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Motivating Adherence Among Adolescents With Cystic Fibrosis: Youth and Parent Perspectives

Gregory S. Sawicki, MD, MPH, Karen S. Heier, PhD, Nathan Demars, MS, and Walter M. Robinson, MD, MPH

Division of Respiratory Diseases, Boston Children's Hospital, Boston, Massachusetts

Summary

As advances in the care of individuals with cystic fibrosis (CF) have resulted in improved survival, therapeutic regimens for treatment of CF have become increasingly complex. This high treatment burden poses challenges to chronic disease self-management, particularly amongst adolescents. The aim of this qualitative study was to understand the barriers and facilitators of adherence to chronic CF therapies as perceived by adolescents with CF and their parents. In a series of structured interviews with 18 youth and their parents, we explored issues related to daily routines, youth and parental roles regarding chronic therapy, and motivators for adherence. All interviews were audio-recorded and coded for themes and patterns. Reported barriers to adherence included time pressures, competing priorities, heightened awareness of disease trajectory, privacy concerns, and lack of perceived consequences from non-adherence. Identified facilitators for adherence included recognizing the importance of therapies, developing strong relationships with care teams, establishing structured routines, and focusing on shifting responsibilities from a parent to their adolescent child. The themes uncovered by these interviews identify areas for intervention and support by clinical programs seeking to improve adherence and self-management strategies for adolescents with CF. *Pediatr Pulmonol.*

Keywords

cystic fibrosis; adolescents; adherence

Introduction

As the predicted survival of individuals with cystic fibrosis (CF) increases to almost 40 years,¹ the challenges of CF self-management also increase due to the complexity of the daily therapeutic regimen and the developmental changes in the patient population. Standard preventive clinical strategies at CF care centers are to initiate early therapies in life, often as a series of incremental and chronically applied therapies, each designed to effect small changes in the trajectory of lung function.² CF therefore presents an illness model in which

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*Correspondence to: Gregory Sawicki, MD, MPH, Children's Hospital Boston, 300 Longwood Avenue Boston, MA 02115. gregory.sawicki@childrens.harvard.edu.

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adolescents must maintain an increasingly difficult and time-consuming regimen every day for life, without being able to see immediate benefit.

Adherence to the daily regimen is a complex issue for individuals with CF and their clinicians. Medications for CF are often time-consuming to administer, and it is estimated that basic recommended therapies (inhaled antibiotics, inhaled mucolytics, chest physiotherapy, as well as oral vitamins, and pancreatic enzyme supplements) entail almost 2 h/day to properly complete.⁷⁻⁹ Such treatment complexity is an important barrier to adherence to therapy. Prior research on adherence in CF has identified that adherence rates vary between treatments, with higher rates of adherence with oral medications, lower rates with nebulized therapy and pancreatic enzymes and the lowest rates with vitamin therapy, dietary changes, exercise and physiotherapy.⁷⁻¹¹ Poor adherence has been shown to be predictive of worse outcomes including hospitalization and pulmonary exacerbations.¹²

CF lung disease often progresses during adolescence, so the need to maintain prescribed regimens increases at a very time of life when youth are vulnerable from a developmental perspective. During this period, adolescents face key challenges of education and vocation that are foundational to their sense of self, and both their medical condition and its management are likely to impact their life choices and relationships with family, caregivers, and peers. Fitness perceptions and beliefs are also being established during this period. Struggles with parents and caregivers over roles and responsibilities likely arise during this time. All of these challenges influence adherence behaviors. Finally, adolescence is a time for preparation for transition to adult-focused medical care, and improving adherence skills is a key part of transitional care.¹³

Although the importance of adherence in CF in the context of an increasingly complicated regimen is widely reported, few studies of improving self-management in CF have been reported.¹⁴ A series of interventions using behavior modification strategies to increase caloric intake has been published.^{15,16} More recently, studies incorporating motivational interviewing and problem-solving into CF clinics have been launched.¹⁷ Furthermore, as many CF care centers implement programs to improve transition readiness for adolescents with CF, the need for understanding how adherence behaviors impact transition and transfer of care warrants further exploration. In order to design appropriate interventions to improve adherence among adolescents, particularly in an era of increased treatment complexity, further understanding of facilitators and barriers to adherence among youth with CF is needed.

This paper presents findings regarding adherence to treatment among adolescents with CF derived from qualitative research interviews with pairs of adolescents with CF and their parents. The interviews were conducted as part of a larger ongoing study of transitional care from adolescent to adult-focused CF care from the perspective of adolescents with CF and their parents. The goal of the interviews was to identify both barriers to adherence and disease self-management while examining factors that parents and youth felt could motivate improvements in self-care.

