



### VOLUME 7 - ISSUE 4

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## Adherence – What You Should be Telling Your Patients

Our guest author is Gregory Sawicki, MD, MPH from Boston Children's Hospital, and Harvard Medical School in Boston, MA.

After participating in this activity, the participant will demonstrate the ability to:

- Identify common barriers to adherence among individuals with cystic fibrosis.
- Describe how nonadherence in cystic fibrosis (CF) can affect health outcomes.
- Discuss strategies to measure and improve adherence among children, adolescents, and adults with cystic fibrosis.

This discussion, offered as a downloadable audio file and companion transcript, covers the important topic of Adherence – What You Should be Telling Your Patients. This program is a follow up to the Volume 7, Issue 3 eCysticFibrosis Review newsletter—Chronic Respiratory Therapies in Cystic Fibrosis: Addressing Adherence

### Unlabeled/Unapproved Uses

He has indicated that there will be no references to the unlabeled or unapproved use of any drugs or products.

### MEET THE AUTHOR



#### Gregory Sawicki, MD, MPH

Director, Cystic Fibrosis Center  
Assistant Professor of Pediatrics  
Harvard Medical School  
Boston, Massachusetts

### Guest Faculty Disclosure

Dr. Sawicki has disclosed that he has served as an advisor for Gilead and has served as a consultant for Genentech and Vertex.

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### PROGRAM DIRECTORS

#### Peter J. Mogayzel, Jr., MD, PhD

Director, Cystic Fibrosis Center  
Professor of Pediatrics  
The Johns Hopkins University  
Baltimore, Maryland

#### Noah Lechtzin, MD

Director, Adult Cystic Fibrosis Program  
Associate Professor of Medicine  
The Johns Hopkins University  
Baltimore, Maryland

**Suzanne Sullivan, RN, BSN**

Senior Clinical Nurse  
Johns Hopkins Hospital  
Baltimore, Maryland

## Podcast Transcript

**BOB BUSKER:** Welcome to this eCysticFibrosis Review podcast.

I'm Bob Busker, managing editor of the program. Our discussion today is a follow-up to our newsletter on Adherence to Chronic Therapies in Cystic Fibrosis. Our guest is that issue's author, Dr. Gregory Sawicki, Director of the Cystic Fibrosis Center at Boston Children's Hospital and Assistant Professor of Pediatrics at Harvard Medical School.

eCysticFibrosis Review is jointly presented by the Johns Hopkins University School of Medicine and the Institute for Johns Hopkins Nursing. This program is supported by educational grants from Gilead Sciences Inc, Vertex Pharmaceuticals Incorporated, AbbVie Inc, and Chiesi USA Inc.

Learning objectives for today's audio program include:

- Identify common barriers to adherence among individuals with cystic fibrosis.
- Describe how nonadherence in cystic fibrosis can affect health outcomes.
- Discuss strategies to measure and improve adherence among children, adolescents, and adults with cystic fibrosis.

Dr. Sawicki has disclosed that he has served as an advisor for Gilead and has served as a consultant for Genentech and Vertex. He has indicated that there will be no references to the unlabeled or unapproved use of any drugs or products.

Dr. Sawicki, thank you for joining us today.

DR. GREGORY SAWICKI: Thanks for having me. I'm looking forward to our conversation.

**MR. BUSKER:** In your newsletter issue doctor, you reviewed some of the newer research describing the connection between therapeutic adherence and clinical outcomes, the differences between actual versus patient-reported rates of adherence, and some of the key barriers that impede patients from taking their medication appropriately. Today, I'd like to focus on how clinicians might be able to apply that information in actual practice. So if you would, please, Dr. Sawicki: start us out with a patient scenario.

DR. SAWICKI: Of course, our first patient scenario is one that is quite common in pediatric CF care. This is a seven 7 year old girl with cystic fibrosis, she also has pancreatic insufficiency. She has a relatively normal lung function, with her FEV<sub>1</sub> 95 percent predicted. Her BMI is at the 25<sup>th</sup> percentile, which is below goal, which is often 50<sup>th</sup> percentile for children her age. But she has been maintaining routine care with the CF center for quite some time since her diagnosis. She's on a routine medication regimen, that of pancreatic enzymes for all of her meals and snacks, multivitamins, and CF-specific vitamins. For respiratory therapy she takes dornase alfa once a day and she also is prescribed a vest for airway clearance, which she is asked to use once a day.

