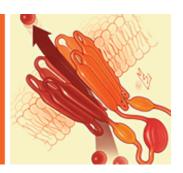


eCysticFibrosis Review Podcast Issue

Presented by the Johns Hopkins University School of Medicine and the Institute for Johns Hopkins Nursing

Supported by an educational grant from Aptalis Pharma, Inc. Gilead Sciences Inc., and Vertex Pharmaceuticals



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VOLUME 4 — ISSUE 2: TRANSCRIPT

Featured Cases: Adherence to Chronic Inhaled Therapies

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

- Discuss the impact of nonadherence on health outcomes, including pulmonary exacerbations and lung function,
- Describe the challenges of accurately assessing for medication nonadherence and,
- Identify risk factors for nonadherence and strategies for supporting patients to improve adherence.

This audio activity has been developed for clinicians caring for patients with issues related to cystic fibrosis. You can also read the companion newsletter. In this issue: we review the most recent data on the importance of adherence in maintaining good health; the challenges and best practices for assessing patient adherence in the clinic setting; the most common barriers to adherence that adolescents and young adults face; and the current data on the efficacy of self-management interventions to improved knowledge, adherence and health outcomes; and we look at the feasibility and acceptability of a new cellphone-based adherence intervention under development.

The Johns Hopkins University School of Medicine takes responsibility for the content, quality, and scientific integrity of this CME activity.

MEET THE AUTHOR



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Unlabeled/Unapproved Uses

The author has indicated that there will be no references to unlabeled or unapproved uses of drugs or products.

Guest Faculty Disclosure

The author has indicated that she has served as a consultant for Gilead Sciences, Inc. and Novartis, Inc.

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J. PROGRAM BEGINS BELOW

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This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education through the joint sponsorship of the Johns Hopkins University School of Medicine and the Institute for Johns Hopkins Nursing. The Johns Hopkins University School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.

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Podcast: This 0.5 contact hour Educational Activity is provided by the Institute for Johns Hopkins Nursing. Each Newsletter carries a maximum of 1 contact hours or a total of 7 contact hours for the seven newsletters in this program.

Respiratory Therapists

For United States: <u>Visit this page</u> to confirm that your state will accept the CE Credits gained through this program.

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There are no prerequisites to participate in the activity.

LAUNCH DATE

This program launched on February 28, 2013, and is published monthly; activities expire two years from the date of publication.

STATEMENT OF NEED

Based on a review of the current literature, including national and regional measures, detailed conversations with expert educators at Johns Hopkins, and a survey of potential program participants, this program will address the following core patient care gaps:

Disease-Modifying Therapies

- Clinicians may be unfamiliar with recently introduced disease-modifying therapies and how they are altering the therapeutic landscape for patients with cystic fibrosis.
- Clinicians may be uncertain how to integrate genotyping into therapeutic decisions and how to communicate with patients and families about the relationship between genotype and therapy

Nutrition

- Many clinicians lack strategies to persuade patients to adhere to CF nutritional requirements, resulting in low body weight and nutritional failure in patients with cystic fibrosis.
- Many clinicians remain uncertain how to optimize pancreatic function in patients with cystic fibrosis.

Treating CF Patients with Inhaled Antibiotics

- Clinicians lack knowledge about the use of existing and emerging inhaled ABX to treat chronic pulmonary infections.
- Clinicians need more information to make informed decisions about the use of inhaled ABX in combination.
- Clinicians lack information about best practices for scheduling ABX therapy to suppress chronic airway infections.
- Common clinician assumptions about treating pulmonary exacerbations lack supporting evidence.
- CF clinicians are not aware of and/or are not actively advocating inhaled ABX patient-adherence strategies.

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There are no fees or prerequisites for this activity.

Estimated time to complete activity: 30 minutes

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No other planners have indicated that they have any financial interests or relationships with a commercial entity.

STATEMENT OF RESPONSIBILITY

The Johns Hopkins University School of Medicine takes responsibility for the content, quality and scientific integrity of this CME activity.

INTENDED AUDIENCE

This activity has been developed for pulmonologists, pediatric pulmonologists, gastroenterologists, pediatricians, infectious disease specialists, respiratory therapists, dieticians, nutritionists, nurses, and physical therapists.