Methods

Study Participants

During a routine visit to the CF clinic at Boston Children's Hospital between November 2009 and May 2011, a convenience sample of adolescents aged 16–21 years and one of their parents was recruited and 20 adolescent-parent pairs consented to participate in a onetime interview study. One adolescent-parent pair dropped out prior to scheduling their interviews. Another pair was not included in data analysis because the adolescent did not complete the interview. Clinical and demographic information on the participants was obtained via a review of the medical records. The research study was approved by the Boston Children's Hospital Institutional Review Board.

After consent was obtained, confidential, 1-hr telephone interviews with a parent and adolescent were conducted separately using interview guides developed by the authors. The interviews were conducted by Dr. Karen Heher, a co-investigator with no relationship to the subjects' clinical care, and with extensive experience in conducting qualitative research, including two prior interview studies involving adolescents and adults with CF. The interview questions focused on adolescents' CF self-management, readiness for self-care, and preparation for living with CF as an adult (Table 1). The interviews were structured by a set of key questions and probes intended to guide an open conversation. If the respondent did not understand a question, or if a question or probe did not prompt the respondent to offer sufficiently detailed information, the interviewer was free to clarify the question in order to solicit a clearer or more detailed response. The interviews were audio-recorded and transcribed. The interviews with adolescents ranged in length from 26 to 78min (mean 53 min). The parent interviews ranged from 30 to 81 min (mean 57 min).

The final interview sample included 18 adolescents (10 females and 8 males) ranging in age from 16 to 21 years, 13 mothers and 5 fathers. At the time of their interviews, the median age of the adolescents was 18 years. The average lung function of the participants was in the normal range (mean FEV1 % predicted 91%, range 38–127%) and their average BMI was 21.9 (range 18.7–24.6). Three participants had CF-related diabetes, and 8/18 had been hospitalized one or more times in 2010 (range of hospitalizations 0–4 during the year). Most of the adolescents (14/18) were diagnosed with CF before age 5. Almost all of the adolescents (16/18) lived with two parents. All of the adolescents were attending school, with the majority (13/18) in college. Four were college students who lived with roommates away from home for part of the year. Most of the adolescents (17/18) also worked part-time.

Data Analysis

The interview transcripts were analyzed using standard qualitative research methods through an iterative process of coding, using both emic codes (based on interview questions and research hypotheses) and etic codes (based on research subject conceptual frameworks), to organize the data into categories that could be retrieved, compared, and linked to one another, and write theoretical memos.^{8–20} An initial set of analytic codes was developed by the interviewer (KH). As a check on the reliability of applying the codes and to guide possible revision of the codes and code definitions, three investigators (KH, ND, GS) coded

the same five pages from each of two interviews (one with a parent and one with an adolescent with CF) using a preliminary set of codes and code definitions. There was 75% inter-coder reliability on the pages from the parent interview and 69% on the adolescent interview. Through a process of in-person meetings to review transcripts and achieve consensus on the coding structure, some codes were dropped or clarified, and new codes were defined and applied as the need arose over the course of analyzing the transcripts. A final set of codes was then applied to the transcripts.

Coded interview transcripts were entered into Atlas.ti, a qualitative research database and software program. Through a secondary level of analysis, coded interviews were analyzed within and across code categories to identify themes, which emerged in multiple interviews. These themes were discussed by the study team and consensus on the key themes was reached through a series of iterative research meetings. In addition, we compared the responses of parents and adolescents with respect to these themes.²⁰

Results

During the interviews, the adolescents and parents discussed self-reported levels of adherence to treatment for CF with respect to three main elements of CF self-care: (i) oral medications, (ii) inhaled treatments using nebulizers and inhalers, and (iii) chest physical therapy (CPT). All of the adolescents reported inconsistency in adherence to treatments ranging from occasionally skipping a medication or therapy to routinely deciding not to participate at all in one or more elements of treatment. Reports of adherence by the adolescents varied depending on the type of therapy. Two-thirds (12/18) of the adolescents reported being usually or mainly adherent to oral medications (rarely skipped a medication or treatment). In contrast, 6/18 adolescents acknowledged that they were often or always non-adherent in their nebulizer treatments, and 5/18 were often or always non-adherent to their CPT (including two who did no CPT of any kind at the time of the interview). Among parents, 13/18 said that their adolescents were usually or always adherent to taking their oral medications. However, fewer parents said their adolescents were usually or always adherent in their nebulizer treatments (5/18) or CPT (9/18). According to both the parents and adolescents, adherence to nebulizer treatments and chest physical therapy was the most difficult.