She comes for her routine clinical visit, and her parents report that over the past several months they've noted that she becomes quite picky with her eating. She had been a picky eater when she was younger and this had been worked on with nutritionists and others throughout the years and had improved over time, but over the past several months they've again noticed that she became more picky. She often skipping breakfast. They say they have to get her to school by 7:30 in the morning, and they find that the battle of getting her up in the morning and getting her to take her medications and then eat breakfast is often a difficult one, and so they find that they're skipping breakfast or shortchanging the time she has for breakfast.

But they were also concerned because they pack her lunch every day, and they've noticed that when they have her lunchbox at home after school they've often found her enzymes still in her lunchbox. Before the last year or so, she had always been going to her school nurse to get enzymes, but this year as she was getting older, she was carrying the enzymes and the school was allowing her to administer her enzymes by herself.

Clinically, when you see her, you walk into the room and notice that her weight has decreased by about 5 pounds since her last visit. Upon further questioning, her parents also report that they're struggling with the daily nebulizer therapy. And as I said, she was prescribed dornase alfa once a day, and her parents say that she's often yelling at them and asking why none of her friends have to take any medicines and why does she have to take time every day to do nebulized therapies when none of her friends have to do that at all. And they find that this has become increasingly frustrating for them and their family.

**MR. BUSKER: Let's look at this first from the perspective of barriers. What are the main barriers to adherence raised in this case?**

DR. SAWICKI: Bob, that's a great question and one that is quite important to address when looking at a case such as this. What we see here are several barriers, both to nutritional therapies and to respiratory therapies. We see evidence that she's not taking her pancreatic enzymes during school, we see that there's conflict around routine meals such as breakfast, and we see that there's conflict around taking the daily nebulized therapies.

I think this illustrates several key barriers that have been identified in terms of adherence in chronic CF care. The first is that of time pressures. There is only so much time in any given day for an individual with cystic fibrosis, a child or an older patient, to complete therapies, and also do normal daily routines such as school, spending time with peers, spending time with family, et cetera. And in that limited amount of time the pressure to complete therapies is often a challenge. and particularly when there's a competing priority such as getting to school or spending time with peers, therapies may be the first thing to fall off.

But in addition to those time pressures, there is this sort of child's sense of feeling different. And what we've like uncovered by the discussion that the parents have raised with the clinicians is that the child may feel that they're ostracized by her peers, she feels different, she does not want to take her medications in school that she's embarrassed to take her medications in school. This feeling of differentness is something that ought to be explored further as a potential barrier for this particular girl and her family.

**MR. BUSKER: Overall, how has nonadherence been shown to affect health outcomes in cystic fibrosis? What's the evidence say?**

DR. SAWICKI: That's a really important question and one that has been looked at in several research studies over the past several years. It's not just anecdote that tells us that nonadherence is related to poor outcomes. In this case, clearly we see that there's weight loss at a clinic visit and we see evidence from the history that the girl is not eating well and is not taking her pancreatic enzymes. So there's a clear physiologic link between not adhering to nutritional care and her nutritional health — in fact, her weight loss.

That's one particular example that I think can happen temporally quite quickly. But in the literature what we've seen is that nonadherence over longer periods of time in cystic fibrosis is also linked to other adverse health outcomes. In the newsletter there are several articles that were reviewed that showed that nonadherence to therapies was linked to increased exacerbations, increased rates of hospitalization, increased rates of ER visits, and increased health care costs. In other studies, nonadherence has been linked to lower lung function and other adverse health outcomes.

**MR. BUSKER: Talk to us about strategies to address these adherence challenges. What should clinicians be considering?**

DR. SAWICKI: I think it's really important for clinicians to be addressing adherence with every clinic visit. Even though most of the research that looks at adherence focuses on adolescents and adults with cystic fibrosis, these patterns of adherence are often established earlier in childhood. And so clinicians really need to think about addressing adherence routinely early in childhood, they should normalize discussions of adherence with both parents, caregivers, and children, with the goal of really improving adherence behavior while a child is younger but also instilling in children and in their caregivers the importance of adherence so that when they become adolescents and adults they know that this is something that is expected and important for them to address.

