

Original Article

Perceptions of barriers and facilitators: Self-management decisions by older adolescents and adults with CF

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Abstract

Background: Adherence to CF treatments is poor, which can lead to negative health outcomes. The objective of our study was to qualitatively investigate the barriers and facilitators of self-management among older adolescents and adults with CF.

Methods: Individual semi-structured interviews were conducted, audio-taped, transcribed verbatim and coded to identify common themes.

Results: Twenty-five patients were interviewed. Four broad themes were identified: *Barriers to Self-Management* (e.g., treatment burden (identified by 64% of patients), accidental or purposeful forgetting (60%), no perceived benefit (56%)), *Facilitators of Self-Management* (e.g., CF clinic visits (76%), social support (68%), perceived benefit (68%)), *Substitution of Alternative Approaches to Conventional Management* (36%) and *Planned Non-adherence* (32%).

Conclusions: Older adolescents and adults with CF identified many barriers and facilitators of adherence that may be amenable to self-management counseling strategies, particularly the use of health feedback.

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1. Introduction

In recent years, the lifespan for people with cystic fibrosis (CF) has markedly improved. Nearly half of all people with CF in the U.S. are now adults [1]. Extended life expectancy is due, in part, to the performance of a complex and time-consuming home program of self-care. The foundations of this treatment plan are oral and inhaled antibiotic therapy, inhaled mycolytic therapy, airway clearance, pancreatic enzymes and nutritional support including vitamins and supplements [2]. A growing number of

older adolescents and adults with CF also have CF-related diabetes, necessitating insulin injections and blood glucose monitoring [1].

For these treatments to be fully effective, CF patients must adhere to a variety of health behaviors, and to the dosage, order, and frequency of medication and other treatments recommended by their CF care team. Objective medication adherence estimates for this population are low, ranging from 31 to 79% regardless of the type of drug (antibiotic, mucolytic, and pancreatic enzyme) [3–10]. A recent study based on food diaries collected at a CF clinic visit found that only 72% of patients met overall calorie recommendations and no patient achieved the recommended intake of fat [11]. Self-reported adherence to airway clearance is also poor, ranging between 41 and 54% [12–14]. Adherence decreases as children transition to adolescence and may remain low through emerging adulthood

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[15]. Poor adherence to medications has been linked to worse health outcomes including an increased number of pulmonary exacerbations and baseline lung function [9].

Adherence to CF treatments involves a variety of complex behaviors and is time consuming as well, placing a significant treatment burden on the patients. Several studies have examined barriers to self-management in CF, but only in pediatric populations [16–19]. It is unclear if the barriers faced by children with CF are the same for older adolescents and adults. A better understanding of both barriers and facilitators of treatment adherence may be valuable for developing effective strategies to promote adherence. The objective of our study was to qualitatively explore the perceptions of barriers and facilitators of treatment adherence experienced by older adolescents and adults with CF.

2. Methods

2.1. Design

Individual semi-structured interviews were conducted with adolescent and adult CF patients to identify perceptions of facilitators and barriers to medication adherence. We conducted individual interviews rather than relying on focus groups because of the potential for cross-infection. Individuals were eligible for participation if they were 16 years of age or older and had a confirmed diagnosis of CF, were scheduled for an upcoming clinic visit, were clinically stable (e.g., not on intravenous antibiotics for the previous 14 days), and had been prescribed inhaled mucolytic, inhaled antibiotic therapy, chronic macrolide therapy and/or hypertonic saline therapy for the last 12 months.

2.2. Sample

We attempted to contact 68 people for an interview who were identified from a review of the pediatric and adult CF clinic schedule. Of the 42 people we reached by phone, 29 agreed to participate; the primary reasons for refusal were work or school conflicts, busy schedules, and lack of interest. Twenty-nine individuals agreed to participate; however, two failed to show for their clinic appointments, one could not be scheduled and one participant was interviewed but later deemed ineligible for the study. Twenty-five participants were interviewed and their transcripts were qualitatively analyzed. Interviews were conducted between March and December 2008. Informed consent was obtained prior to the interview and participants received \$50.00 and a parking coupon. The Johns Hopkins University Institutional Review Board (IRB) approved this project.