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PC: Internet Explorer (v6 or greater), or Firefox MAC: Safari

eCYSTICFIBROSIS REVIEW PODCAST TRANSCRIPT

MR. BOB BUSKER: Welcome to this *e*CysticFibrosis Review podcast.

eCysticFibrosis Review is presented by the Johns Hopkins University School of Medicine and the Institute for Johns Hopkins Nursing. This program is supported by educational grants from Aptalis Pharma, Inc; Gilead Sciences Inc.; and Vertex Pharmaceuticals.

Today's program is a companion piece to our eCysticFibrosis Review newsletter topic, *Adherence to Chronic Inhaled Therapies*.

Our guest is that issue's author, Dr. Kristin Riekert from the Johns Hopkins University School of Medicine.

This activity has been developed for pulmonologists, pediatric pulmonologists, gastroenterologists, pediatricians, infectious disease specialists, respiratory therapists, dietitians, nutritionists, pharmacists, nurses and nurse practitioners, physical therapists, and others involved in the care of patients with cystic fibrosis.

The Accreditation and Credit Designation Statements can be found at the end of this podcast. For additional information about accreditation, Hopkins policies, and expiration dates and to take the post-test to receive credit online, please go to our website newsletter archive, www.eCysticFibrosisReview.org, and click the Volume 4, Issue 2 podcast link.

Learning objectives for this audio program are that after participating in this activity, participants will demonstrate the ability to:

- Identify best practices for determining which patients are nonadherent,
- Identify risk factors for nonadherence, and,
- Describe various counseling strategies to address nonadherence.

I'm Bob Busker, managing editor of eCysticFibrosis Review. On the phone we have with us Dr. Kristin A. Riekert, Associate Professor & Co-Director of the Johns Hopkins Adherence Research Center at The Johns Hopkins University School of Medicine.

Dr. Kristin Riekert has disclosed that she has served as a consultant for Gilead Sciences, Inc and Novartis, Inc. She has indicated that there will be no reference to unlabeled or unapproved uses of drugs or products in her presentation today.

Dr. Riekert, welcome to this eCysticFibrosis Review Podcast.

DR. **KRISTIN RIEKERT**: Hi, Bob, it's a pleasure to be here with you today.

MR. BUSKER: In your newsletter issue, you reviewed some of the recent data investigating the barriers to adherence to chronic cystic fibrosis medications, the challenges clinicians face in assessing patient adherence, and best practices for developing adherence interventions. I'd like to see how that data can be applied in practice. Please start by describing a patient for us.

DR. RIEKERT: Our first patient is a 30-year-old male having a second pulmonary exacerbation in the past year after having had only three previously exacerbations in his lifetime, all when he was a teenager or in college. His medication regimen includes pancreatic enzymes, azithromycin, dornase alfa, and inhaled tobramycin. Aztreonam lysine was added about 10 months ago. He is a successful salesperson who was just promoted to a position with good health benefits. He regularly attends clinic appointments and is knowledgeable about CF and his regimen. While he admits it's challenging to follow his regimen, he finds keeping a strict routine helpful.

MR. BUSKER: He goes to the clinic, he's knowledgeable about his disease, and until recently he's had very few exacerbations — this guy seems pretty together. Why would you consider nonadherence a risk factor for the increase in his exacerbations?

DR. RIEKERT: I see several red flags. The first is that his regimen became more complex a few months ago, and when there is more complexity there is greater burden, and there's a change in your routine. He has also recently had a change in his job, which also changes routines and expectations at work. So his routines might be affected, and that is commonly identified as a barrier. We also know that nonadherence is a significant predictor of the need for IV antibiotics for a pulmonary exacerbation. So given that he's had several exacerbations in the past year

and that isn't his norm, it should be put on the list of rule-outs. It might not be the cause, but it could be contributing.

Finally, he says it's challenging to follow the routine, and that opens the door for a conversation about adherence, because we know when someone says they're having a hard time, there's usually a significant barrier that has to be worked on.

MR. BUSKER: As you just said, his regimen became more complex. You're referring to the addition of the aztreonam lysine. How much of an effect would you expect that to have on his adherence?