In particular, for this case of a girl who is having challenges with adherence, the first step really is to identify the barriers that are unique to the individual and to the family. Walking in to a patient's room and having a discussion around adherence behaviors without identifying barriers will only set up the clinician for failure, because any solutions that need to be worked on need to be focused on those specific barriers. We've identified the barriers earlier, these barriers of time pressures, these barriers of feeling different — and once you've identified those barriers, you can then work on solutions that are specific to the individual.

In this case, when it comes to time pressures, I think the important message from a clinician could really be to think about daily routines and think about structure. If a child has a school schedule, maybe thinking about how therapies can fit into that schedule as opposed to just making blanket statements you need to take this one medication once a day. Really be specific with the family and say your daughter comes home at 4 pm, why don't we schedule 5 pm as the time for therapies right before dinner. Those are the kind of things that are allowing specificity to a routine that I think a lot of parents do find.

And it's interesting, because there is literature to suggest that improving structure and daily routines may improve adherence. One of the studies that was reviewed in the newsletter actually looked at adherence to therapies for school age children during weekends and weekdays. And this was to respiratory therapies, but it did find that adherence to therapies when monitored with an electronic monitor during weekdays when school was in session was better than during weekends. And we all know that weekends are often more unstructured when it comes to family life, whereas weekdays with school are particularly structured. And so that suggests that identifying a structure and sticking on daily CF therapies into that structure,

may actually help enhance adherence behaviors.

But the second thing here is around this feeling of differentness. And I think in that case, we need to aim our intervention at the child and less so at the parents. Children with cystic fibrosis are often diagnosed early in life, sometimes even as newborns, and so the education around the disease often happens with the parents who are the caregivers for the child. But eventually a child needs to learn why they're supposed to be taking their pancreatic enzymes, why they're supposed to be using their vests, why they're taking nebulized therapies. And we need to normalize this behavior and this education with children to make sure they understand that it is for their health and make a link for them so they understand why they are different than their peers.

And it is very possible that the family has never had that discussion with their child or their daughter; they've just assumed that they've been doing therapies every day like enzymes ever since the child was a baby and they haven't empowered the child to understand. And so we as the clinical care team have an opportunity to really aim our therapy, aim our interventions and educational efforts at children to make sure that they understand why they're taking their therapies.

And finally, CF care is always a multidisciplinary effort. and behavioral interventions, whether coming from social work or from nutritionists, are often employed for nutritional nonadherence. Strategies around eating around the table, family mealtimes, and other strategies for reminders for pancreatic enzymes. So really involving the multidisciplinary team in a situation that was described in this case is quite important, as well.

**MR. BUSKER: Thank you for that case and discussion, doctor. And we'll return with Dr. Gregory Sawicki from Boston Children's Hospital in just a moment.**

MR. BUSKER: This is Bob Busker; I'm the managing editor of eCysticFibrosis Review.

eCysticFibrosis Review is a combination newsletter and podcast program delivered via email to subscribers. Newsletters are published every other month. Each issue reviews the current literature in areas of importance to pulmonologists, gastroenterologists, infectious disease specialists, pediatricians, respiratory therapists, dietitians, nutritionists, nurses, and physical therapists.

Bimonthly podcasts are also available as downloadable transcripts, providing case-based scenarios to help bring that new information into practice in the clinic.

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I'd also like to tell you about the CF Family Day Meeting Builder. This is a one-stop shop to help you create patient and caregiver education and Family Day meetings. To find out more, please visit [www.CFFamilyDay.org](http://www.CFFamilyDay.org).

**MR. BUSKER: Welcome back to this eCysticFibrosis Review podcast. I'm Bob Busker, managing editor of the program. We're here today with Dr. Gregory Sawicki from Boston Children's Hospital and Harvard Medical School. We've been discussing how the challenges of patient nonadherence to CF therapies can be addressed in the clinic. So let me ask you to continue, doctor, and bring us another patient scenario.**

DR. SAWICKI: Thanks, Bob. The second case is one about adolescence. And this is a 16 year old girl with cystic fibrosis, she's delta-F508 heterozygous in terms of her genotype. She also has fairly preserved lung function with a baseline FEV<sub>1</sub> of 89 percent predicted. Her BMI percentile is 40 percent. She has chronic pseudomonas infection. She has had some pulmonary exacerbations, but not for the last two years. Her daily prescribed medications include dornase alfa once a day, hypertonic saline twice a day, inhaled tobramycin twice a day, alternating every other month. She's also on pancreatic enzymes with meals and snacks, multivitamins, and an antacid to be taken once a day.