2.3. Procedures

This study used a naturalist inquiry approach [20]. Thus, we had *a priori* research questions (e.g., what are the barriers to adherence?) but did not test any specific hypotheses which we believed would be premature given the scarcity of research in this area. All interviews were conducted by one of the authors (MZ). The mean time for interviews was 45 min (range 23–71 min), and each interview was audio-taped and transcribed verbatim. After

every five interviews the transcripts were independently reviewed by the investigators for common themes, with group consensus determining which themes warranted further investigation. We explored these themes with subsequent participants and retained only those themes that were uniformly endorsed, a method of “member checking” or respondent validation [20]. This iterative process is common to qualitative research [21] and assures that relevant data is retained as the critically important final codes. After 20 interviews, no new themes were elicited; we interviewed an additional 5 subjects to confirm that data saturation had been achieved. Coding of common themes involved multiple steps: group consensus identified and defined initial codes, three reviewers independently coded each transcript with discrepancies resolved through discussion, and the investigators provided a final review of themes to ensure clarity and comprehensiveness of definitions and final thematic names [22].

3. Results

Fifty-two percent of participants were male and 92% were Caucasian with a mean age of 24 years (SD=6.7 years; range=16–35) and a mean FEV₁% predicted of 68.4% (SD=24.7; range=25.2%–118.2%). Seventy-two percent of subjects were not married, 64% had a high school degree or higher education and 52% had full-time or part-time employment. Table 1 shows additional characteristics of the sample.

3.1. Qualitative themes

Four broad themes emerged from the analysis of the transcripts: barriers to CF self-management, facilitators of CF

Table 1
Participant characteristics (N=25).

Demographic variable	N	%	
Sex	Female	12	48
	Male	13	52
Age (years)	16–19	9	36
	20–29	10	40
	30–35	6	24
Race	African American	2	8
	Caucasian	23	92
Marital status	With a partner	1	4
	Married	2	8
	Divorced	4	16
	Single/never married	18	72
Education	Some high school or less	9	36
	High school diploma/GED	2	8
	Vocational school	1	4
	Some college	1	4
	College degree	8	32
Current work/school status	Professional or graduate degree	4	16
	Not attending work/school for health reasons	3	12
	Attending school outside of home	9	36
	Working full/part time	13	52
FEV ₁ Percent Predicted	Mild (>71%)	13	52
	Moderate (40–70%)	11	44
	Severe (<39%)	1	4

Table 2
Additional exemplars characterizing the theme *Barriers to CF self-management*.

Code	Definition	Exemplar Quotes	Frequency of response n (%)
Treatment burden	The length, frequency, and complexity of treatments affects adherence	<ul style="list-style-type: none"> • “The process involved, the time it takes; the reality it makes you face. The more I have to do, the more I don’t do it.” • “My time is more valuable to me than that. It’s not worth it for me.” 	16 (64)
Social demands	Balancing the need to do time-intensive treatments in the face of social demands	<ul style="list-style-type: none"> • “A friend called me ‘Hey, I have tickets to a baseball game. You want to go?’ I am like, ‘Well, can I plan my treatment around it?’” • “If I want to stay the night at a friend’s, I have to do all this crap first.” • “I know that a lot of time when I am sitting there watching TV or playing on the computer I could be doing it (treatment). But I just don’t because it is more fun not to.” 	15 (60)
Work demands	Balancing the burden of work and treatments	<ul style="list-style-type: none"> • “I put my career ahead...sometimes I’ll think about work before I take my medicine.” • “I work full-time and I work probably 50 hours a week right now so wanting to have a ‘normal’ life, where you go out to get drinks with friends, go to spend time with friends, or go for a bike ride, or a run or do something to try to maintain a normal life. The most difficult part is fitting the treatments into that.” • “If it’s a choice between going away for work and taking my machine or taking meds that I think might get in the way, I’m probably going to choose work.” 	15 (60)
Forgetting	Purposeful or inadvertent forgetting	<ul style="list-style-type: none"> • “Just remembering the enzymes is hard. If I got paid—even if I had like \$5.00—to remember my enzymes.” • “A lot of times, laziness or life just gets in the way.” • “It’s just a matter of forgetting.” 	15 (60)
Absence of perceived health benefit	The presence or absence of symptoms, or the failure to experience benefits or consequences from treatment could result in non-adherence	<ul style="list-style-type: none"> • “If I feel like it is doing something, then I will take my medicines. If I feel like I am just taking medicine because my doctors are befuddled...then I don’t take it.” • “If that was an inhaled treatment sitting there for 15 minutes to a half hour and it’s not doing anything? I would be very unmotivated to do it, especially if I did not see any effect at all.” 	14 (56)
Fatigue	Fatigue caused treatments to be omitted	<ul style="list-style-type: none"> • “After a long day at work, a lot of times, I just want to kick back and just, like, go to sleep.” • “If I am out Friday and don’t get home until 12 or 1, I go to bed. That (treatment) is the last thing I want, or feel like, or will remember to do. I’m tired...just literally coming home and not washing my face, not brushing my teeth. So if I’m not doing those things, I’m certainly not going to take the time to set up my breathing medication...that would go out the window after you have been drinking a bit.” • “To just come home and crash just like everybody else...there have been nights where I had to turn down doing my treatment because I couldn’t do it earlier.” 	14 (56)
Stigma/embarrassment	Stigma and embarrassment related to performing treatments in public	<ul style="list-style-type: none"> • “When I was married I wouldn’t do my breathing treatments around my wife...like my nebulizer, after I use it, I push it under my bed. I guess maybe I am hiding it...It is more my concern how they are going to react seeing their sick friend, sick husband, sick boyfriend.” • “I have 2 roommates...I wasn’t going to do it in front of him. I did it while they were off at work. I do that in my room.” • “When I am out with friends, I don’t carry them (enzymes) like my parents tell me to do because I would feel embarrassed.” 	9 (36)

