Assessing Quality of Life in Autoimmune Liver Diseases

Announcer:

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Dr. Turck:

This is ReachMD. I'm Dr. Charles Turck, and joining me to discuss his recent research on quality-of-life indicators in autoimmune liver diseases 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. Turck. It's a pleasure to be with you again.

Dr. Turck:

Now, I'd like to start with a high-level overview, Dr. Bonder. What was the motivation behind this study, and what did you hope to find out?

Dr. Bonder:

This is a great question. So I've been trying to put some thought or research into, what are patient-related outcomes? As people are aware, this part of research is really a growing part of our own day-to-day patient care, and we are really trying to focus more on the patient experience or the patient complaints and how we address them. And again, this is really a good way to involve our patients in our medical decisions and help them to not only improve on their disease activity, but in their quality of life.

Dr. Turck:

Now, when it comes to the tools you used, how did the Chronic Liver Disease Questionnaire and the EuroQol-5 Dimension complement one another in evaluating patient quality of life?

Dr. Bonder:

Let's just start with, what's a CLDQ? So it's a tool measuring quality of life in chronic liver disease as a validated questionnaire, and basically has 29 items across six domains. It involves abdominal pain, fatigue, systemic symptoms, activity, emotional function, and worry. Each domain has three to eight questions rating one to seven on the Likert scale, indicating one is constant trouble and seven is no trouble. And the overall score is an average of this domain, with higher scores reflecting better high quality of life.

Again, I want to make sure that this score has been validated in PBC and PSC, and the Euro Qol-5 has two measurements. The visual analog scale is called EQ-VAS, and a five-dimension questionnaire is called the EQ-5D. So the EQ-VAS asks respondents to rate their health from zero to 100, zero being nothing or worse, and then 100 is the best. A score below 60 indicates poor quality of life. And an EQ-5D assesses five dimensions: mobility, self-care, activity, pain, and anxiety/depression, rating from one, with no problems, to three, with extreme problems. And again, this tool has been validated for liver transplant candidates and recipients.

So now that I answered what those tools are, I try to use these tools to basically validate symptom burden or quality-of-life burden in autoimmune liver disorders. And as you can see, and as we're going to be discussing in my results, it's well described that patients with autoimmune liver disease have really, really poor quality of life.

Dr. Turck:

Let's dig into some of those results right now. Your findings showed that patients with primary biliary cholangitis had the lowest quality-of-life scores. What stood out to you most about this group's symptom burden?

Dr. Bonder:

I think we were expecting these types of results, but let me summarize what we, basically, were able to publish. So, if you look at our three different autoimmune liver diseases—PSC, PBC, and AIH—when we look at specifically each one, we find out the PSC group carries the lowest symptomatic burden regarding quality of life. And what we found is that this aligns with has been published in the past. PSC patients, it doesn't really affect their quality of life. Although, once they get sick, they do get really sick and decompensated. They do really shift to how the other patients look.

But it's interesting, and I think what we've known is, PBC patients had the most significantly impacted high quality of life in all the autoimmune liver disorders—this comparing to PSC and autoimmune hepatitis. And when we look specifically at high quality-of-life symptoms, we have seen that fatigue seems to be the principal factor affecting the patient's quality of life. And again, what we've seen in studies before, according to multiple studies, fatigue—specifically severe fatigue—affects one out of five patients with PBC. And we think it's very debilitating, and it's really the hardest symptom to control. So I think we are seeing what we are getting out of the literature, but now I can put it in paper and say that our results basically reassure that patients with PBC need better assessment and better tools to really improve their quality of life.

Dr. Turck:

For those just tuning in, you're listening to ReachMD. I'm Dr. Charles Turck, and I'm speaking with Dr. Alan Bonder about the health-related quality of life of patients with primary biliary cholangitis.

So, Dr. Bonder, building on the study's results, your analysis identified several key patient-specific factors that predicted worse health-related quality of life. You talked a little bit about fatigue. I was wondering if you'd walk us through any of the other findings that you observed and share what they might mean for day-to-day practice.

Dr. Bonder:

Yes, of course, Dr. Turck. And I would say, in addition to poorly controlled symptoms driving the PBC group's lowest quality of life, we need to actually look at my data, and my data set finds that our PBC group was the oldest cohort with the highest BMI and more females. And again, if you look at studies, those are predictors for bad quality of life. On top of those baseline underlying characteristics, again, fatigue and itching are key symptoms in patients with PBC, and unfortunately, that drives their overall quality of life significantly to a lower standard.

When we look at a different analysis looking at other type of comorbidities, we did not find anything significant except female sex and Hispanic race, as well as BMI. When we look at, for example, other comorbidities, such as metabolic conditions, diabetes, hypertension, or other things, they are not really impacting the quality of life that much. So I think what we need to do is really dig deeper into why the patients with PBC are experiencing all symptoms, and what can we do to improve them, so at the end, we will have better quality of life in those patients.

Dr. Turck:

Now, taking a step back, even though we've seen additional therapies approved by the FDA in recent years for primary biliary cholangitis, patients with the condition still have some of the worst health-related quality of life measures of all the autoimmune liver diseases. How do you interpret that disconnect between treatment availability and symptom experience?

Dr. Bonder:

This is one of the key questions we get asked all the time. As I think people are aware, we have two new approved PPARs or therapies since 2024—in the summer of 2024—and now we are really looking into outcomes related to symptoms based on these therapies. Unfortunately, despite these therapies being so good at controlling disease and doing a really good job managing symptoms, we are not there in the same way controlling their disease activity. So, answering your question, I don't know why we—based on new therapies—can't control symptoms, but my vision of the future is that, based on these new therapies, and as we also design better clinical trials to treat symptoms, we will have better answers for our patients in the future.

Dr. Turck:

I wanted to ask a bit more about that. Looking ahead for just a moment, what do you think the next steps are for research in this area and related areas, and where do you see it going in terms of interventions or policy changes?

Dr. Bonder:

I would say, from a research perspective, what we are looking at now is we are seeing more patient-related outcomes as part of the primary or secondary objectives in our clinical trials. This is so important because we are now basically taking into consideration all of the symptoms and quality of life as part of our response into therapies.

I think what we need to look out for also in the future is if the use of these therapies in the long run really helps quality of life. So we've seen results from most of the studies that long-term use of the new PPAR or the new therapy really controls disease. I think what we need to do is design studies to look at quality of life in the long run to see if this is something that we would explore using in patients, even if they have really good disease control.

Dr. Turck:
Such a great comment for us to think on as we come to the end of today's program, and I want to thank my guest, Dr. Alan Bonder, for joining me to discuss how primary biliary cholangitis impacts patients' health-related quality of life. Dr. Bonder, it was great having you on the program.

Dr. Bonder:
Thank you, Dr. Turck, and hope to see you soon again.

Announcer:
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