DR. RIEKERT: Any time you add a new medication, it changes the regimen and its burden. Aztreonam lysine, while it's every other month, it is also a medication that has to be done three times a day and that can be challenging to integrate into one's routine. For example, this patient is a salesperson, and if he has to make sales calls in the middle of the day he might not be able to get that middle dose in.

MR. BUSKER: What should the care team do to assess his level of adherence?

DR. RIEKERT: First, it is very tempting to assume that this patient is highly adherent because he has good health benefits so money shouldn't be an issue, he is well-educated, he's organized and personable which is a characteristic of a salesperson, he keeps his clinic appointments, and he is very knowledgeable about CF.

The challenge is that just because you have all these positive things doesn't mean you're assured that someone is adherent. So we cannot assume his adherence is good, and in fact, clinician impression about adherence is usually no better than chance. As clinicians, we're not very good at figuring out which person is taking their medications and which ones aren't.

My goal as a psychologist is to always try and get an objective measure, so I like to use either pharmacy records to calculate an estimate of adherence, or preferably use electronic monitors to get a date and time stamp of when people are using, and perhaps whether they're using it correctly. In some parts of Europe they are now using electronic monitors to

follow nebulizer adherence. Unfortunately, those aren't available in the United States.

MR. BUSKER: Since pharmacy records and electronic monitoring are not available in the US, what can the care team do to improve the accuracy of either patient self-reporting or clinician assessment for adherence?

DR. RIEKERT: In this instance, since the patient opens the door to the fact that adherence is challenging, there is a great opportunity to discuss it with him. If a patient is 100% adamant that they do all their medications and never miss, it is hard to have that conversation. And, unfortunately, when someone says they're doing everything, when you compare it to objective data they may be doing nothing to everything, so that is not useful information.

But in this instance, our patient did say he's having a challenge, so we would want to follow that up with an open-ended, nonjudgmental question. So we don't want to make it feel that if he admits nonadherence he'll be punished for that. We need to normalize nonadherence because we know everybody has struggles following a very complex regimen.

All these things will elicit more accurate reporting, and as long as some nonadherence is acknowledged, we can go to the next step of identifying barriers. A key point, though is when someone says, for example, I take half my medications, they're probably taking half or less. No one is every going to say they do less of a good thing, so no one says they exercise less than they do, no one says they floss their teeth less than they do, we always give ourselves maximal credit for positive health behaviors. So we need to acknowledge that if someone says I do half, it is probably half or less.

But clinically when we are trying to counsel them around barriers, it doesn't matter, the exact amount, just that there is an openness to discussing the barriers.

MR. BUSKER: Talking specifically about this patient, what barriers would you anticipate and how would you address them?

DR. RIEKERT: This patient has some pretty obvious barriers of change in routine, either the change in the regimen a few months ago or the change in job

requirements, so possibly he has more responsibilities at work. All those things are known barriers of sticking to a treatment plan.

I'd have him go through his daily routine, what do you do in the morning, etc, and we might find that he used to exercise after work but now he's at work so late or traveling and can't exercise, and that used to be his form of airway clearance. Now he doesn't do that, and because he's feeling so poorly, he's not getting to the gym, he might also believe that his regimen is all or nothing.

We often train our patients that they should do their medications and their airway clearance in a particular order. While that is very important, it also sometimes sets up the expectation that if you can't do one part of that routine, you should do none of it. We need to troubleshoot with him that if he's short on time, what's the most important thing to fit in, if he can't do it all what should we try to do.

But before we even get into that problem solving, we need to address whether there have been any changes in his health beliefs. Health beliefs affect what we anticipate we're going to do and whether it's important to do it. For example, we often hear that once patients get into their 30s they start thinking about their own mortality because they know the median lifespan is about 37. Some people misunderstand that statistic and think they're going to die by the time they're 37, so fatalism sets in. They have the idea that there's nothing they can do, the outcome is sort of predetermined. For him to have a sudden increase in exacerbations when he's turned 30, he might see it as the beginning of the end and so what's the point of sticking to his treatments.