self-management, substitution of alternative approaches to conventional management and planned non-adherence.

3.1.1. Barriers to CF self-management (Table 2)

Table 2 reflects 8 common impediments to CF self-management reported by 24 (96%) subjects. Thus a barrier is anything identified by the subjects as decreasing the likelihood that they will follow a prescribed treatment regimen. The most frequently noted barrier, mentioned by 16 (64%) subjects, is captured by the code *Treatment Burden* which reflects the length,

frequency, and complexity of treatments. One subject noted that “I’m not on as much as I have been before, in part because I am doing well but also because my doctors realized that I don’t do it because there was that much to do...They know that we have lives.”

The next two codes — *Social Demands* and *Work Demands* — highlight the tension between the commitment to perform lengthy CF care and the desire to participate in competing social events or meet professional responsibilities. Fifteen subjects (60%) identified either or both of these barriers: “I want to do it so I can stay healthy and stuff but I also want to go out and hang

out,” and “Doing nebulizers and stuff—that is not normal for most people. They can just go home or go outside or do homework. And you see people outside and you are like ‘I don’t want to be in here doing this stuff. I want to go outside’... occasionally I will skip them and do something that is more fun.” Another said “Holding down a full-time job and living life normally — time is a big thing...I would rather do all the things I *want* to do instead of sit home and do all the things I *should* and miss out on a bunch of stuff... I am quality over quantity.”

Fifteen subjects (60%) identified accidental or purposeful forgetting as another CF self-management obstacle, exemplified by the code *Forgetting*. One subject commented that “During the weekdays I have a set schedule when I go to bed but on the weekend, it is like ‘I’m going to do this later.’ And then I won’t do it later and I will just kind of forget...I don’t remember because I am kind of happier when I am not thinking about it.”

The next code, *Absence of Perceived Health Benefits*, described 14 subjects’ (56%) treatment decisions. For some the absence of symptoms or the lack of negative sequelae for skipped treatments promoted non-adherence. Exemplars include “It is the chicken and the egg sort of thing. If you are not feeling sick then you don’t feel the need to do the medication” and “I have not taken my meds before and it’s not like my PFTs [pulmonary function tests] have dropped significantly or anything has grown.” For others, the failure to achieve symptom relief prompted non-adherence. “There’ve been times where I said ‘I am going to stick with this’ and for 3 or 4 months I did exactly what they said as far as the nebulizers, the TOBI...and to be honest, I didn’t feel any different at all... I just don’t feel like it because I don’t see any benefits.” Still others anticipated the presence of symptoms would facilitate treatment adherence, commenting, “If I started to feel worse, and it did start to affect my everyday life, I would definitely do it more.”

