

### Transcript Details

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Beyond Lab Values: Understanding Symptom Burden in Primary Biliary Cholangitis

### Announcer:

You're listening to *GI Insights* on ReachMD, and this episode is sponsored by Ipsen Biopharmaceuticals, Inc. Here's your host, Dr. Steve Jackson.

### Dr. Jackson:

This is *GI Insights* on ReachMD, and I'm Dr. Steve Jackson. Joining me to discuss the impacts that primary biliary cholangitis, also known as PBC, can have on patient's quality of life is Dr. Alan Bonder. He's an Associate Professor of Medicine and the Medical Director of Liver Transplant at Beth Israel Deaconess Medical Center in Boston.

Dr. Bonder, welcome to the program.

### Dr. Bonder:

Thank you, Dr. Jackson. It's a pleasure to be with you.

### Dr. Jackson:

To start us off, Dr. Bonder, can you briefly describe the clinical landscape of PBC and why symptom burden has become an increasingly important part of the conversation around management?

### Dr. Bonder:

I think we, over the years, have looked at two main pillars of treatment in patients with PBC. On one side, we have what's been known for years. We have the abnormal liver markers. We ask how we get patients better with current first-line therapy, such as ursodiol.

But recently, we have changed our focus significantly, to, I would say, more of a patient-central therapy. So we have identified that patients with PBC have, really, one of the poorest qualities of life out of any other chronic disease. And what we have seen is that recognition of symptoms has really impacted how we can treat them and improve their quality of life in the long run.

So right now, on one side, we have disease activity, which is following the blood test. And on the other side, we have symptom management, which is basically more patient centric.

### Dr. Jackson:

And with that background in mind, I'd like to dig deeper into the hallmark symptoms of PBC: fatigue and pruritus. Starting with fatigue, how common is it, and how does it impact patient's daily functioning?

### Dr. Bonder:

So I would say fatigue is the most common symptom that patients with PBC complain about. From 20 up to 70 percent of patients with PBC complain of fatigue. But the importance of fatigue is we have to differentiate the types of fatigue that are related to PBC. For example, we have what's called central fatigue, or what is described by patients as fogginess, or this profound tiredness without a major clinical explanation.

And the other one is a peripheral, fatigue, which is more like—if you want to describe it better—is when you exercise a lot, how your muscles get really tired. So it depends on what type of fatigue you're experiencing.

You can actually do different types of treatment options or assessments based on these complaints. But it's really important to understand that this symptom can really affect patients' quality of life and can interfere with work, physical activity, and routine daily

responsibilities.

And one of the other key features that we've seen recently in our clinics is, sometimes, we do see the burden of symptoms despite having normal biochemistries. So both fatigue and itching can really look different even if delivered numbers are completely normal.

**Dr. Jackson:**

And switching over to pruritus, how prevalent is this symptom, and what should clinicians understand about its effects on quality of life?

**Dr. Bonder:**

Pruritus is the hallmark symptom of cholestatic liver diseases. Up to 50 percent of people will have, at some point during their disease, some type of itching. The severity is pretty all over the place. Some people have mild itching, although other people can have severe itching.

But what we've seen with this is this is a major disruptor of life. It really happens more at night and interferes with sleep. It can affect energy levels and mood, and then, in some people, it can actually cause severe depression and sometimes suicidal ideations, because of how severe it is. And again, like I said before, like fatigue, the itching or pruritus doesn't always correlate directly with lab markers.

So again, we need to make sure that we ask about symptoms in all of our patients.

**Dr. Jackson:**

For those just tuning in, you're listening to *GI Insights* on ReachMD, and this episode is sponsored by Ipsen Biopharmaceuticals, Inc. I'm Dr. Steve Jackson, and I'm speaking with Dr. Alan Bonder about the symptom burden of primary biliary cholangitis and how it affects quality of life.

So, Dr. Bonder, let's switch gears now and talk about how we can better recognize and address these issues in routine care. One of the challenges in PBC is that symptom severity doesn't always match what we see in laboratory markers. What do we know about this disconnect?

**Dr. Bonder:**

I think, as you just mentioned, we know—and it's a fact—that symptoms and disease activity do not correlate at all. What does that mean? So we've had a lot of patients with no disease activity and a lot of symptom burden, and the other way, where they have a lot of disease activity and really have no symptoms.

So those two worlds don't talk to each other. Individuals with well-controlled lab values may still report substantial fatigue, itching, and, in fact, really severe quality-of-life concerns. So this is why it is so important to try to incorporate symptom management and symptom assessment in our clinic visits in patients with PBC.

**Dr. Jackson:**

And given that disconnect, what practical strategies can we use to more proactively assess symptom burden in patients with PBC?

**Dr. Bonder:**

I think the first question is to notice them. There is enough data out there that we clinicians sometimes don't do enough of a good job asking about those symptoms. So the first thing to do is try to incorporate this symptom assessment in our clinic visits. So, personally, what I've done is use all the tools that we have available in the PBC space, such as questionnaires or patient-related outcomes, that help me to capture or at least create a safe way or a safe space for patients to communicate those symptoms to me.

And then also really encouraging patients to talk about the symptoms. Again, there's a stigma of, for example, itching in certain patients. There is stigma in patients with fatigue about psychiatric disease. So we need to be a little bit more open and really have a better dialogue about what those symptoms mean and that they're part of the disease, because once we know they're there, we can really offer better treatment options.

**Dr. Jackson:**

And as we come to the end of our discussion, Dr. Bonder, do you have any key takeaways you'd like to leave with our audience?

**Dr. Bonder:**

I think the importance of asking about symptoms. I think clinicians are worried about disease activity and lab abnormalities. We need to really now shift and focus more on patients. We need to ask them about their symptoms and, also, with the symptoms, try to improve their quality of life.

And I think with the new tools that we have at label and the new treatments are coming out currently, we are addressing these two pillars of therapy, which are so important and actually give patients with PBC a better quality of life in the long term.

**Dr. Jackson:**

That's a great comment for us to think on as we wrap up today's program. And I want to thank my guest, Dr. Alan Bonder, for joining me to discuss how primary biliary cholangitis can affect patient's day-to-day lives. Dr. Bonder, it was great having you on the program.

**Dr. Bonder:**

Dr. Jackson, thank you for having me and I hope you get to enjoy this podcast.

**Announcer:**

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