Key Themes: Adherence Barriers and Facilitators

Adolescents and parents identified several barriers to adherence to treatment (Table 2) including: (i) Immediate time pressures such as day-to-day schedule variation or lack of stable structure to fit therapies into daily routines. Such time pressures may lead to “forgetting” to complete a treatment; (ii) Awareness of disease trajectory, as evidenced by one adolescent remarking “life is short,” and continuing on that he didn't want to spend it “hooked up to a machine for 45 min at a time”; and another who said, “I really don't do anything that takes away from my life”; (iii) Competing priorities such as being too busy with other activities; (iv) Privacy issues (reluctance to reveal that one has CF), so unwilling to do treatments or take medicines in front of others; and (v) Lack of perceived consequences, such as not recognizing the prophylactic value of a nebulized mucolytic treatment, or believing that if one feels fine, one doesn't need to take medicines or do treatments.

Analysis of the adolescent and parent interviews also identified several key factors that may promote adolescents' adherence to CF treatment (Table 3). Among these are: (i) Recognizing the impact on their health and CF symptoms from non-adherence to treatment, which sometimes was seen as a spur to greater adherence; (ii) Developing a caring, trusting, and mutually respecting relationship with one's CF physician and team, in which the adolescent feels comfortable talking honestly about their life and their adherence to treatment, and feels understood and supported in their efforts to manage the competing priorities in their lives; (iii) Feeling that they were being treated like an adult by their parents and the CF team, including a willingness by parents to cede control and entrust responsibility for their health to them. (iv) Early development of self-care skills through repeated practice and encouragement as adolescents demonstrated their readiness to assume responsibility for their CF self-management, and (v) Establishment of a structure for treatment activity by parents or adolescents that accounts for the importance of the adolescents' schedules.

A subset of these themes is further described below with representative qualitative data and quotes taken from the interviews.

Symptoms as a Motivator for Adherence

Both adolescents and parents commented on the impact of symptoms and health status on adherence to treatment. Representative adolescent and parental quotes on this theme are shown in Table 4. Some adolescents commented that previous experience of the consequences of not completing treatments were reasons for being adherent to their medications and/or treatments. They said they noticed a difference in their depending upon whether they took medicines and did their treatments or skipped them. For example, one adolescent said she was “awake” walking to class if she had not done her nebulized treatments in the morning. One 18-year-old said that after he had gotten sick and was hospitalized following a summer of “slacking off” on his treatments, he got a “wake up call” and “started to take [adherence to treatment] more seriously.” On the other hand, some adolescents said that skipping a medication once or twice did not seem to have an impact on their health.

However, some parents noted that feeling ill because of skipping medications or treatments was not necessarily an incentive to being adherent. The mother of an 18-year-old said that she would have thought that her daughter's PFT test results would make her aware on her own that she needed to do these treatments, but that didn't work.

Relationship With the CF Team as a Motivator for Adherence

Most adolescents reported having a trusting relationship with their CF physician and other members of the CF team. A third of the adolescents (6/18) reported that they would contact their CF physician first if they had any questions about their illness; 10 would ask their parent first if they had questions about their CF, and only a few would first seek information about it from CF or other medical websites on the Internet. Many adolescents also said they felt comfortable talking with their CF team about their general life concerns, and thought that their physician and the other team members were able to understand what their lives were like and how difficult it was for them to adhere to their medical regimens. Most of the

adolescents (13/18) said they thought that their CF physician and team understood what it was like to be an adolescent with CF. Similarly, most parents (13/18) thought that the CF physician and team understood what life was like for their adolescent with CF.

For the adolescents, the major areas of feeling misunderstood focused primarily around balancing the time needed to take care of their CF medications and treatments, clinic appointments and hospitalizations with other priorities in their lives (primarily school, sports, and friends, as well as in some cases, living on their own away from their parents). Another area of misunderstanding expressed by some of the adolescents was that the CF team was not always accommodating about the adolescents' priorities when scheduling appointments. One adolescent said that although he thought the CF team understood what it was like being an adolescent with CF, they expected him to go to appointments "whenever," and he couldn't do that because he had school schedules that he needed to work around. He also thought the team needed to understand "that we have our own thoughts on things and have a reason why we do or do not do things, I guess." Table 5 illustrates these themes with representative quotes.