The code *Fatigue* captures the experience of fourteen (56%) participants, describing how fatigue made CF self-management more onerous. Not surprisingly, this was most often associated with early morning and late evening routines. “When I go to bed I am really tired, and I don’t want to take the extra time to do it,” said one subject. Three (12%) adults specifically identified the combination of alcohol ingestion and fatigue as a problem on weekends; comments included “Friday is usually the problem; it is just because of my lifestyle. And I don’t feel like doing it. Quite honestly, when I’m drunk, I am not thinking, ‘Hey, time to do some TOBI.’ So I do it Saturday morning.”

The final code in the theme barriers to CF self-management was *Stigma/Embarrassment*. This code was identified by 9 individuals (36%) and specifically reflected the stigma of performing treatments in front of others, regardless of whether they were familiar or not. One subject said, “The last girl I was dating for a few months, I stayed at her house probably like half the time, so you know, all that time I wasn’t doing any of it because I wouldn’t do it in front of somebody I don’t know. I just get embarrassed. I don’t know why. I was married for 3½ years, and the entire time, I wouldn’t do anything in front of her.”

3.1.2. Facilitators of CF self-management (Table 3)

The second theme, was also widely endorsed (n=24; 96%); and represents the patients’ perception of things that increase

the likelihood that they will follow a prescribed treatment regimen (Table 3). We identified seven facilitator codes. *CF Clinic*, the first code, illustrates how attending CF clinic, receiving feedback on PFT results, and interacting with the CF team promoted self-management. This code was reported by 19 (76%) subjects. One subject said, “After I have my appointments and I come home, I am really amped up and I am like ‘OK. I can do this’. Then sometimes right before my appointments, I am like, ‘Oh crap! I am going to see the doctor!’ and I do everything.” Another offered, “When I come in here and I have my PFTs done and I see my numbers aren’t where we would like them...then I feel bad about it and I get on it real good for a period of time...If you are here every 3 months, then it is almost the psychological whip to keep you on task.” Regarding her CF doctor, one participant said, “[He] was really funny and outgoing and really nice and that helped a lot getting me back into clinic. Because I don’t come as often as I should, but I come a lot more than I used to.”

The next two codes *Support & Reminders* and *Presence of Perceived Health Benefits* were each reported by 17 (68%) subjects. *Support & Reminders* reflected the role of significant others, reminders, and monitoring devices in improving adherence to CF self-management. Quotes included, “He’ll [boyfriend] make me [do treatments]... I do it more often when he’s around...He will set it up for me.” and “The Vest had a counter on it; how many minutes I did it. The company...would call periodically and I had to read them the numbers to see if I was using it. That only lasted a few months and then it was like, ok, no one is checking up anymore. I lost accountability.” *Presence of Perceived Health Benefits* reflects subjects’ observation that CF self-management improved symptoms and maintained health. This code also captured how the presence of symptoms motivated subjects to perform self-management. Participants expressed these views in the following statements: “The nebulizers—you can really feel them affecting you. So it’s more you are like, ‘This is really working for me’” and “[If I don’t do treatments] I’ll notice the next day—immediately—how awful I feel...The more strict regimen you keep yourself on, the better you feel.”

The fourth code, *Ease of Completion*, reflected the degree of effort the treatment required for 12 (48%) subjects. One participant noted that it “needs to be less complicated and less time consuming. The easier, the shorter, and the quicker it is, the more likely I am to do it...things like popping pills, taking a quick puff of an inhaler—easy! I can do that. But it’s the things that take prep work and take actual time to do them that I just don’t do.”

Perhaps surprisingly, having a routine was only identified by 12 (48%) subjects as a facilitator of CF self-management. *Habit/Routine* described the difficulty subjects had in maintaining self-management practices over the weekend, saying “Pills I don’t have an issue with because...I do it out of habit. Weekends are the worst for me because I am not on a routine in the morning.”

Distractions & Rewards was the code that highlighted how distractions or rewards were used to facilitate CF self-management by 11 (44%) subjects. “You know Facebook? I

Table 3
Additional exemplars characterizing the theme *Facilitators of CF self-management*.

