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Cystic Fibrosis: Overcoming Barriers to Nutrition Adherence

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Here is Dr. William Mencia.

Dr. Mencia:
Cystic fibrosis, or CF, is a progressive, multisystem, autosomal recessive disease that affects about 30,000 people in the United States. Better nutritional status is strongly associated with better pulmonary function and survival in patients with CF. However, there are still high rates of nonadherence with nutritional recommendations.

This is CME on ReachMD, and I'm Dr. William Mencia.

Dr. Sawicki:
And I'm Dr. Gregory Sawicki, the Director of the Cystic Fibrosis Center at Boston Children's Hospital.

Dr. Mencia:
Welcome, Dr. Sawicki. To start off our conversation, can you set the stage for us and tell us about the role of nutrition in cystic fibrosis treatment?

Dr. Sawicki:
Sure thing. That's really an important question, and it's something that those of us who care for families and children with cystic fibrosis think a lot about. Ever since CF was first described, it really has been both a pulmonary and a nutritional disease. In fact, most kids before the advent of newborn screening, where we now diagnose many children prenatally or even at birth, we used to diagnose kids with cystic fibrosis based on failure to thrive or poor weight gain during infancy. And so we realized early on that children with cystic fibrosis for the most part suffered from pancreatic insufficiency or malabsorption of fat and protein in their diet and really required attention to gain appropriate weight. Over time it really became clear that those who were underweight and had CF also had worse outcomes, including worse pulmonary health, more infections, and more rates of hospitalizations. And over the past several decades, it's become very clear that children who start off on a better footing in terms of nutritional status do better later on as well.

There have been some very interesting studies looking at the role of nutritional status and lung function, both in younger kids, teenagers, and now adults living longer with cystic fibrosis. And in many of these studies, it's very clear that patients with better nutritional status at any point in their life are doing better later on in terms of both nutritional as well as pulmonary outcomes. And that's why it's become a really important topic for those of us who work in CF clinics and working with families with kids with CF is that we really try to prevent malnutrition, and we really try to prevent that failure to thrive. And so, as we are seeing kids improve and outcomes improve in terms of CF more globally, we recognize that paying attention to nutrition needs to start from the day 1 of diagnosis of CF and last throughout someone's entire lifespan.

Dr. Mencia:
That's interesting, Dr. Sawicki. We know so much about how nutrition has a considerable impact on patients with CF. Can you tell us about how you go about selecting the proper nutritional approach?

Dr. Sawicki:
That's also a very important question and one that I think our CF care teams grapple with a lot. Pretty much at the time of diagnosis, if a baby or an infant with CF has pancreatic insufficiency, we start them immediately on both caloric supplementation as well as pancreatic enzyme supplementation. And we consider nutritional health and outcomes and weight gain as really important markers of health throughout the first year of life and then throughout toddlerhood and into school-aged children and beyond. And so we really recommend that a family or a patient with CF have a relationship, as I said, with a dietitian and actually meet specifically with our dietitian on a yearly basis and more frequently if there are concerns around weight or nutritional status.

And as we sort of watch kids grow and watch them receive therapy, such as pancreatic enzyme supplementation, we often then have to think: What's the role of additional supplements? Calories are very important. High-calorie diets are recommended from the beginning, and a lot of parents with kids with CF sort of question sometimes why we always encourage things like whole milk in school when there's a lot of pressure around things like low-fat milk or "healthy eating" for other kids. We encourage extra dairy, extra vitamins, extra fats, extra proteins in terms of diet. And sometimes it gets to the point that a family can't necessarily keep up with this in the routine environment of what they might cook for them or their families, and so then we also ask them to think about additional supplementation. That can include supplements such as special formulas like PediaSure, special formulas that are sort of concentrated with sort of higher caloric density like special shakes. We often will use things like Scandishakes or Carnation Instant Breakfast as other possible supplements, but we ask our families to work with our team to develop a good regimen that works for each individual child.

We also have to pay a lot of attention to gastrointestinal symptoms, symptoms of reflux, symptoms of bloating or gas or constipation that may be prevalent in kids with CF. And ultimately, if a child is not able to tolerate high supplementary nutrition or high-caloric diets and is still not gaining weight, we then start the progression to a discussion around G-tube feeding, placement of a gastrostomy tube, using overnight enteral feeding. This is sort of not necessarily a mechanism of last resort, but it's one that we try to sort of avoid right off the bat. We want to make sure that we work with families in trying to understand healthy eating for a child with CF, and that includes attention to caloric needs, attention to intake, attention to supplementary feeds, and for some families then it means a progression to a G-tube. Although, I think as we sort of educate families early on and try really hard to impart the importance of nutrition early on, we find this less and less common, particularly as other therapies in CF have also improved.

Dr. Mencia:
Thank you for that, Dr. Sawicki. And certainly, as we just heard, setting up the proper diet with the proper caloric intake is very important, and also important is watching out for those gastrointestinal impacts that we could see. All of that is going to have potentially some influence on patient adherence. So, how can we identify those patients that are going to be most at risk for nonadherence?

Dr. Sawicki:
Thanks for that really important question because it's a topic that's important for any family dealing with a child who has a chronic condition. What I often say to families is that CF is a marathon, not a sprint, and there's a lot of things that need to happen on a daily basis. But ultimately, our goal is to maintain optimal outcomes and healthy outcomes throughout childhood into adolescence and into adulthood. And so with that sort of frame in mind, day-to-day variations in eating behaviors or caloric intake are something that I think we ask parents not to sort of focus on, but we ask them to focus on thinking through sort of week to week, month by month, what is the overall intake and diet of an individual child that they have with CF.