Being Treated Like an Adult as a Motivator for Adherence

Both parents and adolescents indicated that giving adolescents greater responsibility for their CF self-care overall both affected and reflected the extent to which the adolescents were adherent to treatment. All of the adolescents were taking some or complete responsibility for their CF self-care at the time of their interviews. Five stated they were wholly responsible for CF decision-making and self-management of their medicines and treatments. However, all of the adolescents reported being still dependent upon their parents to some extent for support of various kinds, including emotional support (18/18), financial support (18/18) including paying for CF care through the parents' insurance (17/18), making medical appointments for them (10/18), ordering prescription refills (9/18), organizing the adolescents' medications (7/18), and driving them and/or accompanying them to medical appointments (9/18).

Thirteen parents said they still actively monitored their adolescents' CF self-care, particularly their adherence to medication, nebulizer treatments, and PT. Three parents said they had backed off reminding their adolescents to take their medicine or do their treatment, and two said they no longer monitor their adolescents' CF self-care because they no longer saw the need to do so. According to many of the interviewed adolescents and parents, seeing the doctor alone or having the doctor address them rather than their parents were important indicators that the CF team was treating the adolescent like an adult.

Another factor that adolescents and parents mentioned with regard to promoting adolescents' adherence to treatment was the degree to which parents sought to instill early habits of CF self-care in their adolescents and then gradually to "let go" versus retaining a lot of control over the adolescents' CF care themselves. Parents also indicated that a willingness to allow their adolescent to make and learn from mistakes may also be important in promoting the adolescents' adherence to self-care.

Shifting Parental Roles During Adolescence impact Adherence

As illustrated by representative quotes in Table 6, parents' willingness to "let go" of close monitoring of their child's self-care was a factor identified as bearing on the ability of adolescents to manage their care successfully. Several parents acknowledged that giving responsibility to their adolescents for their CF treatments and medications was difficult and even frightening. One mother, for example, said that any parent of a child going off to college might feel some anxiety, whether or not the child had a life-threatening disease, but she indicated that this separation and necessary reliance on the adolescent to adhere to treatment and manage his CF care completely independently could be especially difficult for a parent who had put years of effort into ensuring that their child would have a good quality of life for as long as possible. Other parents acknowledged feeling ambivalent about their adolescents' growing independence of the need for parental involvement in their daily care. For example, one mother noted, "I would be scared... that he might not... take care of himself as good as I might (laughs)... It is just really fear that he might get lax..." She saw it as her parental responsibility to ensure adherence to treatment for as long as she felt it necessary. Some parents expressed views their parent-child relationship drove them to let go of more of their adolescent's care. Similarly, some adolescents said that having their parents "on them" all the time about taking their medications or doing their treatments had a negative impact on their behavior and relationships, and when their parents stepped back and gave them responsibility for their own care, they did better.

Early Development of Self-Care Skills as a Facilitator of Adherence

As seen in representative quotes in Table 7, habit and repeated practice ("because I've always done it") was an important factor in developing and maintaining adherence to their medications, according to both adolescents and parents. Several interviewees discussed the importance of learning about medications from an early age. One mother of a 19-year-old girl said that she had trained her daughter from age 9 to know and manage all of her medicines, and concluded that consequently her daughter was "invested" in her CF care. However, early practice did not necessarily guarantee adherence to treatment, and some parents expressed the need to continuously reinforce the need for self-care amongst their children, particularly since adolescents might "think they know better."

Discussion

With improving survival, widespread adoption of aggressive care guidelines, and frequent monitoring for complications, overall treatment complexity for the growing population of adolescents and young adults with CF is increasing.²¹ As such, supporting adherence to chronic therapies is a significant challenge for clinicians at CF care centers, and efforts to understand and address adherence are critical. Although knowledge and disease education are often used as a cornerstone for adherence interventions, other factors affecting adherence behaviors need to be addressed in order for such programs to achieve success. In our study, we identified multiple important barriers and motivators for adherence behaviors that could be used as target areas for future youth-focused interventions. Our qualitative approach provides novel data to better understand population experiences and adds value to the existing literature examining barriers to CF adherence previously reported using

questionnaires and self-report assessment). Key recommendations for future interventions based on our data are listed in Table 8.

Similar to other studies of adherence in CF, there was relative agreement between parents and youth on the types of barriers encountered.²² Not surprisingly, time management emerged frequently as a barrier to adherence. In previous studies, adults with CF reported an average of over 100 min for daily therapies, which is clearly a significant time commitment.³ However, the time pressures noted in our study went beyond simply the actual time spent using a particular therapy, and reflect broader issues related to how an individual is able to structure their medical care into daily routines.

Specifically, time tradeoffs were reported based on other competing priorities; particularly those that allow a youth to engage in “normal” developmentally appropriate activities with their peers.

