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ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

Strengthening Patient Trust in ILD Care: Strategies from the First 5 Minutes Framework

Announcer:
You're listening to *Deep Breaths: Updates from CHEST* on ReachMD. This series is produced in partnership with the American College of Chest Physicians, and this episode is a non-promotional, non-CME educational program brought to you by CHEST in collaboration with Boehringer Ingelheim. And now, here's your host, Dr. Susan Corbridge.

Dr. Corbridge:
Welcome to *Deep Breaths: Updates from CHEST* on ReachMD. I'm Dr. Susan Corbridge, Professor Emerita at the University of Illinois Chicago College of Nursing. Today, we'll be discussing a very important topic—we're going to be discussing the First 5 Minutes approach and then apply it to caring for patients with interstitial lung disease.

So the First 5 Minutes program from the American College of Chest Physicians is an educational initiative that's designed to help all of us as clinicians build trust and strengthen our communication with patients, particularly early in the encounter.

Joining me today, I'm so excited to welcome Drs. Brad Bemiss and Debasree Banerjee.

Dr. Bemiss is an Associate Professor of Pulmonary and Critical Care in the Department of Medicine and the Director of the Interstitial Lung Disease Program at Northwestern University in Chicago.

Dr. Bemiss, it's great to have you with us.

Dr. Bemiss:
Thank you.

Dr. Corbridge:
And also joining us is Dr. Banerjee, who's an Associate Professor of Medicine in the Division of Pulmonary, Critical Care, and Sleep Medicine and an Associate Medical Director of the MICU at Brown University in Providence.

Dr. Banerjee, thanks so much for being here today as well.

Dr. Banerjee:
Thanks, Susan, for having me. I'm really excited.

Dr. Corbridge:
Great. Well, it's just so wonderful to be here with you both to talk about this exciting initiative and how we can apply this skillset of relationship-centered communication to patients with interstitial lung disease.

But before we dive into that, let's start with the big picture, which is interstitial lung disease, or ILD. And as we know, it encompasses a broad and complex group of disorders, and sometimes, the journey to a diagnosis and management can be a long, involved process. And it can really be filled with uncertainty, fear, and frustration.

So Dr. Bemiss, I'd like to turn to you first and ask for some additional background on ILD. Since we know it is a broad and complex group of disorders that can challenge even experts, can you walk us through a basic classification scheme to help simplify how we think about these diseases, especially as a foundation for communicating with patients?

Dr. Bemiss:

This is an unusual disease—a rare disease, even—and one that often requires a lot of education and explaining at the top so a patient knows what we're dealing with. The word interstitial itself is not a usual word we use in medicine, and it's oftentimes a foreign language for patients. Like you said, even for lung doctors, the alphabet soup that we get into sometimes when we talk about interstitial lung disease can be very complex.

I find it most useful to start with the classification scheme that I talk about with patients in clinic, and I frame our questioning and our review of systems around a group of three larger classifications that we can break down interstitial lung disease into.

And so we'll often talk about ILD as being caused by exposures—something that someone might breathe in in their day-to-day life, usually in their workplace or hobbies, or something about their home that's abnormal. We ask some questions about that.

The second big group of diseases we refer to as systemic and autoimmune rheumatic diseases—SARD, better known as connective tissue disease-related. These are scleroderma, lupus, rheumatoid arthritis, and Sjogren's. These are the common diagnoses that we know about that are connective tissue diseases, but they can also go on to affect the lungs.

And then the third group we talk about is idiopathic, meaning we're not sure what's caused that or what the primary cause might be. We just know that it develops. We know a lot about these diseases. We know a lot about how they're treated and what their natural history is, but we don't have a primary cause for why these things happen. We end up calling them idiopathic disease.

Dr. Corbridge:
Great. Thanks for breaking that down. So given the complexity then of ILD, we know that it often takes time to arrive at the correct diagnosis. And I mentioned earlier, it can really present with frustration for patients and a lot of uncertainty and fear.

So Dr. Banerjee, I'd like to turn to you now. If we zero in on the core principles of the First 5 Minutes program, give us your thoughts about how you would approach a conversation with a patient who perhaps has been misdiagnosed, and they're frustrated by the process, while gaining their trust, maintaining trust, and helping them move forward with their care.

Dr. Banerjee:
Yeah, thanks, Dr. Corbridge. I think that's such an important question. And I think at the core of it is first to acknowledge patient frustration. So this is a long journey that people have had.

And importantly, I think we can bring this conversation back to the origins of the First 5 Minutes. So CHEST actually did a listening tour to understand what it is that the community that the membership serves found to be the challenges in their care. And the themes that emerged included things like lack of access, equity, and trust, which is exactly what we hope to address here.

So patients felt that this primarily centered on the importance that trust plays in the patient and clinician relationship, and barriers to establishing this as expressed by patients related to a few different things. So the first was a perceived dismissal by providers. And I think the first thing to do by acknowledging the patient frustration is to validate their experience.