Code	Definition	Exemplar quotes	Frequency of response n (%)
CF clinic	Attending CF clinic promoted CF self-management	<ul style="list-style-type: none"> • “If it is coming close to an appointment here I might get nervous, like ‘Well, if I don’t do it, my lung functions might be down more.’ So that may make me do it more.” • “I have fallen off the bandwagon like a month after I was at clinic last but I snapped back into it and started back on the bandwagon and doing things right before my [next] visit...I jumped back on to look OK to the doctors... because I was running around and doing a lot of partying and I didn’t want them to know what I was doing so I jumped back on and got into the swing of things maybe 2 or 3 days before my visit to make myself a little above where I was the last time and it would work.” • “If I go to the doctor and my PFTS are lower than usual...it does make it more likely to take my medicine and be on a tighter regimen.” 	19 (76)
Support & reminders	Significant others and reminders encouraged adherence	<ul style="list-style-type: none"> • “My mom carries enzymes in her purse so I have them.” • “We actually bought...a small hand held thing (FEV₁ meter) that you blow into...so you sort of know how you’re tracking...that is definitely a good thing to have.” • “My mom nags me to do it so it is not really like I have a choice.” • “I have a little calendar in the drawer that I keep everything, and I check it off too.” 	17 (68)
Presence of perceived health benefits	Treatment adherence improved symptoms and maintained health; symptoms motivated individuals to adhere	<ul style="list-style-type: none"> • “I can tell the difference when I do my Vest and when I don’t...When I don’t do my enzymes, I can definitely tell the difference. My stomach hurts.” • “I can be as close to normal as possible by taking these medications.” • “The nebulizer is so helpful in keeping you healthy to the utmost... Whenever you cough the stuff out of your lungs, I always say ‘That is 5 min more on my life.’ It is a good feeling.” 	17 (68)
Ease of completion	A low degree of effort required to do treatment enhanced adherence	<ul style="list-style-type: none"> • “I would probably do the Pulmozyme and the Acapella because they are both quick...just those two [and] the enzymes are not that big of a deal—because it is just throwing then down the throat.” • “Taking pills is fine. I am good at that because it is just a split second thing.” 	12 (48)
Habit/ routine	Having a routine helped facilitate CF self-management	<ul style="list-style-type: none"> • “It is a lot easier to do it during the week because I have a routine. I am not out. I am home. Weekends are unpredictable.” • “I’m one of those people who follows the schedule to an ‘anal T.’ Honestly, my life is scheduled to the second so I usually have exact times when I take my things daily...nothing really throws me off...Monday–Wednesday–Friday—it hasn’t changed in years. So I guess it is my routine is a habit now.” 	12 (48)
Distractions & rewards	Distractions and rewards were methods used to promote adherence	<ul style="list-style-type: none"> • “I would do my homework while I was doing nebs and stuff, so that was something I didn’t particularly enjoy anyways so then I would be done with my medicine and done with my homework and then I could do whatever I wanted to do after that.” • “I do my Vest in front of the computer. It is on (Vest) so I am on the computer doing other stuff and I normally don’t think about it.” 	11 (44)
Guilt	Feelings of guilt about non-adherence promoted adherence	<ul style="list-style-type: none"> • “I feel bad about it...I am not the sort of person who doesn’t do the treatments.” • “I kind of feel a little bit guilty, like I am supposed to do this and I didn’t, you know? I did it yesterday, why couldn’t I do it today?...So the next day I make sure I do it. It works to give me a little slap in the face to do your stuff even when you don’t want to.” 	11 (44)

love Facebook. I made this deal that I couldn’t go on Facebook until after I had done my therapies for the day,” said one subject. *Guilt* was the code that described how guilt was a motivating force for eleven (44%) participants. “When I’m doing it right (taking treatments) I feel a little better just because I am doing what they tell me to do...when I don’t do it, it’s always weighing on you,” offered one individual.

3.1.3. Substitution of alternative approaches to conventional CF management (Table 4)

Substitution of alternative approaches to conventional CF management was the third theme identified by content analysis. It was reported by nine (36%) subjects and is composed of one

code, *Substitution of Alternatives*, which identified alternative approaches to standard CF care (Table 4). Quotes included, “If you are staying active and are doing pretty well — if you go hiking or swimming or to the gym — they consider that pretty good chest PT [physical therapy],” “The Acapella that I am supposed to do, I never do that because the saline works like 5 times better than the Acapella ever did. So it’s like, why do two things when one doesn’t work half the time?” and “Sometimes I will go out and run. It is doing the same thing.”