Therefore, interventions to address time pressures as a barrier to adherence would require more than simply shortening the actual administration of medications as has been suggested through the use of novel nebulizer devices or inhalers. Discussions with adolescents and parents need to identify the reason that time is an issue and likely address the overall place of therapies in the context of an individual's other daily routines. Examining family relationships, focusing on problem-solving skills, are therefore robust targets for adherence interventions. Such interventions might best be implemented using techniques such as motivational interviewing.

Prior studies of adolescents with CF also reported that forgetting or losing medication, as well as unintentional forgetting, were common identified barriers to adherence.^{23,24} Interestingly, although forgetting therapies was cited by some of our participants, it was clearly not the most common barrier cited. In fact, some parents felt that if their child forgot to take therapies it was more likely due to denial around their need to take therapies or lack of understanding or appreciation of longer-term benefits rather than the simple act of forgetfulness. The lack of immediate perceived benefits to chronic therapies therefore needs to be discussed specifically during any adherence intervention approach. Similarly, forgetting therapies was more often discussed as a component of competing priorities. Currently, some interventions to improve adherence rely on reminder systems, and although such systems may provide a structure upon which an individual is able to improve adherence, these interventions alone, particularly in a complex therapeutic regimen for a youth with CF, likely would not lead to dramatic changes if not accompanied by a greater understanding of the global context of an individual's day to day needs.

Our interviews uncovered several key motivators for adherence behaviors including developing trusting relationships with the CF care team, being treated as an adult, and early and repeated practice and skill building. Facilitators such as communication and social support have been identified in other studies as well.²⁵ From this work, it is clear that effective CF care during adolescence needs to address the developmental progression from child to young adult, recognizing that the development of the child occurs in tandem with the progression of the illness. While in childhood, self-management of CF rests in the hands

of the parents; at school age, optimally there should be an initiation of the transition to a shared model based on partial self-management, and in adolescence, there should be an increasing assertion of independence on the part of the teenager. Our interviews have documented that for an adolescent with CF, progress toward taking full responsibility for one's care may not always proceed in a linear or smooth fashion. Clinical programs need to incorporate evaluations of an adolescent's developmental progression and resultant family relationships in order to appropriately tailor their approaches to improving or maintaining adherence over time.²⁶ The gradual immersion into independent self-management needs to be tracked by clinicians throughout adolescence, and parental support needs to be augmented.²⁷ Encouragement of this progression into adulthood should be the cornerstone for programs to enhance adolescent disease knowledge, skills, and self-management.

Since illness perceptions and treatment beliefs have been identified as barriers to adherence in CF,²⁸ and adolescence is a crucial time point for the emergence of such beliefs, parents of adolescents with CF need to be taught at an early time point that ceding responsibility should occur over a span of years, starting with simple tasks and progression to monitoring disease self-management from afar. Similar perceptions of parenting styles and preparation for adulthood were identified by an adolescent CF cohort in Denmark as well.²⁹ Importantly, none of our youth recommended that parents be completely absent in terms of their treatments. They endorsed a simultaneous desire for independence with a need to have a safety net, most often provided through their caregivers. Such concepts are not surprising; in fact, many adults with CF continue to report significant caregiver involvement in their daily lives and routines.³⁰

Developing a strong relationship with a CF care team, particularly with respect to communication and respect, was endorsed in many of our interviews as a key driver of improved adherence. Recent opportunities for improving such interactions have entered the realm of health information technology. For example, a recently developed cell phone support program for teenagers and young adults with CF was designed to provide CF information and social support.³¹ Such technologies are likely to enhance existing care models and allow for innovative adherence interventions outside routine visits to CF care teams. However, such programs would still need to promote structured knowledge, support, and shared decision making while enabling youth to develop effective communication with their treating clinicians.

As with any single-center qualitative study, our analysis is limited by the small sample size of individuals that receive care at the same institution, so therefore their perceptions on adherence and self-management behaviors may not reflect more generalized viewpoints. Additionally, we did not assess actual adherence behaviors among the youth interviewed in this study. It is well-known that self-reports of adherence behavior are less accurate than other forms of measurement, and thus what the youth and parents have identified as barriers and facilitators may underestimate the full scope of the issues. However, every single participant identified challenges with adherence and disease self-management, which likely resulted from our interviews occurring in a non-clinical setting with an interviewer removed from the individual's medical care. Finally, our sample consisted of older adolescents and did not capture the attitudes and beliefs of younger children who are embarking on a

developmental pathway towards independence. Although adherence barriers likely would be similar, future research is needed to explore this topic in a younger population.