The second was a lack of understanding or appreciation about their social determinants of health. And I think this is something we also fold into our First 5 Minutes related to ILD.

Third is the overuse of very technical or jargony language that can be intimidating or just not understandable to many patients, and even other providers, as we write consult notes. And this is the crux of communication—to use clear language.

And then finally, a general cultural and philosophical difference might contribute to implicit and even explicit biases at times.

The second tenet would be to rebuild trust by validating these experiences, which can be done specifically through using these principles of empathic listening, building trust, and respecting needs and values.

And finally, reframe the focus towards the next steps in care. And I think using a negotiated agenda in order to center the patient's concerns and their frustrations, and also to address the medical priorities that the provider has, helps create a team approach to tackling the issue at hand.

Dr. Corbridge:
And then turning back to you, Dr. Bemiss, building on what was just said, tell us a little bit more about why relationship-centered communication is so important—in particular in caring for patients with ILD.

Dr. Bemiss:
Yeah, you're exactly right. Not just the first five minutes, but really the first few seconds that you start talking to patients with ILD, you establish, "I understand the journey you've been on. You've probably seen four or five different specialists to try to get an answer for what could be causing some of these symptoms—shortness of breath and cough—that are often life-limiting and personal relationship-

limiting.” Oftentimes, patients have had to cut a lot of things out of their life because of symptoms they're developing.

And being able to acknowledge, “you're still a person, this disease does not define you, and I'm here to try to do the best I can to help and get you back to feeling the way that you want to feel” is really an important goal to set to let your patient know that you're on a team together.

This is often not as simple as prescribing a medication, symptoms go away, and you get better. This is a team that you're joining—a journey that you're going to be a part of likely for the rest of that patient's life. And being open to forming those relationships early on in the course of establishing a rapport with your patient on that first visit, then follow-up visits, and being able to follow up on complex testing and these complex disease states is a very important piece of the doctor–patient relationship.

Establishing that trust and understanding and allowing that patient to know that in many circumstances, it's not just me that's playing a big role in this—it's a team of doctors, whether it's my radiologist, my pathologists, other pulmonologists I work with, or other folks like nurse practitioners and physician assistants that work with us—we're forming this team that's really aimed at a lifelong goal of getting that patient's quality of life as high as it possibly can.

Dr. Corbridge:
For those joining us, this is *Deep Breaths: Updates from CHEST* on ReachMD. I'm Dr. Susan Corbridge, and I'm speaking with Drs. Brad Bemiss and Debasree Banerjee about patient-centered communication strategies that build trust and guide care in interstitial lung disease.

Now Dr. Banerjee, I'd like to go back to you. Many patients who are newly diagnosed with ILD turn to the internet, and they quickly encounter the worst-case scenarios. Often, things don't apply to them, but they don't know that. So how do you acknowledge their fears about the disease while also providing accurate information and building trust?

Dr. Banerjee:
I think we're all guilty of doing this on first pass when learning new information.

The first thing to do is to validate the emotional response. I think it's inaccurate to think that a provider will truly understand what a patient is experiencing when they're grappling with a new diagnosis, especially of something like ILD.

I think it's important to acknowledge that the experience will be shaped by so many factors in the patient's life—prior experiences with healthcare and their personal circumstances. So it's really important to note that the goal of First 5 Minutes is not necessarily to make people feel completely at ease or even happy with their diagnosis or avoid conflict. This may not actually be possible.

I think our goal is actually to provide accurate information and equip the patient with what they need to have in order to participate in shared decision-making and hopefully to center and incorporate the patient values in order to plan diagnostic and therapeutic steps in their ILD journey.

The next part would be to offer some credible resources to the patient. And this has really come to the forefront since the pandemic given how information has deviated from normal protocol for publications of scientific studies—or the engagement of the public in responding or having agency in what was considered historically under the purview of just scientists and medical professionals. So this is a shift, and it's imperative for providers to give the most accurate and relevant information for their patients.

With the advent of resources like ChatGPT, large language models, or AI-trained algorithms, self-education using the internet will be even more widely adopted. While some of this can help them advocate for themselves, as you pointed out, Dr. Corbridge, some of this information may be inaccurate or not appropriate for the context—not applying to that patient. And this is where the provider will be given an opportunity to educate and build trust, which is a part of the First 5 Minutes. I do think it will become an ever-increasing responsibility for the provider to do this.

And one of the tools would be to use very clear, compassionate language that is free of jargon. It's important to remember this is communication 101, and ideally, it'd be in the form that the patient prefers to hear—so in the preferred language, at the grade level, and potentially even supplemented with written, visual, or audio references. And maybe even a support person can listen on their behalf and understand things for them.

So we can be more creative in how we speak with our patients. But inevitably, there are other pressures that keep us from having the ideal interaction.

Dr. Corbridge:
Absolutely. Thank you so much for that. And definitely, this is going to be, as you point out, something that we all need to keep at the forefront during patient care, as with the advent of AI and such as well.