Conversely, he might not think these medications are working for him anymore, so we need to help provide him evidence for that. We want to make sure we understand the patient's beliefs before we jump into the problem solving. But once we decide that beliefs are an issue, we work on how to create a new routine we can do now. Sometimes with certain people who work different shifts, we have to shift their morning dose to later in the day and their evening dose even later to make sure we can get that to all fit in and more important, how to adapt if they run out of time. If it's not possible to do it, what's the next best thing to get done.

MR. BUSKER: Dr. Riekert, thank you for that case and discussion. Please bring us another patient now.

DR. RIEKERT: Our second patient is a 14-year-old girl. Today her FEV1 predicted was 64% and her BMI percentile was 20. This is down from one year ago when they were 73% predicted and 35. Her parents divorced about two years ago, but both attend clinic visits without signs of overt conflict, although sometimes you feel there's some tension in the room.

The mother reports that the patient has become the typical teenager, staying in her room, sleeping most of the day, and not interested in activities that she used to love. The patient spends most of the visit on her smart phone. The family has been very open in the past few years about their troubles doing treatment because they're busy or forget. You review with them why it's important to do each aspect of the regimen, suggest several reminder strategies, including apps for the smart phone, and make sure there are no financial barriers to obtaining the medication. However, you've given this speech so many times you are sure the family could recite it verbatim. While the family says they know adherence is important and that they'll try harder, you're not optimistic that anything will change.

MR. BUSKER: This is a very complicated and challenging case. Where do you start with this patient?

DR. RIEKERT: There is a lot going on with this family, but unfortunately, it's a typical scenario. Most families have more than one barrier to adherence and a lot going on. It's also typical that the care team feels very ineffective when it comes to adherence counseling, so this is a very, very typical case.

With this case I would start with a depression assessment. I'm very concerned about this patient because even though teenagers do sleep more and change their interests in activities, this patient's reported as sleeping most of the day and not interested in any activities she used to love. I am highly concerned that she might be depressed. We care about depression because depression, in and of itself, is a bad thing that affects your quality of life and your mental health, and it also doubles the likelihood that someone will be nonadherent. That could be a contributing factor to her nonadherence.

If she turns out to be depressed, I would recommend a counseling referral, either alone or in combination with an antidepressant, because so many other factors are present that are quite complex. There may or may not be some family conflict and challenges in adjusting to her parents' divorce. The nonadherence has been long-term now, so what's been done in the clinic hasn't been enough to get them over that hump.

MR. BUSKER: You mentioned giving the family the "adherence speech" about the importance of medication adherence so often that they could probably recite it back to you verbatim. Most clinicians, we can assume, have their own version of this speech, and I think we can also assume that in most cases it's pretty comprehensive. Why isn't "the speech" working?

DR. RIEKERT: The content is good but it doesn't work because it's not tailored to the family's specific barriers, and by now they've heard it so many times they've just tuned out the clinician. In this instance they talk a lot about forgetting, and forgetting is a easy answer, but unless there are cognitive deficits or dementia, it's usually just the tip of the iceberg and requires a lot of follow-up questions. They don't have memory problems, so just recommending a reminder system on your phone is not going to solve the problem.

In this case I would ask them about their typical morning and their typical evening, and on days they forget, what else is going on. I could imagine that things they might disclose could be that they don't have a second vest or medications and the nebulizer for the dad's house. So if the daughter is now going to the father's home for joint custody straight from school, she's not carrying those things to school because that would be embarrassing and cumbersome. So the equipment not being at the second home might be a challenge.

Parent/child conflict always affects the extent to which people can follow the regimen; they just don't want to have another battle. And as we talked about before, depression coming up, so if she is definitely sleeping more, there is certainly less time to be following a treatment regimen.

Addressing these barriers requires more than an app and a little bit of knowledge of why it's important to involve some in-depth counseling and understanding. That might require a referral out because it's just too much to do in a clinic visit.

MR. BUSKER: You're right, of course, that in some cases, referral to outside counseling may be needed. But that brings in a lot of variables that go beyond the scope of today's discussion. So rather than get into that, I'd like to keep the focus on what the care team can do. I want to ask you about education: what doesn't the family understand about how important it is to keep up with all of the treatments, and what can the care team do about it?