In summary, adherence to chronic therapies for adolescents with CF is a challenging problem in an era of increasing treatment burden. In light of the negative health consequences of poor adherence, many CF care centers invest considerable time and resources in improving adherence; however, there is little evidence-based guidance on the use of any particular approach to improving adherence. Including youth and parent report provides a richer understanding of barriers and next steps for intervention development and delivery within the family context. Our interviews have uncovered several key themes from a parent and youth perspective that will help clinicians design appropriate intervention strategies to improve adherence in the future.

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Table 1
Key Interview Questions

Adolescent interviews

- How have your daily routines and managing your medicines changed, as you've gotten older?
- On a typical day, when do you take your medicines and do your therapies?
- How do you balance managing your CF with your other activities? What makes it easier to fit it all in? What makes it harder? What happens when you can't fit it all in?
- Are there other things, besides the time involved that make it difficult to do your therapies or take your medicines?
- Does anyone help you manage your daily CF care?
- How has your parents' involvement in your CF care changed, as you've gotten older?
- What changes in your parents' involvement in your care do you anticipate in the future?
- Do you feel you need help with managing your daily CF care? In what ways?

Parent interviews

- How involved are you as a parent in your child's CF care?
 - Do you help your child manage his/her medications and daily therapies? If so, how?
 - Have you changed how you monitor your child's health as they have gotten older? How?
 - How do other people—other members of your family, friends, people at school, work or other places—help with managing your child's health care?
 - How ready do you think your child is to manage CF and its treatments by him/herself?
 - What would signal to you that your child is ready to manage their care?
 - How concerned are you about allowing your child to manage his/her CF by himself/herself?
 - How hard will it be (or was it) for you to give responsibility to your child to manage their CF care?
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Barriers to Adherence

Table 2

<p>Immediate time pressures</p> <ul style="list-style-type: none"> • Having an uncertain schedule or no schedule around which to plan to take one's medications or do one's treatments • Having too much structure (e.g., a schedule with no breaks or a schedule that begins too early) which interferes with morning treatments • Difficulty finding time to do one's treatments or medication • Feeling rushed for therapies • Feeling too rushed to complete therapies • Forgetting to complete therapies • Busy schedules of both adolescent and household that affect both the adolescent's ability to fit all the treatments in and parent's ability to keep track of adolescent's treatment <p>Awareness of disease trajectory</p> <ul style="list-style-type: none"> • Recognizing the potential for utility in adhering to a therapeutic regimen • Avoiding therapies in favor of other activities due to a sense that life may be limited • Trade-offs between completing therapies and other life goals • Recognizing the potential for utility in adhering to the therapeutic regimen <p>Competing priorities</p> <ul style="list-style-type: none"> • Making trade-offs between completing therapies and other goals, such as a desire to succeed at school or in one's career • Resenting time spent doing treatments, away from other life activities • Parental priorities: chat logs, choosing one's battles, dealing with other adolescent issues, not wanting to jeopardize the parent-child relationship by continuously focusing on therapies <p>Privacy concerns</p> <ul style="list-style-type: none"> • Wanting to be "normal" / not wanting to seem different or disabled • Self-consciousness about taking medications at school • Not wanting to bring equipment outside the home to friends' homes • Parent wanting their child to be seen as healthy <p>Lack of perceived consequences</p> <ul style="list-style-type: none"> • Not recognizing or taking seriously the value of treatments • Thinking that adherence to therapies "makes no difference" in how one feels • Thinking there is no need for therapies if one feels fine • Not seeing an impact on one's health right away from skipping treatments or medication 	<hr/>
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Table 2
Facilitators of Adherence

Recognizing the importance of therapies	<ul style="list-style-type: none"> • Becoming knowledgeable about taking medications and their purpose, as well as other aspects of their care • Accepting responsibility for one's health and CF care
Relationships with the CF care team	<ul style="list-style-type: none"> • Having a trusting relationship with the CF doctor and team • Encouraging the CF physician to talk frankly to the adolescent and reinforce the importance of adherence to the medication and treatment regimen • CF team should provide "tools" and tips to assist the adolescent in maintaining adherence • CF team should be creative in problem-solving with the adolescent and parent
Being treated as an adult	<ul style="list-style-type: none"> • Openness about CF with others to offer opportunities for support • Enabling parents to cede control and entrust responsibility to adolescents • Allowing adolescents to experience the negative consequences to their health of non-adherence in order to increase the likelihood of future adherence to treatments
Early development of self-care skills through repeated practice	<ul style="list-style-type: none"> • Completing treatments consistently from an early age ("always have done it") • Gradually increasing responsibility given to the child for self-care • "The sooner he/she knows how to do it, the sooner it becomes second nature."
Establishing a structure	<ul style="list-style-type: none"> • Having a regular, predictable schedule • Having a daily routine, "making it a ritual" • Learning to multitask, for example, do homework, video games, etc. while doing CPT

