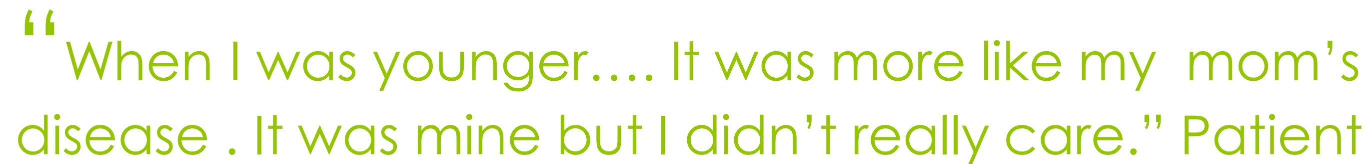
Evidence for Transition Programs in Cystic Fibrosis Care

Advanced Lung Disease Program : Adult Cystic Fibrosis

Transfer Verses Transition

Transition Planning in Pediatrics

- Envisioning the future
- Age of responsibility
- Age of transition



"Proactive patients can make the transition smooth, but some patients wait until they are sick to make the transition, and that is hard." Provider

Differences in Current Programs at SUH

Adult Clinic

- Group Practice Model
- Mid Level Providers
- Concurrent Clinics with Endocrine monthly
- Weekly Teaching Sessions

Pediatric Clinic

- Primary Care Physician Model
- Supportive Setting

SUH Transition Plan 2012

- Start at 8 years
- Booklet with specific expectations
- Explains how to prepare for parent and patient
- Medical Summary completed by the patient

SUH Communication and Coordination between Adult/Pediatric Teams

- Adult Coordinator attends weekly Pediatric Meeting
- Adult Coordinator attends weekly inpatient rounds
- Complete Adult and Pediatric Team meet quarterly together

SUH Adult Clinic Services

- Support Group monthly with WebEx access
- Referral to support services through Skype or face to face sessions
- Weekly teaching sessions for new diagnosed patient or fallen away CF patients
- Inpatient support : volunteer visitor, care packages, meals

Transition Programs: Pediatrics to Adult: Common Features

- Patient preparation
- Patient readiness assessment
- Coordination of services
- Benefits assessments
- Medical summary
- Primary and preventive care services
- Patient follow up
- Program evaluation

Transition and Transfer

- Models of care: separate clinics, separate location
- Barriers : patient/family , disease severity, developmental delay
- College patients either stay with pediatric team until graduation or move to college location site

Difference between Pediatric or Adult Clinic

- Different cultures
- Adult clinics may expand to include subspecialists
- Adult support may include emphasis on thinking for the future
- Patient concerns include infection control and leaving Peds provider

Suggestions for Transition Programs

- Promote self care
- Communicate and share responsibility between teams members and patients
- Insure visit to adult team and inpatient unit
- Individualize care for patients with special needs

CF and Transition to Adult Medical Care

- Barriers: confidence of Peds providers in adult providers
- Infection Control concerns
- Insurance coverage: greater expenditures over non CF expenses for health care

Findings

- Models of care base on clinical experience or best practice approach
- Validation is lacking based on evidence for systematic study
- Found increased hospitalization rates within year after transfer

Transition of Pediatric Chronic Vulnerable Patients

- National Initiative
- Medical Home Concept
- Disability financing
- Vocational support
- Provisions for work

Transition with Vulnerable Population

- Scope of problem
- Written plan by age 14 years
- Models: disease based, subspecialties based, PCP based
- Transition not based on age of patient

Transition with Vulnerable population

- Emphasis on medical summary
- Plan should include services and how they will be financed
- Barriers: for Peds provider: finding and securing adult clinicians, lack of support time for transition
- Barriers: for adult provider: meeting psychosocial needs of chronically ill, facing disability and end of life issues with early relationship with patient

Transition Program Assessment of Pediatric to Adult CF Care

- 105 question Survey
- 195 US Cystic Fibrosis centers
- Team participation
- Method: email and phone call follow up

CFF Transition Survey Findings

- 85% of CF patients are followed in centers
- Median age to initiate transition discussion was 17 years of age
- Age of transition age was on average19 years with a range of 14 -30 years.

CFF Transition Survey Findings

- 50% of programs did readiness assessments
- 10% use a written list of self management skills for the patient
- 80% of programs assigned a team member to assess patient's insurance benefits

Transition Survey Findings

- 80% of programs reviewed patients in pediatric meeting
- Minority of medical summaries include assessment of patient self care skills or review of communication problems with provider team and patient

Assessment of Satisfaction on Transition

- Patient
- Parents
- Pediatric providers
- Adult providers

Evidence Based Recommendations

- Transfer and transition is a process
- Development of trust is also a process
- Disease severity will drive level of support needed in transition
- Patients may do better with transition than parents or providers

First Appointment in Clinic

- Co Visit with Pediatrician if possible
- Parent in the room until Fellow or Nurse Practitioner come into the room
- Parents may return when plan of care discussed with Attending MD
- Questions Questions Questions

How can parents help patient with Transition ?

- Try to be a coach rather than a player
- Encourage forward movement
- Count to 10 before critical comments
- Remember how you felt in the early years of taking care of your child with this diagnosis

Come Ride with Us to Better Health

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