For airway clearance, she uses her vest occasionally, but her primary form of airway clearance is exercise. And her care team has recommended that she use her vest twice daily on days when she is not exercising. She's a busy high school student, she has quite an active social life, she and is training to secure spots on the swim team and the soccer team, and she will tell you that she has quite an erratic schedule every day in terms of her school, sports practices, and other extracurricular responsibilities.

She comes to see you for a routine clinic visit and she says that she's had some more cough, particularly during soccer practice, and she also noticed some cough at night. You measure her FEV<sub>1</sub> and her FEV<sub>1</sub> is down eight points from her last visit. You talk to her about her medication routine, and she tells you that she is consistently takes her medications. But it's at

that point that her parents interject and say that they don't agree, and they're really worried about her and taking her medications.

They say that they're constantly arguing with her about the need to use her nebulizer, and that their daughter tells them that she feels she doesn't need to take them all the time because she's doing really well and she's really active with sports and in fact, she's the fastest player on the soccer team. Her parents also are quite busy with two younger children, and they do tell you that they do rely on their teenage daughter to take her medications and they can't always be there to remind her, and so they're starting to feel quite guilty.

**MR. BUSKER: So a teenage girl, involved in sports, busy social life, with a heavy but not atypical treatment burden. Summarize it for us, if you would, Dr. Sawicki: what are the key clinical concerns related to treatment adherence that are raised by this case?**

DR. SAWICKI: In this case the key concerns are that you have an adolescent female who is coming to clinic with a declining lung function below her baseline, and increasing symptoms. There is evidence now that she may not be taking her medications on a routine basis. There's also evidence that there's conflict with her parents around her daily routines. Both she and her parents seem to be expressing some competing priorities, as well, that may be getting in the way of her ability to take her routine therapies. All of these are things that should be explored by clinicians when approaching this patient scenario.

**MR. BUSKER: The main barriers to adherence during adolescence — overview those for us if you would please, doctor.**

DR. SAWICKI: I think we've realized that as patients with cystic fibrosis come into their adolescence, we start seeing some more unique barriers that may not be present in terms of earlier childhood. Some of the themes we see are consistent with what was seen in the first case we discussed — mainly that of time pressure and the ability to fit therapies in during a quite busy day. But in this case, as is the case with many adolescents, there's a much higher treatment complexity that is recommended than maybe seen in earlier childhood.

In our case our patient is prescribed not just the nutritional therapies, but several nebulized therapies twice daily. She's on inhaled antibiotics twice daily, alternating every other month. She is recommended to do exercise but also a vest for airway clearance. All of these things add up in terms of time, and if you look at sort of the amount of time that's required for each nebulized therapy, it can be upwards of 90 minutes to 120 minutes a day that a clinician is prescribed medications, just by looking at the recommended dosages and intervals. And thinking about fitting in two hours of therapy a day, on top of a busy social life, school, homework, sports practice, et cetera, is quite daunting for anyone, and particularly daunting for an adolescent.

We also see the barriers of lack of consistent schedules. So the teenage girl noted that she has an erratic schedule; she doesn't do the same thing every day, so that makes structuring routine much more challenging.

We see this struggle between caregivers and adolescents that is a normal developmental milestone for adolescents, namely the desire for independence. As adolescents grow older, they want to be independent from their families and their parents, they want to spend more time with their peers, they want to do more care on their own. And, in fact, this family is trying to give their daughter some space and they say they really don't have the time to micromanage her daily routines. And so even though there's a desire for independence, perhaps that independence is not being fully supported.

And finally, as with most adolescents, there's a sense of invulnerability, not doing something today has no immediate consequences. So this girl says I don't take my therapies for a day, I am still the fastest runner on the soccer team. She doesn't see that perhaps there are longer-term consequences to not taking her therapies and she is really focusing on the short-term consequences, which to her appear quite minimal.