3.1.4. Planned non-adherence (Table 4)

Planned non-adherence was the final theme noted by eight (32%) subjects. Two codes characterized this theme: *Rebellion*

Table 4
Additional exemplars characterizing the theme *Substitution of alternative approaches to conventional CF management* and the theme *Intentional non-adherence*.

<i>Substitution of alternative approaches to conventional CF management</i>			
Code	Definition	Exemplar quotes	Frequency of response n (%)
Substitution of alternatives	The substitution of an alternative approach for standard CF self-management.	<ul style="list-style-type: none"> • “The 10 or 15 min that you want me to do that I could be in the gym and I guarantee you, what I am doing in the gym... is the best medicine that I take.” • “I am supposed to do the Vest three times a day...I don’t because I go to the gym at night and run.” • “Riding that bike, in my mind replaces the Vest.” • “When I am able to run and do things. I almost feel like that is a substitute.” 	9 (36)
<i>Intentional non-adherence</i>			
Rebellion	Planned non-adherence as a rebellion against parents’ mandated adherence	<ul style="list-style-type: none"> • “When you are moving out of the house and everything and get your independence, you are like ‘Screw this!’ It was pretty much as soon as I moved out. It (non-adherence) was kind of refreshing; a relief.” 	8 (32)
Reward	Planned non-adherence as a reward, or break from adherence, or as a gift	<ul style="list-style-type: none"> • “Once a year on my birthday I get a complete day (of non-adherence) if I am healthy.” • “Not wanting to let CF run the show all the time...you feel better when you are not doing your treatments.” 	

and *Reward*. In the code *Rebellion*, non-adherence was a purposeful rebellion against parents’ mandated adherence. It is characterized by the following quote: “I am away from home now and I am going to make my own decisions; and I am not always completely responsible as much as my parents would like me to be.” The code *Reward* captured planned non-adherence as a reward for adherence, as a necessary break from the monotony of CF self-management, or simply as a gift. “I skip it once in a great while... [It’s] something to look forward to, just like I look forward to a night out,” offered one subject. Another said “Knowing you can skip something every once in a while—that is really fun and really exciting.”

4. Discussion

To our knowledge this is the first qualitative study that examines the barriers and facilitators of adherence to chronic CF regimens among older adolescents and adults. As more individuals with CF enter adulthood and as additional chronic therapies are added to the regimen, it is increasingly important to identify factors that impede and facilitate adherence unique to this segment of the CF population. Four broad themes contributing to non-adherence emerged from the interview process: barriers to CF self-management, facilitators of CF self-management, substitution of alternative approaches to conventional management, and planned non-adherence. While we identified many of the same barriers and facilitators that have been found in the pediatric CF population, such as regimen complexity, forgetting, and lack of a routine, we also found several that appear unique to adults with CF and likely reflects the normative changes in social networks and time demands during adulthood.

To our surprise, the most common facilitator identified by participants was not day-to-day reminders or having routines for treatment, but rather the role that the CF clinic played in encouraging self-management. Improved adherence in the

weeks preceding and following a clinic visit (“White-coat compliance”) has been well-documented in other illnesses. Our participants’ comments supported this finding and offered possible explanations for this behavior in the CF population. Most frequently mentioned was the influence of anticipating and receiving PFT results which motivated participants to be more adherent. Several participants also highlighted the benefits of positive interactions with the care team, including receiving empathy for the challenges of adhering to the regimen and encouragement to persevere. The high value placed on clinic visits may reflect a developmental shift from parents initially receiving the bulk of information during pediatric clinic visits to the patients directly receiving the support and guidance that their healthcare providers offer. Previous research has shown that centers with a higher proportion of patients attending four or more clinic appointments per year had better lung health [23]. These results suggest that one strategy to improve CF outcomes among adults may be to encourage frequent clinic attendance that includes feedback of health information (such as PFT results), and patient-centered counseling. However, clinicians should be mindful of the time burden of appointments and tailor the length of the visit to their patients’ circumstances and preferences to maximize regular attendance.