DR. RIEKERT: What we know from many illnesses and CF included, is that knowledge is necessary but not sufficient to be adherent. Our care teams must keep providing that information and education, but they might have to do some more. When we have interventions, we regularly find that we can increase people's knowledge, but that doesn't always translate into a change in behavior. We know that interventions that are most effective in changing behavior are multicomponent. They include providing education but also target other barriers, such as problem solving and motivational interviewing to try to get people's intrinsic, internal reasons for why they want to be adherent because it's consistent with their other life goals. We want to enhance parenting skills because sometimes the issue is just general parenting skills that could be improved to support adherence, and offering social support to the patient and to the family.

MR. BUSKER: And we'll return, with Dr. Kristin Riekert, in just a moment.

MS. MEGAN RAMSEY: Hello my name is Meghan Ramsay, Nurse Practioner and Adult Clinical Coordinator for the Johns Hopkins Cystic Fibrosis Program at The Johns Hopkins University School of Medicine.

I am one of the program directors of eCysticFibrosis Review these podcast programs will be provided on a regular basis to enable you to reiceve additional current concise peer reviewed information through podcasting, a medium that is gaining wide acceptance throughout the medical community. In fact today there are over 5,000 medical podcasts.

To receive credit for this educational activity and to review Hopkins' policies please go to our website at <u>www.ecysticfibrosisreview.org</u>. This podcast is part of eCysticFibrosis Review a bi-monthly email delivered program available by subscribing. Each issue reviews a current literature on focus topics important to clinicians caring for patients with Cystic Fibrosis.

Continuing education credit for each newsletter and each podcast is provided by the Johns Hopkins University School of Medicine for physicians and by the Institute for Johns Hopkins Nursing for nurses. Subscription to eCysticFibrosis Review is provided without charge and nearly a thousand of our colleagues have already become subscribers. The topic focus literature reviews help them keep up-to-date on issues critical to maintaining the quality of care for their patients.

For more information to register to receive eCysticFibrosis Review without charge and to access back issues please go to www.ecysticfibrosisreview.org.

MR. BUSKER: Welcome back to this eCysticFibrosis Review podcast. I'm Bob Busker, managing editor of the program. Our guest is Dr. Kristin Riekert, Co-Director of the Johns Hopkins Adherence Research Center. Our topic is Adherence to Chronic Inhaled Therapies.

We've been discussing how the new information Dr. Riekert presented in her newsletter issue can be applied in clinical practice, so please bring us another patient.

DR. RIEKERT: Our final patient is an 18-year-old male who recently graduated from high school and will be moving to college about three hours from home in approximately two months. His FEV1 predicted was 80% and BMI percentile was 44 three months ago. One year ago, they were 85% predicted and 51. He averages about one pulmonary exacerbation a year. He's been prescribed pulmonary medications that include dornase alfa, azithromycin, and inhaled tobramycin.

The team's perception at a preclinic meeting is that his adherence is pretty good. Today a care team member suggests adding hypertonic saline to the regimen.

MR. BUSKER: I want to ask you a couple of questions about this case. You said "the team's perception is that his adherence is pretty good." That raised a red flag for

me. based on things you've said earlier today, and research that was described in your newsletter issue. So my first question is, how much value would you place on the team's perception of his adherence?

DR. RIEKERT: As we discussed in the first case, it's pretty hazardous to use clinician estimate of adherence, because it is not always accurate. To expand on that, in the Daniels¹ paper as discussed in the newsletter, they showed some fascinating data that showed a huge scatter plot that none of the care team providers — and they looked at every single one, physicians, respiratory therapists, dietitians, nurses — none of them were accurate in identifying whether specific patients were adherent or nonadherent. This is a big concern because if you think someone is adherent and they're not, you may be inadvertently reinforcing their nonadherence.

For example, if you say, Joe, you've done a great job sticking to your regimen, it's helping you, because Joe's been fairly healthy and he's doing nothing, so he'll continue to do nothing and think maybe this medication just isn't important for me. Conversely, if you have someone who is doing their best to reach 90% percent adherence, close to 100% some weeks, and you perceive that patient as being nonadherent, perhaps because they're having some health problem, and you say, you have to do a better job, you really have to get more of these medicines in because it's important for your health, and they know they're doing just about everything possible, they will also become less adherent because, again, the perception will be this must not make a difference to my health. So it is very important not to make assumptions but to try to get some objective data and patient perception of what's going on.