**MR. BUSKER: How would you recommend health care teams address nonadherence in cases like this?**

DR. SAWICKI: I think this type of case is probably the most common case of nonadherence that clinicians in pediatric CF programs face. I think the most important thing is to open a line of communication with both the adolescent and their caregivers. It is important, just as in the first case that we discussed, to assess individual barriers, because again, particularly for a teenager. Coming in with a generic educational program or a generic statement around you have to take your medications is probably going to fall on deaf ears. But really understanding what it is that are the priorities for each individual patient and what are the barriers that get in the way of taking medications, that's going to be the recipe for success in terms of interventions.

That will allow a clinician to customize a treatment plan and think about treatment complexity and think about treatment burden with the caregivers and with the adolescent, themselves. If the schedule is erratic, for instance, maybe think about what does twice daily really mean: does twice daily really have to be morning and night, or can it be after school sometime and before bed? And so these are the kinds of discussions that really need to be specified around someone's individual

barriers and routines.

In addition, it is important for clinicians to empower adolescents to take ownership of their care. We need to make sure they understand why they're taking their medications, why they're prescribed, and think about the long-term consequences of nonadherence. Even though I said that adolescents think a lot in the moment and have a sense of invulnerability, I think we, as a health care team, need to talk to them about what it means to grow older with cystic fibrosis, what it means to become an adult with cystic fibrosis, and how we share the same goal of maintaining health and improving health throughout a longer period of time.

And that may involve discussions around ways to monitor adherence. Think about reminders. Adolescents like technology, so think about whether they could use apps on their smartphones or other devices to help with their therapies. Or how they might be able to build their own schedules. Give adolescents a sense of ownership around their schedules. Try to reduce the conflict between adolescents and parents around that sense of independence and be the mediator.

I think our role as health care providers is often to take viewpoints from parents viewpoints from adolescents and try to figure out where there might be common ground and where might an appropriate way to think about improving behaviors around adherence. And none of these need to be interventions that need to be tried for long periods of time. What I often recommend to my patients is try something for a week, try something for a month, see how it goes, and if that doesn't work, let's talk about it next time. Let's schedule a time where we can call and have a discussion about what may be working and what's not. Be creative, be open, and keep those communication lines open.

**MR. BUSKER: Thank you for that case and discussion. If you would, please bring us one more patient.**

DR. SAWICKI: So the final patient we'll discuss is that of an adult with cystic fibrosis. And this is a 28 year old male who has cystic fibrosis, his genotype is delta-F508 and G551D. He has relatively mild lung disease with a baseline FEV<sub>1</sub> of 70 percent predicted. He has chronic pseudomonas infection and his BMI is 22, which is about average.

His prescribed CF medications include ivacaftor taken orally twice daily, dornase alfa once daily. He's also recommended to be on a continuous alternating regimen of inhaled antibiotics, alternating monthly between inhaled tobramycin and inhaled aztreonam. He's on pancreatic enzymes, multivitamins, nutritional supplements, and oral azithromycin three times per week.

He's been on this regimen now for several years, but recently began a new job that requires significant travel. He also was married about four years ago but also at your routine clinic visit tells you that his spouse has moved out of the house and they're going through some marital difficulties.

When you see him in clinic you note that he spent the last three years without an exacerbation, but over the past several months he's now had two exacerbations. The last time you saw him his FEV<sub>1</sub> had declined 10 points and you were treating him with oral antibiotics. Despite that, he continued to report increased respiratory symptoms and also reports some difficulty sleeping.

His current FEV<sub>1</sub> at your visit is 50 percent predicted, and he is now also noted to have a five pound weight loss. When talking to him about why this may be the case, despite some of these more recent therapies you've initiated such as antibiotics, he tells you that with his new job and the stresses at home, he has stopped most of his daily nebulized therapies.

You have an electronic medical record review that looks at his pharmacy refill data and you also see that no medications have been picked up for the past three months.

**MR. BUSKER: So here we have an adult patient. He's under stress at work and at home, and he's decided to self-discontinue his therapies. Talk to us about the challenges to adherence that this adult with CF illustrate.**

DR. SAWICKI: We spent some time earlier in the podcast talking about challenges for adolescents and children with cystic fibrosis when it comes to treatment adherence, and in this case I think we've, I've uncovered some challenges that are unique to older adults.

