone or MUHealthe electronic portal **(Fig. 2)**

Data

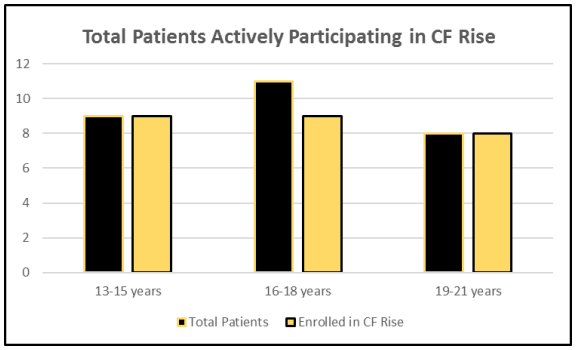

Fig. 1

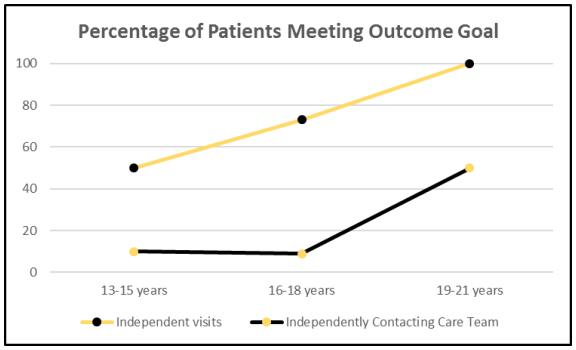

Fig. 2

SDSA Cycles

- Implement the use in clinic of CF Milestones™ **(Fig. 4, Handout 1)** and CF RISE™ **(Handout 2)** materials to assess each patient's progression in their level of knowledge and responsibility for their CF care needs
- Using results of CF Rise™ assessments, guide patients to accept increasing responsibility for their CF care
- Identified each patient's transition needs in weekly CF clinic preplanning conference and documented on CF Clinic Roadmap **(Fig. 3)**
- Organized CF Rise™ modules into age-specific goals and assigned them to multi-disciplinary team members based on scope of practice
- Implemented process for documenting and tracking each patient's needs and progress through the transition process

Tools

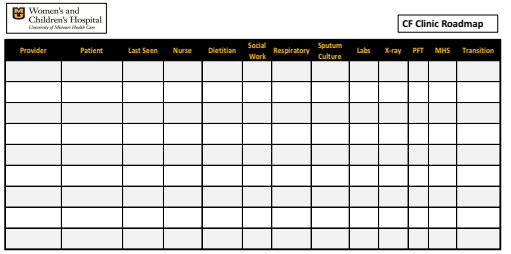

Fig. 3

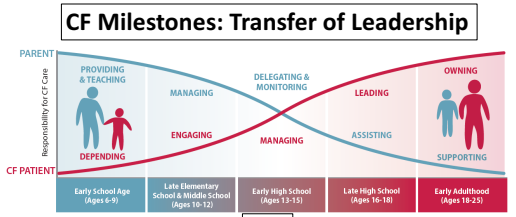

Fig. 4

Learnings

- Most but not all patients/families are receptive to the transition program
- Patients and families like concrete guidelines, expectations, and milestones
- There is a need to focus on and support the parents' role in the transition process
- The transition process is smoother when patients and families begin preparations earlier in childhood

Next Steps

- Design and implement an active process to help patients achieve their progressive transition goals
- Design and implement a documentation tool in Powerchart (EMR)
- Design and implement a patient survey prior to transfer to continue improving the transition process
- Refine our quarterly transition clinic involving both pediatric and adult CF care teams, including a combined pre-clinic planning meeting with both teams

Acknowledgements:
Cystic Fibrosis Foundation
The Dartmouth Institute Microsystem Academy