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

The Daily Struggles of ISM: Understanding and Addressing the Vast Impacts

Announcer:

You're listening to *Project Oncology* on ReachMD, and this episode is sponsored by Blueprint Medicines. Here's your host, Dr. Charles Turck.

Dr. Turck:

Welcome to *Project Oncology* on ReachMD. I'm Dr. Charles Turck, and joining me to explore the profound impact of indolent systemic mastocytosis, or ISM, on our patients' daily lives is Dr Thanai Pongdee. He's the Research Chair in the Division of Allergic Diseases and an Assistant Professor of Medicine in the College of Medicine and Science at the Mayo Clinic in Rochester, Minnesota. Dr. Pongdee, thanks for being here today.

Dr. Pongdee:

It's a pleasure to be here. I appreciate the opportunity.

Dr. Turck:

Well, to start us off, would you tell us a bit about how ISM symptoms can be unpredictable?

Dr. Pongdee:

Certainly. Patients with ISM can have a variety of symptoms affecting virtually any organ system, anywhere from skin symptoms such as itching, flushing, or hives to gastrointestinal symptoms such as nausea, abdominal discomfort, or diarrhea to issues with general fatigue, general body aches, and a whole host of symptoms that vary from person to person. So because of the multitude of symptoms and the variety of them from person to person, it makes it hard to predict for a patient what symptoms they may or may not experience.

Dr. Turck:

And what are some common concerns or challenges patients encounter on a day-to-day basis because of that unpredictability?

Dr. Pongdee:

Well, it really makes it hard to perform your activities of daily living, or if you're at home or at work, you really don't know if that's going to be a good day or a bad day for the symptoms. When the symptoms occur during the day, there's a lot of fear about doing certain activities; you may limit your calendar or limit what kinds of activities you participate in. It may affect the kind of job duties you pursue because many of the symptoms can be quite debilitating and really put one out of commission, so to speak, for a period of time. So it's very challenging to manage those symptoms based on those aspects.

Dr. Turck:

And I was wondering if you could further paint a picture for us of how we see those challenges playing out, affecting patients' professional and personal lives? Are there any specific patients who come to mind?

Dr. Pongdee:

One particular patient was a chef, and many people with ISM have heat intolerance and flushing episodes. You can imagine cooking all day in the kitchen where lots of other people are around, and you have this sudden flushing episode, and you're actively cooking food, and you have to stop dead in your tracks. There's a busy staff going on, and it obviously affects his occupation. How long can this individual work? When can they work? What kind of activities do they do at work? And that would be a similar story for many individuals.

You can imagine, too, if you have lots of gastrointestinal symptoms, you have to make it to the restroom fairly quickly; that's also going

to limit what kind of jobs or activities you're going to pursue. And especially in one's social life, it may limit how far away from home you go if you're having outdoor activities. Do you go to large social functions? And what's the availability of places where you can kind of manage your symptoms or rest while they become under control?

So it's constantly going through their mind like, what if this happens or what if that happens? If it happens, are any people there to help me manage it? Am I on my own? Where is the closest hospital or emergency room if I have an anaphylactic event? So for some, it can be quite paralyzing really to plan out just going from day to day.

Dr. Turck:

For those just tuning in, you're listening to *Project Oncology* on ReachMD. I'm Dr. Charles Turck, and I'm speaking with Dr. Thanai Pongdee about the burden of indolent systemic mastocytosis, or ISM.

So, Dr. Pongdee, now that we've discussed the unpredictability and challenges of ISM, let's focus on how we can help patients successfully navigate the delicate balance of their disease and their personal and professional lives. What patient education and counseling strategies do you employ to help them in their journeys?

Dr. Pongdee:

So ISM is a relatively rare condition. Many that are in their life, either through healthcare or through friends or family, may have never heard of this condition, so those patients become the experts themselves. What kind of symptoms could I experience? What are some management strategies for those? And many of those management strategies focus around different types of medications and working closely with their healthcare provider to get kind of a custom medication regimen for their particular symptoms. And thankfully, for many, we can design a regimen that hopefully gets their symptoms under control where they don't have to worry so much about many of the living aspects that we just discussed.

Dr. Turck:

Are there any key factors to consider when developing treatment plans for patients with ISM?

Dr. Pongdee:

Yes. I think you really have to get a good sense of the spectrum of symptoms for that individual patient because they're just so variable from person to person, and there's not really great laboratory markers that are predictive of this person will have this kind of symptom profile and the next person will have this type. So you really have to listen to that individual about what they're experiencing on a day-to-day basis and also what kind of activities they like to pursue. What is their occupation? You have to kind of take all these factors into the account because, obviously, if you have someone who's really on the go and travels a lot, that's going to affect what kind of medications may work best for them. And on the flip side, if someone has a more stable work or family environment, something may work better for that individual. So it really is a customized plan for every patient.

Dr. Turck:

And last thing, Dr. Pongdee, what additional advice do you have for clinicians and others who help patients in their journeys to better understand, support, and address the unique challenges that patients face?

Dr. Pongdee:

Yeah, focus on the educational aspect. I know I touched on this previously, and on the patient's side, it's really getting to know their disease. They're many patients who interact with other patients through various platforms, and they learn from each other about what's new on the horizon and ideas about how to manage certain social or work situations that's invaluable. And for clinicians, many don't have another patient with ISM in the community or they may just have a handful, so really keeping up to date on all the new developments in the treatment space. It's a very exciting time for ISM research, so stay up to date on that. And thinking of the long-term, ISM is not a disease that goes away, so we really want to develop a good long-term relationship with our patients because as they evolve, as we all do through one's lifetime, their needs will evolve.

Dr. Turck:

Well, given the significant impact ISM can have on our patients, I want to thank my guest, Dr. Thanai Pongdee, for sharing his insights on how we can best support them. Dr. Pongdee, it was great speaking with you today.

Dr. Pongdee:

It was a pleasure. I appreciate the opportunity. Thank you.

Announcer:

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