Earlier I had mentioned that treatment complexity was quite a barrier to adherence for adolescents, and it remains so for adults. And this particular patient also has quite a burdensome and complex regimen that would require a lot of time; and in the context of a job requiring travel, it is easy to see how those treatments would be quite burdensome.

But, in addition, he has now been on these therapies probably for well over a decade and it's possible that he has identified, if not consciously, subconsciously, some form of treatment fatigue. Having to do these therapies day in and day out, year after year, can certainly lead to a burdensome approach to therapy that an individual with CF may perceive.

We see here a lot of stressors: family stressors, employment stressors, marital stressors, and particularly in this case it leads

us as clinicians to think are there some mental health concerns that might be leading to challenges with adherence.

And finally, with his new job, another challenge may, in fact, be disclosure. We talked about disclosure with the first case and the child at school, but in this case, has there been a challenge with disclosure to his new employer around cystic fibrosis. If he's being asked to travel so much, perhaps he hasn't told them that he has a chronic disease and may need to be hospitalized, because he's afraid of losing health insurance or losing his job quite frankly.

**MR. BUSKER: You mentioned mental health issues. Let me ask you to expand on that point. What's known about the effect of mental health issues on adherence in the CF population?**

DR. SAWICKI: I think that's a very important question and one that is getting increasing attention among CF care centers. A few years ago there was an international epidemiologic study, called the TIDE study, which looked at the prevalence of depression and anxiety using structured questionnaires in individuals with cystic fibrosis in many different countries. And this study was quite important because it identified that almost across the board there was a higher prevalence of both anxiety and depression in individuals with cystic fibrosis.

In the current newsletter, one of the papers that is reviewed looks at the impact of depression on adherence behaviors. And this was a study that was done at one center and looked at adults identified that depression was a key risk factor for worse adherence. In this particular study, those individuals who identified more depressive symptoms had worse adherence as measured by their prescription refills. They also found those with higher depression had what they called "less positive medication beliefs." So these were individuals that felt less strongly about the importance of their medications and that somehow there seemed to be a link between depression and this sense of medications not perhaps working as well as they should. And so it was a study where they identified a potential mediating mechanism between depression and poor adherence.

As a result of this kind of study and the work that was done in the epidemiologic study identifying high rates of depression and anxiety in cystic fibrosis, in the past year the Cystic Fibrosis Foundation has issued guidelines that CF care centers implement routine mental health screening for both anxiety and depression on a yearly basis with all adults, as well as and adolescents with cystic fibrosis. And it is possible that identifying these mental health comorbidities through such screening efforts may allow for interventions, not just to improve mental health, but to improve adherence behaviors longer term.

**MR. BUSKER: Now this patient — as you noted, he's genotype F508-del and G551D, so not surprisingly he's on the CFTR modulator ivacaftor. What data do we have on adherence to these relatively new CFTR modifying medications?**

DR. SAWICKI: Bob, as you note, these medications such as ivacaftor are part of a new class of medications called CFTR modulators, which are oral medications which are aimed at the basic defect causing cystic fibrosis. We don't have a lot of data on adherence to these medications, but there is one study that was reviewed in the newsletter that sheds a light on adherence behaviors for ivacaftor.

When ivacaftor was introduced into the clinical market, it was thought that adherence to this medication would be quite high, particularly because it's an oral medication doesn't take a lot of time to fill and has quite good clinical benefits. But the study that was reviewed in the newsletter was done by Chris Siracusa and colleagues. It was a small study, only 12 patients were enrolled, and what they did in this study was give patients something called a MEMSCAP, which is an electronic monitor for oral medications that documented how frequently an oral medication was taken. And also looked at prescription refills for ivacaftor in this small group of patients.

And what they found was quite disheartening: overall adherence rates were 61% percent by electronic monitor, which means that doses were being missed on a regular basis by almost every patient. They also identified that even though patients were self-reporting that they were taking all of their medications, when looking at monitored data and looking at refill data, there was really no good correlation.

So this study, even though it's a small group of patients, suggests that adherence to ivacaftor suffers from similar deficiencies as other CF medications. And really makes us think, as clinicians, that we have to think about monitoring adherence to oral medications such as ivacaftor, in addition to some of the more burdensome medications that we've addressed earlier.