But given the progressive nature of some ILDs, Dr. Bemiss, how do you approach conversations with patients and families about prognosis, treatment goals, and palliative care planning?

Dr. Bemiss:
To just jump on one of the last things that Dr. Banerjee said, you have to be honest with patients. This diagnosis—interstitial lung disease—is, as I referred to before, not a great diagnosis to have. There are going to be bumps in the road, and there likely will be progression in many cases.

And so understanding that a patient needs to have that transparency and openness to discuss what the future holds, and for me not to just try to give them all hope, I need to be pretty clear with them that if things are progressing, there are things that will happen. They will lose independence. They will potentially need oxygen. They will suffer hospitalizations and exacerbations—things that we don't like to talk about but that we have to talk about if we're going to be able to serve as a guide and serve as a source of that good information—that clear language that patients need to hear as part of their journey. That journey can include a couple different things, including treatments, things like transplant—which is something else that I spend a lot of time talking about—and palliative care.

And I'd be remiss not to include a short statement to say palliative care is a vastly underused resource in the ILD community. While we think about palliative care somewhat often, we struggle to bring it up with patients, partially because it's harder to talk about. There's also a bit of a stigma around palliative care—“Is this the same thing as hospice? Is there nothing else that can be done, and that's why you're talking about palliative care to me, doctor?” No. Palliative care should be a layer on top of the care that I'm giving my patients when they're starting to feel short of breath, when they're coming to terms with the fact they have a chronic, incurable lung disease, and they’re starting to suffer things like anxiety and depression about those things.

Palliative care is a layer on top of my treatments, and often, I don't have time to have these discussions with patients as much as I would love to. A palliative care team—a nurse practitioner, a doctor, whether it's coming into a patient's home or making a separate in-office visit—is a very important thing to keep in mind as a part of our treatments for interstitial lung disease as well.

Another layer on top of that as well—something that I've been lucky to have some experience with—is the use of support groups. I meet monthly with the support group that I started about seven or eight years ago now as a community support plan to introduce topics like palliative care, to introduce topics like research, and to introduce topics like transplant. Patients talking to patients is a very powerful tool that should also be utilized. There are plenty of support groups available. If you search for them online, there are good databases and resources to send patients to, to find that information.

And then lastly, when we're trying to make a decision about, “Are we going the palliative care route? What are our treatment goals? What are my patients wanting? What are their desires? What are the things that they have set for goals in their life? Do they want to make it to a wedding out of state?” I had a patient recently tell me that they had a wedding planned for Breckenridge, Colorado, and we had to be honest and say, “I don't know that that's a great idea. You're on oxygen, and we're not sure that you're going to do well with that altitude.”

Try to identify what is important for a patient, do our best to meet those needs, and again, be a good resource and teacher for them as they travel this sometimes-difficult road.

Dr. Corbridge:
As we come to the end of a conversation, I'd like to ask each one of you to share an actionable takeaway from the First 5 Minutes approach that clinicians can use to foster trust with patients who have ILD.

Dr. Banerjee, I'll start with you.

Dr. Banerjee:
I would say the skill that I benefited from the most in the First 5 Minutes would be eliciting a list of all concerns—using the “what else” approach. It really changed my practice when I was able to use this more skillfully.

It's remarkable what patients will tell you as they hear you wanting to learn about what their concerns are. And when you ask “what else” and you don't stop at the first thing, they can really feel that you're present, that you're listening, and that you care about what it is they're experiencing and what their goals are. So I find that to be a really useful tool.

Dr. Corbridge:
Thank you. That was actually when I started really using the First 5 Minutes toolkit as well. That was really what changed my practice as well, so it's interesting to hear you say that too.

And, Dr. Bemiss, I'll give you the final word. What actionable takeaway would you share with us today?

Dr. Bemiss:
I think creating a partnership with the patient, with their caregivers, and with that care team is really important to have. As we all know, having worked in the hospital and worked in some difficult situations, having an advocate for your care, and having someone who can be there for you to listen to the tough times, but also to help you push through the difficult times, is really important and can lead to really important outcomes in patients' health and patients' care.

So creating that partnership up front, knowing that patient and that family can depend on you, whether it's through a MyChart message or a phone call—however they need to get in touch with you to create that team right up front—is a very important step.

Dr. Corbridge:
As those key takeaways bring us to the end of today's program, I really want to thank my guests, Drs. Brad Bemiss and Debasree Banerjee, for joining me to discuss how we can integrate the core tenets of the First 5 Minutes approach into our work with patients with interstitial lung disease.

Dr. Bemiss and Dr. Banerjee, it was so great having you both on the program.

Dr. Bemiss:
Well, thank you so much for having me. Thank you to CHEST for everything, and I really appreciate the opportunity to be on here.

Dr. Banerjee:
Yeah, thank you both.

Announcer:
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