Outcomes of a Transition Education Program for Patients with Cystic Fibrosis

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To discuss results of an educational program to prepare adolescent/young adult (AYA) patients with cystic fibrosis for successful transfer to an adult healthcare program.
Background and Significance

- Larger number of adults with CF
- Lack of structured programs
- Consensus guidelines recommend transition program
- Complex disease
• Formed intra-disciplinary team
• Reviewed current process
• Reviewed the literature – research and EBP
  • Identified key components/common themes of transition programs
• Contacted other centers
• Modified current process to include key components
• Developed structured program starting at first contact/diagnosis
• Implemented
  • Tracking interventions
  • Evaluating/measuring/improving
## Cook Children’s CF Transition Tracker

**Patient name: ___________________________**

<table>
<thead>
<tr>
<th>Date transition initiated:</th>
<th>Planned transfer date:</th>
<th>Actual transfer date:</th>
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<tbody>
<tr>
<td>□ Welcome letter &amp; brochure provided</td>
<td>□ Certificate &amp; book provided</td>
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### GOALS, ASSESSMENT TOOLS, & EDUCATION

| 13y | 14y | 15y | 16y | 17y | 18y | 19y | 20y | 21y |
|---------------------------------|
| Knowledge: CF and Medications |
| Interacts directly with CF team (asks questions) |
| Able to describe symptoms of an exacerbation |
| Verbalizes names, dosages, and order of meds |
| Verbalizes purpose of meds |
| Able to give medical hx independently |
| Verbalizes understanding of basic CF concepts (e.g. malabsorption, infection control, etc) |
| Able to describe personal CF course (e.g. sputum growth, comorbid conditions) |
| Administer knowledge assessment |
| Administer self-care skills/readiness assessment | n/a | n/a |
| Review “CF 101” age TBD by MD |
| Provide “Cruisin’ on to Adulthood” | n/a | n/a |
Results

- 64 patients enrolled in scheduled education program
- 16 completed at least one yr of care in adult care center
- 15/16 seen within 3 months after last pediatric appt.
- All maintained baseline lung function

Lung Function Measures

![Chart showing lung function measures over time for patients in the program. The chart includes a line for the average FEV1 last pediatric year and another for the first adult year.](chart.png)
Also tracking
- Knowledge scores
- Readiness assessments
- Other potential measures
  - ED utilization
  - # of exacerbations/hospitalizations
  - Satisfaction surveys
Implications

- Improved patient outcomes
- Provide feedback for improvement
- Lead to research projects:
  - Is there a relationship between knowledge and readiness?
  - Is there a relationship between knowledge or readiness and specific outcomes?
References

- Cystic Fibrosis Foundation Annual Data Report 2012