That's sort of cornered with—or coupled with the need for enzyme therapy with every meal, with every snack. Every kid has to eventually go to school, and eventually it's the progression of how are they going to get their enzyme supplementation or their caloric needs done at school while they are not under the supervision of their parents. And then as kids grow into adolescents and they're out with their friends, how are they going to remember that if they're out for pizza with their friends that they need to take their enzymes? Or if they go off to college and no one else is providing any supervision and they're responsible for going to the grocery store and cooking their own food, how are they going to get that knowledge?

And so, through each of these touchpoints, there's a challenge that an individual may start losing track of either their intake or their ability to take enzyme therapy on a regular basis. And that can be, again, conflated with challenges that we see in kids and adolescents and young adults with chronic disease, such as depression, anxiety, feeling awkward about having to take pills in front of other peers and not disclosing their diagnosis.

So, through each of these sort of elements of the lifespan, whether it be toddlerhood and picky eating or adolescence and more rebellion, there are some real challenges to adherence to these kind of daily care plans. And so it really is individual patient approaches

to how they're living with their chronic condition and how they tackle it. For some families, this becomes second nature and really easy, but for other families it becomes quite a challenge to maintain that kind of a daily routine that involves not just their respiratory care, which we're not even talking about today, and their nutritional care, which involves, as we said, both attention to diet and calories and attention to therapeutics like pancreatic enzymes.

Dr. Mencia:
For those just tuning in, you're listening to CME on ReachMD. I'm Dr. William Mencia, and here with me today is Dr. Gregory Sawicki. We're discussing the importance of selecting the right nutritional approaches for patients with cystic fibrosis.

So, as you've just gone over, there are a myriad of reasons for nutritional nonadherence. What are some of the best practices you can share with our listeners on how you counsel patients and their families on the importance of nutrition and adhering to that diet?

Dr. Sawicki:
As I said, there is really no one-size-fits-all approach to approaching nutritional care in CF, nor is there a one-size-fits-all approach to approaching nonadherence. And I think the first piece is recognizing that every patient and every family is going to have different circumstances. And as a clinician and as a CF care team, we need to do our very best to try to identify what the individual circumstances are. For some families, it's going to be a fear of disclosure of their diagnosis. But for others, it may be simply things around food insecurity, not being able to have the ability to have as much on their table, whether it be from lower income or challenges in the home. And for others, it may be related to just feeling like they're doing okay and that they don't need to be paying attention to their diet every day. And for others it may be, "Well, I'm very active in sports or physical activity, and I don't recognize that my caloric needs are high," and so it's sort of nonintentional nonadherence. It's not that I am trying to not follow the rules in terms of getting extra calories, it's just that I'm so active and I am unable to keep up. And all these things need to be unpackaged by sort of close monitoring, close follow-up, and real questions to each individual family and patient with CF, asking them to sort of address what are their barriers, what are their challenges when it comes to nutrition and coming up with goals that are really directed to the individual.

And that's why we, again, encourage families and patients with CF to meet regularly with our nutrition teams to then talk through sort of: Where are you today? What's your current weight? What's your current caloric needs? How are you doing it? What supplements are you using? What supplements may you need in the future? But also think about what those goals are for the future, whether they be over a 3-month period, a 6-month period or a 1-year period.

Dr. Mencia:
And that's also the foundation for shared decision-making, where it's a partnership between yourself and the other members of the healthcare team, like the nutritionists and the family and the patient. There are certainly going to be barriers to nutritional adherence, and as part of that shared decision-making process, you talked about working towards a common goal. What are some of your recommendations on how to tackle those barriers and to have the whole team focused towards that common goal?

Dr. Sawicki:
I think that that's really the sort of secret sauce to the multidisciplinary care approach in cystic fibrosis. It's because I think all of us recognize that each of us have an individual part in the care of a family or a patient with CF. We may think about their mental health; we may think about their respiratory health; we may think about their nutritional health. But for a family, they're not necessarily breaking down the health of themselves or their child into these individual buckets, and we need to have conversations around where the major challenge is. If a child is underweight and struggling, we have to explore why that is, but we need to also understand that it may not be because of their eating behaviors. It may be because there's conflict in the family, or there's a struggle with school, or there's a challenge in terms of paying for medications. And so we have our social workers involved, we have psychologists involved, we have our nursing staff, our physicians and our nutritionists working together to sort of understand a family's individual circumstance.

Dr. Mencia:
Well, this has certainly been a fascinating conversation, but before we wrap up, Dr. Sawicki, could you please share with our audience your one key take-home message?

Dr. Sawicki:
I appreciate the opportunity to talk with you today, and I think the one key message here is that we recognize as clinicians caring for those with cystic fibrosis that nutritional outcomes are as important if not more important than pulmonary outcomes at many levels and that we have many resources available to help patients and families achieve optimal nutritional outcomes. It's important that care teams take into account lots of different individual patient factors when addressing nutritional outcomes and make sure that families know that the team really cares about addressing these different barriers that may come up when it comes to achieving better nutritional care for living with CF.

Dr. Mencia:
That's an excellent point. Unfortunately, that's all the time we have today, so I want to thank our audience for listening in and thank you, Dr. Sawicki, for joining me and sharing all of your valuable insights. It was great speaking with you today.

Dr. Sawicki:
Thank you very much. It was a really interesting conversation.

Announcer:
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