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IMPLEMENTATION OF A MULTI-INSTITUTION, MULTISTATE CYSTIC FIBROSIS TRANSITION PROGRAM

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Abstract

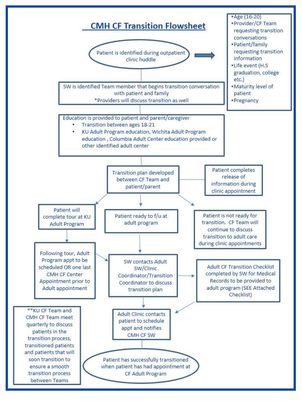
Background: Children's Mercy–Kansas City (CMKC) is an independent children's hospital in Kansas City, MO. Its CF Care Center (CFCC) provides care for 250 patients. The University of Kansas Medical Center (KUMC) is an academic medical center in Kansas City, KS. Its CFCC includes adult/pediatric programs (230/50 patients). Interactions between CMKC and KUMC were minimal prior to 2013. CMKC provided care through adulthood despite CF Foundation mandates requiring transition of patients aged 18-21 years. Transition only occurred per patient request.
Methods: The CMKC CFCC underwent restructuring and staff expansion in 2013-2014. KUMC underwent staff expansion in 2012, adding a nurse, respiratory therapist (RT), social worker (SW), and dietitian. These changes fostered improved communication and provided a foundation for developing a more robust transition program (TP). Elements of the TP included SW to SW driven initiation of quarterly meetings (none occurred prior to 2013), chaperoned tours of KUMC ambulatory and inpatient care areas, creation of a "Welcome Packet" by KUMC, and expanded inclusion of KUMC at the CMKC CF Family Education Day. In 2013, KUMC staff were invited to participate in breakout sessions and Q&A sessions with parents to help address concerns related to the TP and care at KUMC. KUMC also created co-clinic coordinator positions in 2013 with the SW and RT. This streamlined the TP by assigning education to the SW and logistics (medical records and scheduling) to the RT. The KUMC and CMKC teams worked together to create a TP Worksheet & Checklist to ensure that needed records were available. KUMC also developed a peer-to-peer program for transitioning and pre-transition patients to connect with adults already receiving care at KUMC.
Results: The number of patients transitioned each year varied. The largest number of patients transitioned in a given year followed changes discussed above. The age range at transition narrowed between 2010 and 2016, with all patients transitioning by age 21 in 2015. Mean age at transition decreased.
Conclusions: The unique situation at CMKC and KUMC resulted in impediments to a functional TP. Barriers included payer issues related to MO and KS Medicaid, a culture of "patient-driven" transition, and insufficient staffing at both institutions. Reorganization of the CMKC CFCC and improved staffing at both institutions led to an improved TP, with transition of all adult patients from CMKC to adult CF programs . Communication and sustaining a "culture of transition" are key elements in the development of a successful TP.

Background

- Children's Mercy – Kansas City
  - Kansas City, Missouri
  - 248 Pediatric; 24 Adult
    - 45% Commercial; 13% MO Medicaid; 22% KS Medicaid; 20% Other
- University of Kansas Medical Center
  - Kansas City, Kansas
  - 50 Pediatric; 221 Adult
    - 63% Commercial; 19% Medicare; 7% MO Medicaid; 6% KS Medicaid; 5% Other
- Transition
  - Perceived shortcomings in the KUMC adult program led to reluctance to transition on the part of CMKC provider
  - Transition only occurred at the request of patients
  - CFF accreditation was down-graded to "provisional" and site visits increased to every other year secondary to failure to develop a formal transition process; CF Center Grant reduced

Methods

- Children's Mercy – Kansas City
  - Restructuring and improved staffing 2013-2104
    - Three additional outpatient CF providers
    - Additional dietitian and social worker
    - Mandate to transition by age 21 years
  - Leadership change 2014-2015
    - Mandate to transition all CF patients by 21 years of age
- University of Kansas Medical Center
  - Staff expansion 2012
    - Ambulatory nurse, fulltime respiratory therapist, social worker, and dietitian
  - Co-clinic coordinator positions created in 2013
    - SW assumed responsibility for transition education
    - RT assumed responsibility for logistics (record transfer and scheduling)
  - Peer-to-Peer mentoring program developed for pre-transition and transitioning pediatric patients to connect with adult who had completed transition process
- Transition
  - Social work driven (CMKC SW to KUMC SW) transition program with quarterly meetings at alternating location
  - Chaperoned tours of KUMC ambulatory and inpatient facilities
  - "Welcome Packet" developed by KUMC for transitioning patients
  - KUMC participation in CMKC CF Family Education Day started 2013
  - Co-development of a transition Flow Sheet & Checklist to ensure adequate preparation for transition



Transition Checklist for Incoming Patients into the Adult CF Program

In order to provide a smooth transition for CF patients in transition from a pediatric program to the adult program, we will follow the outline below. It is our goal to make the transition for the patient as seamless and comfortable as possible.

1. Referral call and/or e-mail made to the adult program to note incoming referral. Please call Tisha Bromstedt: 913-588-1157 and/or e-mail Tisha (mbromstedt@kumc.edu) and Abby Moog (amoog@kumc.edu).
2. Prior to patients being scheduled, records will be sent to the KU Pulmonary office and faxed to 913-588-8814 including transition of care sheet.
3. Records will be reviewed by the adult care team (will be split between teams): this will include:
   a. Clinic notes (last 12 months)
   b. Microbiology (last 12 months)
      i. Please send any positive results of: burkholderia cepacia
   c. Pulmonary Function Testing
   d. Laboratory studies including sweat chloride and/or genetic testing
   e. Hospital discharge summaries
   f. Radiology films (CD is fine)
   g. Consulting/Specialty office visit notes where appropriate. Please include notes from: Endocrinology, Psychology, GI/Hepatology, ENT, Neurosurgery, Ortho, Other
4. Appropriate timing for appointment in the adult clinic will be made after transition conference and/or once records are received.
   a. The initial visit may be a get acquainted visit and the patient may return to their pediatric practice for further discussion of the transition
   b. Patients will be encouraged, once they have agreed to transition, to stay with the adult program
   c. Selection of the appropriate patient will be critical to achieve a successful transition
5. Patients may be scheduled for an emergent transition care visit by calling Tisha Bromstedt at 913-588-1157.

Results

Year	Number of Patients Transitioned	Patient Age Range at Transition	Mean Age at Transition
2010	18	18 - 28	22.2
2011	12	17 - 27	20
2012	14	18 - 28	20.5
2013	5	19 - 24	21
2014	19	18 - 22	19.8
2015	11	18 - 21	19.3
2016	10	18 - 20	19.1

- Significant variability in the number of patients transitioned each year
  - The single highest number of patients followed implementation of changes
- Age range at transition has significantly narrowed from 2010 through 2016
- Mean age at transition has steadily decreased from 2010 through 2016
- Culture shifted from a patient-driven process to a system-driven process

Conclusions

- The unique structure of the relationship between CMKC and KUMC (history, staffing, culture, financials) led to significant challenges in developing a robust transition program
- Appropriate staffing (all allied healthcare providers) needed at both Centers to assure success
- Leadership change and a dramatic culture shift was needed to drive transition
- Communication essential through process of change