Table 4
Symptoms as a Motivator for Adherence

<ul style="list-style-type: none"> • “I do definitely feel it when I am not being compliant with everything.” (18-year-old female) • “It’s a preventative medicine, so it’s not like if I don’t take it I’ll have an attack of some sort or whatever. But, I mean, if I don’t take it, I get more likely to be sick more often.” (17-year-old male) • “He knows that if he doesn’t [take his enzymes], then he gets worse stomach problems and... if he forgets to, that he is going to pay the consequences later with his stomach. He pretty much stays on top of it.” (Parent of 20-year-old male) • “...if I had cystic fibrosis and I felt like crap when I didn’t take my medication, I would think that taking it on a daily basis would be the same as breathing, and I would know that I have to take my medicine when I wake up in the morning or before I go to bed and then I need to do my treatment in the afternoon and I would know that.” (Parent of 16-year-old male)

Table 5
Relationships With the CF Team as a Motivator for Adherence

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- “[The CF team doesn’t get that I am] stretched every which way, between my parents wanting me to come home on the weekends, my grades at school, my girlfriend wanting me to spend time with her, and then trying to manage the CF stuff and make sure I get that done as well. I mean, there’s a certain point where you’ve got to put your health first, which is what the doctors always press [but] there [is] other stuff, too” (20-year-old female)
 - “[the CF team did not understand] the demand on, you know, all these nebs... and [the demand to] keep up the schoolwork, but still have a good social life. It’s kind of like something’s got to give... She can either do the meds or she can go out, but she can’t do both.” (Parent of 18-year-old female)
 - “If you find somebody [a CF physician] that you trust, you are going to be compliant. You are going to do what he says or she says...” (Parent of 17-year-old female)
 - “...one thing that my doctor has done that’s been fantastic [is]...like when I was back doing hypertonic [saline] all the time, she would say, ‘Well, you’re doing it three times a week, that’s fantastic, but just so you know, if you did a little more, it could improve, you know what?’...she hasn’t started me down when I haven’t done things that haven’t been necessarily completely healthy. She’s just kind of like, ‘Oh, I’m glad that you’re at least doing it some.’...And you know, I don’t get my PT often, and I don’t really do physical exercise other than walking, and they haven’t completely slammed me. Which has been really nice. Because sometimes, I think, on the whole they’ve actually been very understanding that I have a life other than having CF...my entire day doesn’t consist of just doing meds...I kind of wish that sometimes they knew exactly...what they’re asking patients with CF to do, because you know it’s like, ‘well, you should be getting an hour to two hours of exercise a day, do PT, do all your nebs twice a day,’ but I also have to manage other things too.” (19-year-old female)
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Table 2
Shifting Parental Roles During Adolescence Impact Adherence

•	“Before that, like in the summer, I just slept really late and not doing any of my stuff. Going out and not worrying about it, but as I have gotten older, my dad, he knew that he couldn't be always on me about doing it because it just agitated me a lot, and knew that I had to take the responsibility of doing everything on my own. So, as I got the responsibility I started to take it more seriously, and just making time for what I have to do more than what I want to do” (18-year-old)
•	“So, for the most part, once she turned 17 or 18, her doctor basically said, you know, ‘Mom-out,’ you know, ‘you need to let her come in and do this by herself,’ and I was like, ‘okay.’ I am taking my cues from him because I believe that my job is to make my children independent and highly functional people, so you know, [...] as long as she needed me or wanted me there, I was there, but the moment he told me that she come in on her own and that she is a grown up or on the verge of being adult, she needs to do this on her own, I had to do that [...]. I mean, honestly, I hope it doesn't come out like I don't care. I do care, but I may not always be there, so to me, it makes more sense for her to know how everything works” (Parent of 20-year-old)
•	“[My wife] is more of the watchdog per se. Of course that is her baby and she will fight until whenever, but she needs to let go. She doesn't want to. I don't know if that is a parental instinct not to want to let go. The fact that he has cystic fibrosis and she has fought for 10 years advocating for him to keep him's health as he is, and to give that chance to him and him to end up in the hospital and on the transplant list because he completely didn't do anything that he was supposed to do would break her heart, and unfortunately it is true, and he does have to take care of himself at some point... (Parent of 16-year-old)”
•	“I don't want to say my son doesn't need you, but needs you less, which is a great thing, but you know, you still want to be part of it... sometimes being a parent, you can't let go but you know when you have to let go, and I think that transition would be the time that you need to let go. I am in no rush [for him to transition his care] because I just feel it is the next step to, not losing your child, but just [...] your son getting older and taking the next step to his own care and moving forward... it is a sad day, you don't want it to happen. Is it going to happen? Absolutely. We never thought he would go to high school and before you know it, he is going to be graduating high school... So, I don't know. It just shows that he is going to be older, you know? [...] It's a great thing!” (Parent of 16-year-old)
•	“...we emphasize telling him that you have to continue. You know, you have to constantly maintain, and for the most part he is pretty good, but sometimes he drives you crazy where he is not as good as he could be... because he is a 16-year-old kid, and he just kind of [thinks he] knows a little bit more than we do” (Parent of 16-year-old)
•	“it was down to the point where it was nothing but, you know, the rules. It is hard for a parent to be a nurse at the same time. It just changes the whole dynamics of the relationship.” (Parent of 18-year-old)
•	“I might be over the top and do more and maybe should give him more responsibility, but it is the kind of thing that, you know, you don't really ever take a chance with... It's not like you're ever going to say, okay, well, he has to learn this lesson on his own [...] it is not like, okay, well, he has to figure it out himself... the homework or something in his life or death... I think as a parent, you have to just always be on top of them (laughs)... it really is on how you normally parent to begin with... for me, I think, you know, you stand on them as long as you have to and as long as it takes, and... continue to follow up... unless I knew there was someone else stepping into my shoes... to do it for me. I think I would always have concern and... check up on him... You don't take chances with your kid whether it is their health or their anything [...] And so, if they [the CF team] said well, you know, it is time that you stop doing this or that, they can say whatever they want, that wouldn't make me do it. Other parents might say, okay, the doctor said... but this is a parent thing not a doctor thing... so far as I am concerned” (Parent of 18-year-old)

