

# Good Enough Care: Decreasing Barriers to Treatment Adherence in School-Aged Patients with Cystic Fibrosis

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**Background:** Cystic fibrosis is a life limiting disease that affects approximately 30,000 people in the US. The complexity of this disease often leads to a complicated treatment regimen. Although research shows treatment adherence to be beneficial in increasing survival time and quality of life, pediatric patients often have difficulty adhering to the regimen. The UFHealth Cystic Fibrosis Center falls below the national average in multiple categories measured by the Cystic Fibrosis Foundation, and this is likely affected by lack of adherence. Research questions include: What differences exist between parents and healthcare providers regarding perceived barriers to treatment adherence in school-aged children with Cystic Fibrosis? In what ways can the UFHealth Cystic Fibrosis Center improve so that patients can get the most from appointments?

**Method:** Interviews with parents of patients at the UFHealth Cystic Fibrosis Center were conducted at the end of patient appointments. One focus group was conducted with healthcare providers of patients at the UFHealth Cystic Fibrosis Center. All participants were asked to complete a demographic survey. Survey results were analyzed using Microsoft Excel. Qualitative data were analyzed into themes and codes using NVivo 9 software.

**Results:** Seven interviews took place with a total of 9 participants. One focus group took place with a total of 7 participants. Parents and providers had different perceptions of which treatments were most difficult to follow, negative attitudes toward treatments, perceived behavioral control, and subjective norms. Treatments that were discussed included the vest, nebulized treatments, diet, and enzymes. Negative attitudes included not wanting to sit for the required time, not finding treatments necessary, and treatments being nuisances. Aspects of perceived behavioral control included time and exercising control over adherence. Participants believed subjective norms to come primarily from doctors and parents.

**Conclusion:** Despite interacting during multiple clinic visits, healthcare providers and parents have differing perceptions of barriers to treatment adherence in school-aged children with Cystic Fibrosis. There are multiple ways providers can assist families with treatment adherence, including compromising on treatment regimens and providing a summary at the end of each clinic appointment.