**MR. BUSKER: What about strategies, doctor? What strategies can you recommend for clinicians to help improve adherence among their adult patients?**

DR. SAWICKI: I think the strategies for adult patients really mirror quite closely the strategies that we've talked about earlier with respect to adolescents and younger children. The first is to identify the unique barriers that an individual adult with CF may face. The second is to think about reducing treatment complexity whenever possible, looking at the regimen in total and seeing where changes can be made to reduce the overall treatment burden. The third, as we talked about earlier, is to address any mental health concerns and think about the link between mental health concerns and nonadherence.

And finally, and I think most importantly, think about an approach to shared decision making, where an adult with CF is

brought to the table as a partner in terms of their CF care planning, and not just in a paternalistic approach where a clinician makes a recommendation and expects an adult to follow. Using these kinds of shared decision making behaviors and techniques as a clinician will, I think, allow for more open conversation with adults with CF, and perhaps allow for creative problem solving that could lead to better, improved adherence behaviors.

**MR. BUSKER: Dr. Sawicki, thank you for sharing your insights in today's discussion. I'd like to wrap things up now by reviewing what we've talked about in light of our learning objectives. So to begin: the common barriers to adherence among individuals with cystic fibrosis.**

DR. SAWICKI: There are several common barriers to adherence that span from childhood to adulthood in cystic fibrosis. The first is that of treatment complexity and treatment burden. Clinicians ask patients with cystic fibrosis to take a lot of different therapies — nutritional therapies, respiratory therapies and others — and this complexity can lead to quite a challenge for most individuals.

The second is that of time pressure and competing priorities. Individuals with cystic fibrosis are asked not just to take their therapies every day, but they're asked to live full, robust lives, and those competing priorities can often get in the way of completing daily therapies.

The third is lack of structure. Lack of structure often causes challenges such as forgetting therapies, skipping therapies, or missing therapies.

And the fourth as discussed earlier, is mental health challenges. They should be assessed on a regular basis because the more we identify them, the more likely we are to intervene.

**MR. BUSKER: And our second objective: how does nonadherence to cystic fibrosis therapies affect health outcomes?**

DR. SAWICKI: As we've learned over the past several years, nonadherence to all types of cystic fibrosis therapies is quite suboptimal. We've also learned that nonadherence leads to worse health outcomes. What we know is that nonadherence can lead to worse nutritional outcomes, increased rates of pulmonary exacerbation, increased hospitalization, increased acute care visits, and decreased lung function. Finally, we've identified that nonadherence can lead to increased health care costs.

All of these adverse impacts of nonadherence are quite important to address, both from an individual patient level, as well as a health system level.

**MR. BUSKER: And finally: strategies to measure and improve adherence among children, adolescents, and adults with cystic fibrosis.**

DR. SAWICKI: Any effort to improve adherence among individuals with cystic fibrosis has to start with identifying unique barriers. Without identifying barriers that are unique to an individual, interventions will most likely not be successful. In addition, clinicians should think about strategies to more accurately monitor and measure adherence, utilizing things such as pharmacy refill data or electronic monitoring of nebulizers or other devices.

Just getting that data is a start, but that data also has to lead to better conversations. And the best strategy to improve adherence is really to improve conversations between clinicians and individuals with cystic fibrosis. And particularly focus on shared decision making, problem solving, and other techniques such as motivational interviewing. These techniques may lead to developing shared care plans between individuals with cystic fibrosis, their caregivers, and their care teams with the goal of improving adherence over a longer period of time.

**MR. BUSKER: Dr. Gregory Sawicki — from Boston Children's Hospital and the Harvard School of Medicine — thank you for participating in this eCysticFibrosis Review Podcast.**

DR. SAWICKI: Thank you, Bob, for this great discussion. It's been a real pleasure talking with you today.

MR. BUSKER: To receive CME credit for this activity, please take the post-test at [www.ecysticfibrosisreview.org/test](http://www.ecysticfibrosisreview.org/test).

This podcast is presented in conjunction with eCysticFibrosis Review, a peer-reviewed CME/CE credit publication that is emailed monthly to clinicians treating patients with cystic fibrosis.

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