Evidence-Based Cystic Fibrosis Transition Program

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Background

- Cystic fibrosis (CF) is the most common life-shortening autosomal recessive disease among Caucasians.1,5
- There has been a steady growth of the CF population entering adulthood and unfortunately, the best method for transitioning CF patients is unknown2
- Incorporating a developmental, structured approach to transition increases independence while decreasing anxiety and disease non-compliance3
- Post-transition patient satisfaction significantly increased when patients were enrolled in a structured transition program1,4,6
- Findings suggest a structured transition program should be utilized for all cystic fibrosis patients transitioning from pediatric to adult care beginning at age 111

Project Aims

1. Design CF transition program using blended learning model
2. Recruit local experts to assess actionability and usability of CF transition program
3. CF patients will exhibit enhanced knowledge following education completion as evidence by a passing score of 80% or higher

Methods

- **Design**: Performance improvement (PI) project to create an education bundle and evaluate post-intervention design. Local evaluators used validated tools PEMAT-P and PEMAT-AV
- **Setting**: Outpatient pediatric CF clinic in urban mid-Atlantic academic medical center
- **Sample**: The project involved a mixed learning data set sample consisting of local pediatric CF experts and a complete learning data set of CF patients 11-22 years old
- **Intervention**: 8 topics created in CF transition education bundle.
  - PEMAT-P and PEMAT-AV distributed to mixed learning data set local experts to evaluate education
  - Learning data set patients complete transition education

Results

- The higher the percentage score, the more understandable or actionable the material is perceived to be by the evaluator.
- According to local experts, the printable material was more understandable (92.5%) than the audiovisual material (88.7%). Conversely, the audiovisual material was more actionable (90%) than the printable material (78.09%)
- As patient’s age increased, their scores for the completed CF transition education also increased
  - 80% of patients (n=8) 11-14 years old scored under 80%
  - 60% of patients (n=6) 15-17 years old scored over 80%
  - The majority of patients 18-22 years old (93%; n=13) scored over 80% on transition education
- Local experts believed a CF transition program was beneficial and the audiovisual aids embedded in the education bundle were valuable to potential CF patients transitioning to adult care

Conclusions and Implications

- Education regarding the transition process should be offered to all pediatric patients with CF to ensure adequate comprehension and promote independence prior to the transition to adult care
- The education bundle was understandable and actionable for use by transitioning CF patients
- Positive participant survey reports of potential distribution to patients indicate consideration for long-term implementation in outpatient clinic setting

References