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## Mental Health Screening: Cystic Fibrosis Foundation Guidelines and Specific Recommendations: The Benefits and Risks

Narrator:

Welcome to CME on ReachMD. This segment: *Mental Health Screening, Cystic Fibrosis Foundation Guidelines and Specific Recommendations: The Benefits and Risks*, is supported by Prova Education. Your host is Dr. Barry Mennen, who welcomes CF Mental Health Coordinator and social worker, Erin McElroy Barker, from the Cystic Fibrosis Center at Rutgers Robert Wood Johnson Medical School in New Brunswick, New Jersey.

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Dr. Mennen:

Patients with cystic fibrosis and their families are at a higher risk for mental health issues which have been associated with other complications. Today we will discuss how the CF community recognized the need for mental health services and the guidelines the CF Foundation recommends for screening patients.

You are listening to CME on ReachMD and I am your host, Dr. Barry Mennen. Erin, welcome to ReachMD.

Erin McElroy Barker:

Thank you for having me.

Dr. Mennen:

Our pleasure. Erin, what is the origin of the new mental health guidelines from the Cystic Fibrosis Foundation?

Erin McElroy Barker:

Well, as you know, cystic fibrosis is a multisystem disease that affects every area of the body and the family system, and despite new drugs to modify the effects of this disease, management of CF is very complex and time consuming, averaging about 2 to 4 hours per day from childhood through adulthood. As a result, CF continues to be one of the most difficult chronic conditions to manage with a significant treatment burden. So for the last several years, many years, CF centers and the CF Foundation have become increasingly concerned with the cost of living with CF from a mental health perspective. And so, they have in recent years devoted a great deal more time and energy into formally researching the prevalence of anxiety and depression in the CF community both among patients and

parents.

Dr. Mennen:

And specifically, these guidelines were developed when?

Erin McElroy Barker:

These guidelines were published last year and are being initiated in CF centers as of January of this year.

Dr. Mennen:

Now, from your experience, why are CF patients and, perhaps, their families at higher risk for mental health issues?

Erin McElroy Barker:

In my experience, as a social worker in a CF center for many years, I work with both pediatric and adult population, and in my experience, I believe that cystic fibrosis can cause increased psychological and family distress at multiple stages of the life cycle. Just a short list of this would be increased parental fear during infancy, possibly interfering with bonding and increases in parental stress, interruptions in daily routines due to the treatment regimen, possible challenges to growth and development due to nutrition and respiratory concerns in childhood. The issues around being different, experimentation and building independence in adolescents, as well as concerns about leaving home, letting go, going away to college, family planning, and the progression of the disease in adulthood. So all of these issues are present for families from day one through the life cycle, and I do believe put a tremendous amount of pressure and stress on patients, families, caregivers, spouses, etc. That, in addition to potentially multiple hospitalizations, procedures, interruptions in one's regular life and fears around illness and death, as well as the variability and unpredictability of this disease, I believe lends itself, unfortunately quite well, to increased levels of anxiety and depression.

Dr. Mennen:

And importantly, what are the consequences when these issues are not either treated or diagnosed?

Erin McElroy Barker:

So, a review of the research as well as my own observations, has shown significantly that there are higher levels of anxiety and depression in this community and some of the consequences that have been established by some of this research have been that when people who are living with higher than normal levels of anxiety and depression, there are significant effects on decreased lung function, lower BMIs, poor adherence, poor quality of life scores, more frequent hospitalizations and increased health care costs. They have also found that parents with elevated levels of depression and anxiety also then have children who also demonstrate higher levels of depression and anxiety and then suffer with the consequences I just mentioned.

Dr. Mennen:

Now, could you discuss the TIDES study and what it revealed about the need for mental health services in the CF community?

Erin McElroy Barker:

Sure, so the TIDES study was an international study that included people from 9 countries. It was sponsored by the CF Foundation and the European CF Society, and it looked at the prevalence of anxiety and depression, specifically in the CF community. They screened over 6000 patients, 12 and older, and 4000 parents of children 0 to 17. The study showed significantly higher rates of depression and anxiety in both parent caregivers and children 12 and up than those found in the non-CF population. So, it was pretty significant what

they learned and they used the information that they gathered in this very large study to guide the recommendations that have come out. The prevalence of depression in the CF community is 2 to 3 times that in the non-CF community, as well as anxiety.

Dr. Mennen:

What are the guidelines for screening and for whom do they apply?

Erin McElroy Barker:

So the guidelines for screening apply to really the whole CF community. All CF patients and families who are receiving care within a CF-accredited center. So the guidelines apply to every CF center. All CF centers have been asked to implement these guidelines as part of their routine care with CF patients and families. Some of the key recommendations of the guidelines have been that all CF centers are being asked to provide ongoing support and education to patients and families promoting stress management, healthy coping skills, etc. That is something we've all been doing to now anyway, but it reinforced that. CF centers have also been asked to initiate a screening program for anxiety and depression to include annual screenings during clinic visits, which are face-to-face visits conducted by either a clinical social worker or psychologist or whoever the mental health coordinator is on that staff to all patients 12 and up and parent caregivers 0 to 17. The two screenings that will be used are the PHQ-9 to screen for depression and the GAD-7 to screen for anxiety. Their recommendations are also that children ages 7 to 11 will be evaluated for depression and anxiety when caregiver depression scores or anxiety scores are elevated and/or when the child presents with significant symptoms of their own. So, those are the key recommendations to at least initiate screening and then based on the results of the screening, the recommendations also include a flexible step-care model for treatment for anyone who is experiencing higher than average levels of depression or anxiety, and to go a step further, the recommendations have included some detail on the types of therapeutic interventions that they have researched to be the most effective. They are not required, but recommended, specifically cognitive behavioral therapy and interpersonal therapy and then some recommendations about pharmacological interventions when necessary.