MR. BUSKER: I also want to ask you about lifestyle change. I think this is something all clinicians have seen — that one of the biggest challenges to continued adherence is when a patient undergoes a major change in their life. This patient is getting ready to go away to college. How would you expect that change is going to impact his adherence?

DR. **RIEKERT**: College has a huge impact on everyone's lifestyle, but particularly when you have a chronic illness. There are new routines, new schedules. You are not on the same schedule every day so there is irregularity in your academic life and also in your social life. There's a lot more socializing

with peers, sometimes that translates into late nights of drinking and as one patient once told me, after I come in from drinking I don't plan to brush my teeth, much less do my medications.

There is also change in social support. When you move away from home, you don't have your parents there to help scaffold you and support you, and even if they're just reminding you or making sure you don't run out of medication, parents tend to be very involved in the patient's daily care and that is removed. So even if mom's texting and phoning, it is still enough removed that it doesn't have the same impact it has at home.

On top of that, you have disclosure of your diagnosis. Because you are coughing all the time you don't always want people to know that you have an illness; you want to be treated as the person you are, not a person with an illness. And when you're at home, people have just known your whole life that you have CF, but when you get to college it's an opportunity to not be the person with CF, and so sometimes you don't tell people your diagnosis. And if you're not telling them you have CF, you are certainly not going to want to take your enzymes in front of them when you're having a meal together and you're not going to want to do your treatments in front of them.

What we often recommend as a care team is, well, it's a pretty simple fix, just get the single, don't have a roommate. But as another patient told me, who wants to be the dork with the single with all this noise and coughing coming from out of the room. So they want a normal college life and that means roommates, but sometimes it's embarrassing to do therapies in front of roommates, or if you're fine doing it in front of your roommate, you don't necessarily want to do it in front of your roommate's friend. Also, the equipment makes noise and so you don't want to interrupt your roommate and disrupt them, plus cleaning the equipment, etc, there's just a lot of logistical issues with dorm life.

Finally, some patients perceive this as this opportunity to take a break from CF. They've been living with this for so long, they just want a few years where they're just themselves, they are not themselves as a person with CF. and so the best way to do this is to just not do your therapies because then you are not reminded that you have CF.

So going to college may not be the best time to start a new medication, but it's an optimal time to try and anticipate these barriers with them and how they're going to address them moving forward. It's very hard for them to envision this happening, but we see it time and time again through our experience with more people.

MR. BUSKER: As you just said, going to college may not be the best time to start a new medication, but the team has suggested adding hypertonic saline. What can the team do to encourage good adherence when a patient starts a new medication?

DR. RIEKERT: Whenever a patient starts a new medication, it's important to provide some good information mixed with what I'll call marketing strategies. The education has to tell the patient what the medication name is, what it's going to do, how it works, and how they should take it correctly. But we also need to set outcome expectations. By that I mean what should happen right away when they take their medications and what should they expect to happen long-term. Because if they're not going to feel any immediate difference we need to let them know that because many people will stop taking their medications if they don't feel different.

With hypertonic saline, it's quite different. You cough a lot with it, and this is where the marketing comes in, in that we want to set up the expectation that this coughing is good coughing, not "you're sick" coughing. You want people to think they're coughing because they're getting the mucus out, and getting the mucus out will help prevent infections and help prolong their life.

People who have that mindset are very faithful to taking their saline, whereas those who say the coughing makes them feel awful and miserable and sick, I hate it, are much less likely to be taking their saline. We already know that adherence to hypertonic saline is usually about 15% to 20% lower than their other medications, mostly because of this coughing issue. It's very important to address that right up front and set proper expectations that we want them to cough and that the coughing is good.

One of my colleagues considers a trial of home spirometry monitoring before and after starting a new medication, having the patient do some PFTs at home on a meter that you can download the data so it's not all that much extra work, and then start the new therapy and see if there is a change.

