Communicating Patient Experiences with Fatigue, Brain Fog, and Liver Pain

Presenters:
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Brian Thorsen, PSC Partners Patient Registry Director

At the PSC Partners 2025 annual conference, one breakout session addressed a major frustration for the PSC community: the frequent disconnect between how a patient feels and what their lab results show. Led by Brian Thorsen, a PSC patient and Director of the PSC Partners Patient Registry, and Dr. Donna Evon, a clinical health psychologist with over 20 years of experience in chronic liver disease, the session highlighted new tools designed to bridge this gap.

Thorsen opened by sharing a familiar story of having intense symptoms while doctors, looking at good lab results, are not always listening. The session focused on a solution: the development and use of **Patient-Reported Outcome (PRO) measures**. Dr. Evon explained that PROs are essential because symptoms are subjective experiences that must be captured directly from the patient. Research shows a poor association between clinician grading of symptoms and the patient's own reporting.

The PSC Partners Symptom Assessment Project

Dr. Evon detailed the **Symptom Assessment Project (SAP)**, a three-year initiative funded by PSC Partners to develop specific symptom measures for use in clinical trials and healthcare. The project's first step was conducting in-depth qualitative interviews with patients to fully characterize their symptoms.

This research, which involved 126 symptomatic patients, confirmed that a high symptom burden is common. In the last month alone, 83% of participants reported fatigue, with high rates of anxiety, liver pain, cognitive dysfunction (brain fog), and itch also present. This data clearly showed that as symptom burden increases, both physical and mental health status deteriorates. Based on this patient-centered data, the project focused on developing measures for the three key symptoms that lacked adequate tools: **fatigue, brain fog, and liver pain**.

The qualitative interviews provided a rich, nuanced understanding of these symptoms. Patients described fatigue not simply as being "tired," but as a "whole body heavy experience" that limits daily activities and necessitates napping. Brain fog was characterized by difficulties with memory, concentration, and verbal fluency—the frustrating inability to pull the right words.

Significantly, the research strongly validated the existence of liver pain, a symptom often dismissed by clinicians. Dr. Evon noted that doctors sometimes state the liver has no nerve endings, but she clarified that the *capsule* surrounding the liver does. Patients described two distinct types of pain: "intense, sharp, stabby" pain and a "dull, achy discomfort". Crucially, this pain was not just limited to acute cholangitis attacks but was reported by some as a day-to-day experience.

Using these insights, Dr. Evon's team customized fatigue and cognitive function measures from the robust, NIH-developed PROMIS system , ensuring the items selected truly reflected the PSC experience. They also developed an entirely new liver pain measure to capture the different pain types separately.

From Research to Reality: Audience Discussion

The new measures were recently launched in the PSC Partners Patient Registry to validate their performance. Thorsen shared initial data showing that 90% of respondents for this survey reported experiencing fatigue in the last seven days, confirming these symptoms are widespread.

The session then opened to a lively discussion. One audience member asked if the end goal was for these surveys to be used in hepatology clinics, similar to how primary care physicians screen for depression. Both speakers affirmed this was a primary goal.

Another attendee, who works in standards development, inquired about the rigorousness of the process and the inclusion of stakeholders like caregivers. This sparked a meaningful exchange about the caregiver's role. One participant noted that caregivers often recognize symptoms the patient has "normalized". Thorsen agreed, highlighting the challenge of normalization, where a patient's "fine" is a new, diminished baseline.

Patient Agency and Bridging the "Discordance"

Dr. Evon presented data on "discordance," showing that clinicians consistently under-report symptoms, noting them later and at lower severity than patients do. This happens because symptoms are subjective , labs often don't correlate , and clinic visits are short.

The solution, the speakers emphasized, is patient agency. Patients can and should use these tools *now*. Handouts of the measures were provided, and attendees were encouraged to make copies, fill them out, bring them to appointments, or upload them to their patient portals.

Thorsen stressed the practical importance of this advocacy. Having these symptoms documented in the medical record ensures doctors will ask about them in the future, provides evidence for disability claims, and improves continuity of care when seeing new specialists.

The power of this approach resonated strongly. A caregiver in the audience called the new tools "awesome," expressing relief at finally having something to help patients feel "heard and seen," especially after being told liver pain wasn't real. Another audience member shared his experience of being viewed as a "drug seeker" during a hospital visit because his labs were clean, underscoring the urgent need for these forms of documentation.

As the session concluded, attendees confirmed that the patient quotes from the research deeply resonated with their own experiences, validating the new measures as a critical step forward in centering the patient's voice in PSC care.