Dr. Mennen:

Please explain the algorithm for screening and treatment, that is, how will it work in practice?

Erin McElroy Barker:

So, screening will take place in clinic. It is a self assessment. So typically, the centers will hand out screenings to patients and/or parent caregivers depending on the age of the patient. Usually at the beginning of a clinic visit they will conduct the assessment on their own independently and then they will be collected and scored and reviewed with the social worker or the psychologist or whoever the clinician is after that is done. The recommendation is that they be done annually and if the screening results are within what is considered normal limits, they will then only be rescreened annually unless something comes up during that year. If the algorithm suggests that if the screening reveals symptoms and it is a step-care model, so going from mild to more severe symptoms, the recommendations go from either supportive interventions to recommendations for therapy to specific evidence-based therapies that can take place either at the time of the clinic visit or ongoing afterward, and then, to also include pharmacological therapies in the more severe anxiety and depression range combined with therapy, psychological therapy, and/or on their own if patient preference is only for medication.

Dr. Mennen:

How have the new guidelines been put into practice in the clinic setting?

Erin McElroy Barker:

So the CF Foundation in preparation for a roll out of the guidelines and implementation in clinic put forward a request for proposals last

fall for mental health coordinator to be an active part of the CF team. The mental health coordinator's task has been to establish a care pathway in the clinic to address the following areas: identify the mental health clinician who will be conducting the screenings and followup; develop and use recommended educational materials around depression and anxiety; develop a process for screening all patients, followup and referral; develop referral sources within the community, and then, of course, develop a plan for emergency situations like suicidal ideation for parents and/or caregivers.

Dr. Mennen:

Excellent. Now, what, if any, have the barriers been to a successful roll out of the mental health guidelines in the clinic?

Erin McElroy Barker:

So, one of the barriers has been that while the CF Foundation was able to provide a 3-year grant for mental health coordinator position to many centers, not all centers were able to receive that. And so, they have been forced to try to implement these additional guidelines within their clinic day without additional support. So that has definitely been a barrier for some centers. But, for centers, even for centers who have a mental health coordinator and have enough staff, the primary barrier in the clinic day is that it is a multidisciplinary team already, clinic visits are often 2 hours long even not including the new mental health screening, and so there have been a lot of concerns around the time that it takes to both screen and followup with screenings within that clinic day. Patient and family fatigue, you know, spending hours at a clinic and then, of course, I think the additional barrier is some hesitation around addressing the issue of mental health concerns on the part of the patients and families, that this is not necessarily typically what they have come to clinic to discuss, and there is some apprehension in the community around being more open to mental health services as part of their CF care.

Dr. Mennen:

Now, Erin, as a wrap up, what do you see as the benefits to providing these mental health services to CF patients and families and, on the flipside, are there any risks?

Erin McElroy Barker:

So, in my own setting, I believe that I have already seen a number of benefits to providing a specific screening. As social workers we typically informally screen and talk with our patients and families on a regular basis. The formal screening, however, gives us, I believe, a larger window into what might be going on for people, not just when we see them in clinic but on a day-to-day basis. And it is rather eye opening to discover just how much some are suffering and how in need some are of additional support. And so, I think, it's been terrific in highlighting that and helping us, as clinicians, to get to that more easily through the screening process. So that I think has been a huge benefit. I am also hoping that there will be a lot of benefit in terms of developing a really good psychological support network for patients and families that currently doesn't really exist in the psychological community due to issues around insurance and the cost of mental healthcare and that being a significant barrier. On the flipside, I think, one of the biggest risks and I think one of the biggest risks that the foundation had to struggle with in coming up with these guidelines and helping centers consider how to implement the guidelines, is really having a complete and comprehensive plan for how to deal with the mental health issues that we uncover in these screenings and that we are sufficiently prepared to provide support when it is needed, i.e., you don't want to screen somebody for depression if you don't have the skills or the referrals or the structure to provide adequate support, if they show you that their need is much greater than you maybe anticipated. And so, I think building that infrastructure in each CF center has been a challenge and it will continue to be a challenge that we need to make sure that we face effectively so that we are not making matters worse by shining a light on something that we can't actually do anything to help with.

Dr. Mennen:

It makes complete sense. I would like to thank CF Mental Health Coordinator and social worker, Erin McElroy-Barker for joining us today and discussing these important guidelines and recommendations for treating mental health in cystic fibrosis patients. I am your host, Dr. Barry Mennen, for ReachMD.

Narrator:

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