One wonderful example was a patient who was doing the spirometry for a different purpose and all of a sudden had this huge spike up in her lung function. When they asked what was going on around this time, she looked in her calendar and she said that's when I started my saline. And in a subsequent study that I did with a whole bunch of people with CF (she was in it), and we asked the question what's the one medication you will always make sure you do even if you are running short on time, and she picked hypertonic saline. And she might have been the only person that picked hypertonic saline, but it was because she had this profound visual display of what good it was doing for her body, so she wanted to keep doing it.

So the more we can set up the expectation that positive things will happen from doing the medication, the more people will want to make the effort to try to do it every day.

MR. BUSKER: Dr. Riekert, thank you for today's cases and discussion. Let me change focus now and ask you to look into the future of medication adherence in patients with CF. What should clinicians expect to see?

DR. RIEKERT: It is a very exciting time for treatment adherence in CF. Several research trials are under way that should have data coming out in the next few years to help us see whether different types of interventions are helpful, not helpful, worth the effort, etc, and whether improving adherence is associated with improved health outcomes. So that's a great opportunity and an exciting thing to be seeing coming down the pike.

The health care environment in the US and Europe has focused on trying to prevent readmissions to hospitals and improve quality of care, but focus is now turning toward treatment adherence and what's happening at the patient level at home. The physician can only do so much, and now we have to empower the patient to be able to take care of their health optimally to get the best outcome. There is a lot of increased interest in how adherence affects outcomes and what we can do to help support our families.

I think that's translating into increased research dollars to explore this topic. In the past it's been assumed, that once you discover the drug, everybody will take it. Now people are realizing that even if you make the best drug ever, people will still struggle to take it, even if it's a cure. So we need to think about lifelong support, and the Cystic Fibrosis Foundation is interested in taking this on as a hot topic to move forward and hopefully give their leverage.

MR. BUSKER: Thank you for sharing your thoughts. I'd like to go back now and review today's discussion in light of our learning objectives. So to begin: best practices for determining which patients are nonadherent.

DR. RIEKERT: The key points for assessing adherence is to A) Try to get an objective measure whenever possible. That's increasingly possible through ePrescribing and electronic health records. When you form a clinical judgment, to know that that it might not be accurate and so to focus in on the conversation with the patient and have a good conversation with them about where they're struggling and where they could use some support.

MR. BUSKER: And identifying specific risk factors for nonadherence.

DR. RIEKERT: There is an infinite number of risk factors for nonadherence, but I think the ones that we covered today are the key ones that are highly important. One is just having life events and barriers and other responsibilities that get in the way, so we can help them solve that problem. Mental health problems, such as depression, are a highly predictive risk factor for nonadherence. Regimen complexity, health beliefs, outcomes expectancies, what they think they're going to get out of the regimen versus the effort they have to put in. Motivation, is this working for me, is this fitting in with my value system. And then general family issues are also risk factors.

These are just a taste of the many risk factors out there, and we could probably talk for another half hour about many others.

MR. BUSKER: And finally, counseling strategies to address nonadherence.

DR. RIEKERT: Education is a key one that I think many clinicians are already providing, and I

encourage them to keep providing the excellent education that they give. The next step will then be to identify the specific barriers that a family is experiencing and help them discover what has to be done to overcome them. It might be as easy as rearranging a routine or modifying the regimen, or it might be as complex as referring out for mental health services or family counseling to enhance their ability to manage the illness. There's also motivational interviewing and a plethora of other things, but ultimately what patients find helpful is just a supportive ear, knowing you understand that this is very hard and complicated, and that you know you're asking them to do a lot but it's important and you wouldn't ask otherwise.

MR. BUSKER: Dr. Kristen Riekert, from The Johns Hopkins University School of Medicine, — thank you for participating in this eCystic Fibrosis Review Podcast.

DR. RIEKERT: Thank you. It has been a pleasure to have the opportunity to share this information with you and the audience.

MR. BUSKER: This podcast is presented in conjunction with eCysticFibrosis Review, a peer-reviewed CME and CNE-accredited literature review emailed monthly to clinicians treating patients with cystic fibrosis. This activity has been planned and implemented in accordance with the Essential Areas and policies of the Accreditation Council for Continuing Medical Education through the joint sponsorship of The Johns Hopkins University School of Medicine and The Institute for Johns Hopkins Nursing.

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