A second theme that emerged that differs from the pediatric adherence literature is the influence of social support. Older adolescents and young adults often have dramatic changes in their social network, shifting away from the central role of parents in their day-to-day lives towards more emphasis on peers and romantic relationships. Several participants spoke of the important yet distal role parents played in self-management decisions, but others viewed the separation as an opportunity for freedom from the regimen. Similarly, some participants developed relationships that supported and enhanced their adherence, while others participants found it hard to integrate treatments into their social and romantic lives and their adherence suffered. Therefore, clinicians should strive to be

knowledgeable of changes to the patient's social support system and, with patient permission, consider including supportive others in treatment planning.

Outcome expectancies — confidence in the efficacy of a prescribed treatment — also affected self-management practices. Patients who perceived a therapy to be positively affecting their health were more likely to adhere to it. However, many participants did not perceive any short-term benefit from their treatments and therefore found adhering to the chronic regimen to be challenging. This may be reflective of an inadequate understanding of the purpose of a treatment. Fortunately, data on the positive association between adherence and better health outcomes are emerging [9] and may be of value to discuss with patients as a method to increase an individual's outcome expectancies. Moreover, care teams should ensure that patients have appropriate knowledge of the purpose of a therapy to ensure reasonable treatment expectations.

By far the most significant barrier to adhering to the regimen is treatment burden. Not only is there the aggravation of setting up and cleaning the equipment, there is the challenge of fitting the time-consuming regimen into daily life — school, work, relationships, and other responsibilities and interests. Establishing routines and having social support can help, but clearly the regimen interferes with the spontaneity and independence that characterize late adolescence and early adulthood. Weekends and socializing (particularly if it includes alcohol consumption) were regularly pinpointed as triggers for non-adherence. Indeed, a third of participants reported being intentionally non-adherent to rebel against having a routine, permit spontaneity, or reward themselves for high adherence on weekdays.

Taken together, the themes identified in this study may have direct implications for addressing non-adherence in the clinic setting. In addition to the recommendation provided above, a better understanding of the patient's lifestyle, health goals, and routine may help to address issues of treatment burden. Open-ended questions that normalize non-adherence, such as, "You have a very busy life. What parts of your regimen are easy for you to fit in and what parts are more challenging?" are likely to offer opportunities to problem-solve barriers collaboratively rather than queries that produce socially desirable responses such as "Any problems with adhering to the regimen?"

Patients sometimes omit, substitute, or combine therapies in an attempt to reduce treatment burden and these alterations may or may not affect the treatment's therapeutic value. It is therefore incumbent upon the CF clinic team to provide guidance on these regimen modifications beyond stating that the patient should be 100% adherent every day. All patients were able to identify barriers and facilitators of self-management and while most intellectually accepted that they should adhere to their regimen there was clear ambivalence about what that should entail. Therefore, counseling strategies that help resolve ambivalence, such as motivational interviewing, may be more effective than approaches that focus solely on education. Building rapport with patients and creating a non-judgmental atmosphere is a way to obtain an unbiased appraisal of patient self-management strategies.

Our study had several limitations, the vast majority of which are inherent in qualitative studies. For example, we assessed the

barriers and facilitators as reported by patients with CF. However, this study cannot quantify the extent to which these factors correspond with actual behavior and people may not be aware of or unwilling to discuss some factors that influence their behavior. Furthermore, we enrolled a small number of subjects from one clinic limiting the generalizability of our findings. However, relevance, and not generalizability, is the goal of qualitative research. A limitation of this study not specific to qualitative research is the risk of self-selection bias, as individuals had to be reachable by telephone, and had to be healthy and motivated enough to attend the interview. In addition, social desirability may also have played a role; that is, subjects may have answered in a manner to satisfy the researchers. As there is strong social stigma associated with non-adherence, actual adherence may have been over-reported. Despite these limitations qualitative research offers the opportunity to identify novel information that cannot be obtained by quantitative methods. Indeed, we uncovered previously unknown barriers and facilitators of CF self-management that provide essential new knowledge for clinicians.

Treatment non-adherence is common in CF. Before effective counseling interventions can be developed it is critical to understand the barriers to self-management faced by individuals with CF. This qualitative study identified several barriers and facilitators experienced by older adolescents and adults with CF amenable to clinical intervention. Further quantitative research is needed to measure the impact these facilitators and barriers have on actual adherence.

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