



Patient Power

MPN Symptom vs. Side Effect: What's the Difference?

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Andrew Schorr:

Dr. Scherber, so, let's first of all define for people, what's the difference between a symptom and a side effect?

Dr. Scherber:

All right. So, symptoms are really something, when we look at different types of MPNs, that we think are due to the disease itself. We know that there's a lot of inflammation with MPNs, so, that could be a source of symptoms. We know there can be blood clots that cause symptoms, disease progression, anemia, and organ dysfunction. So, things like a very large spleen that can cause bad problems with weight loss, or getting full very fast, or abdominal pain, or constipation.

That's very different than a side effect. And really, a lot of the way we can try to help to see the difference is in the timeline of when the symptom developed. But if I start hydroxyurea, and all of a sudden I have bad nausea, just not feeling well, acid reflux, or mouth sores and ulcers that we mentioned, or even skin ulcers, that gets me thinking, you know what? I don't think this is due to the disease itself. I think this might be due to the medication.

Andrew Schorr:

Okay. All right. So, that—but then Andi brought up something else is, some people have other conditions, or they've had surgery, like she had. So, how do you know when to attribute it to not just the medicine, but let's say to the disease, to the MPN? How do you know that?

Dr. Scherber:

Yeah. The timeline is always very helpful to know in clinic visits. So, a lot of times, I'll actually try to write in my notes everything in sequential timeline. And I'd like to know specifically when the different symptoms occurred. Things like you mentioned, with the night sweats or fatigue, sometimes – especially in the setting of something like your hysterectomy, when you're dealing with a whole bunch of hormonal issues—can be very difficult to pick out. But knowing when things happened can help.

The other thing that can really help are laboratory tests. So, things like checking for hormone levels, or checking to see if a thyroid function is low, or if maybe someone's low on vitamin D. I had someone just in my office today that was complaining of horrible 10-out-of-10 fatigue. So, we checked a whole bunch of things. Again[T(D3)], we checked thyroid function. I checked cortisol levels, vitamin D, B12, folate, iron levels. There are a lot of different things we can kinda do, depending on what the actual symptom is.

But I think finding a provider that's willing to really work with you, and that just doesn't pretty much say, "Well, it's your MPN." It very well might be a bigger picture. And that's worth looking at, especially when it's your life. I mean, it's your functioning.

One of the things—I go on a bit of a rant about this—but what our data showed is that quality of life is one of the most important things for MPN patients. And symptoms are a huge contributor or detractor for quality of life. And that making quality of life better in the long term can actually help with overall survival through the effect of improving functioning and time with loved ones and just enjoyed experiences. It makes us eager to live. It makes us continue to function better, which ultimately makes our body better.

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