Table 7
Early Development of Self-Care Skills as a Facilitator of Adherence

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- “Obviously at this point she is completely responsible for her own care, but we turned things over to her very gradually and very early. By the time she was in kindergarten she was coming out her pancreatic enzymes. As soon as she could read the label on the medications, she was responsible to get them, and she was always just very compliant with things. So, because we started early, we never really had any fights over her doing her treatments or being responsible for them, but I would say really since middle school she has been completely independent in terms of doing it. I mean other than saying ‘oh did you do that’, you know, ‘yeah I did—ok’... When she was very little we just made very deliberate decisions that... as she was developmentally able to do things, we would just let her do them and encourage her to do them. So... she pretty much transitioned to being relatively responsible for her own medications at a very early age... So we didn’t see any of that kind of stuff [rebellion, denial, non-adherence to treatment] through her adolescence” (Parent of 20-year-old)
 - “... since she was 5, I would overlook, check everything that she is doing. I would watch what she was doing and make sure that if she had a question when we went to the doctor, I would try to make her fill out the paperwork. Do you know what I mean? Because I mean, I can do it. There is no problem with me doing it, but it is not teaching her to do it, and I am that kind of mom. I kind of think that this is going to be something that is with her for the rest of her life. The sooner she knows how to do it, the sooner it becomes second nature to her. The better off she is going to be. And like I said, she’s incredibly responsible... So I would have to say she has been taking it seriously and doing it on her own since almost the very beginning” (Parent of 17-year-old)
 - “To be perfectly honest, I am kind of hands off in that area because she has been doing that on her own for a long time. I mean, I have provided support when she needs it younger, but she has been able to recite what medicine she is on since the very beginning, and because I [...] put that on her that that was as much her responsibility as anyone else’s” (Parent of 19-year-old)
 - “They really had to learn to let me go, mainly, and that started when I was younger when they handed over my medications to me and gave me the responsibility of taking them” (18-year-old)
 - “It’s always just been something that I know I need to do, so I do it. I mean, there is no ‘oh well, I don’t have to do this today,’ no, I have to do it today.” She said that her parents had instilled in her at an early age that it was really important for her to do her treatments and take medicine faithfully, and they transferred the care of her own medications to her when she was only 7 or 8 years old. She said “I know my medications better than my parents do and I have been the one answering to the doctors for so many years that it has just become a habit” (20-year-old)
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Table 3
Recommendations for Youth-Centered Approaches to Promote Adherence

1	Develop structured communication systems between youth and clinical care teams that incorporate a mutual understanding of competing priorities and time pressures.
2	Provide education to youth and caregivers on how lack of immediate therapeutic benefit does not equate to lack of long-term benefit.
3	Promote adult developmental milestones through early initiation and repeated practice of self-management skills.
4	Initiate discussions of adherence barriers with adolescents and caregivers early and often.
5	Facilitate youth-derived goals for adherence behaviors that incorporate parents, peers, and multi-disciplinary clinician input.
