

'Near-universal' negative experiences with healthcare providers reported by Lyme disease patients

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<https://danielcameronmd.com/near-universal-negative-experiences-with-healthcare-providers-reported-by-lyme-disease-patients/>

"Healthcare providers frequently struggle to provide effective care to patients with chronic Lyme-associated symptoms...potentially causing these patients to feel misunderstood or neglected by the healthcare system," [the authors wrote](#).

They listed 6 themes that emerged from the participants experiences: Late diagnosis, abandonment, loss, unpredictability, lack of understanding, and a need for a holistic experience.

The authors unfortunately found, "Negative experiences with healthcare providers were near-universal, also in patients with short-lived CLD-associated symptoms."

Here are a few of the participants experiences with healthcare providers.

Lack of in-depth questioning

"If the GP had asked something, then I would have remembered. If he had asked: "Have you been in the woods, have you had a tick bite?", then I would have [said]: "Yeah, I did have a tick bite." And then maybe, well, then you hope that it [would have] been treated at that time. But that didn't happen and he didn't ask."

Lack of seeing the 'big picture'

"They only look at that one thing, [...] but all that time no-one looked at the entire picture."

Need to fit into clinician's viewpoint

"You go to a doctor with the anticipation that they are going to make an effort for you, but along the way you notice that they have their own interests and ideas, and if you don't fit into their frame of reference then you can go. Yeah, the doctor is only insulting."

Patients feeling not heard

"What I think is a pity, is... you go through a lot in a short while, all sort of things happen, and, uhm, there's a doctor in front of you who doesn't want to hear it. Look, when you try to describe a symptom, you experience that for the first time, you also don't know what the medical term is. You try to describe something, but you just notice that the other side of the table is completely disinterested."

Symptoms dismissed as psychiatric

“Well, they can’t find anything, so it must be ‘between the ears.’”

"In summary, we find that CLD patients experience significant symptoms, for which they only rarely find adequate relief from regular medical practitioners."

The authors concluded, “Verbalizing these themes, patients use various repertoires for their shared experiences, such as a feeling of abandonment or not being heard by the medical system, feelings of loss with respect to their previous health, and the idea that they might have been better off had they been diagnosed sooner.”

Furthermore, "We hypothesize that these findings are not unique to CLD, but may also be applicable to other conditions with an uncertain aetiology, such as Long COVID," they wrote.

Related Articles:

[Symptoms of Lyme disease are not excessive](#)

[Dismissing chronic Lyme disease for somatic symptom disorder diagnosis](#)

[My child has Lyme disease: parents describe fear and frustration](#)

References:

1. Baarsma ME, Claassen SA, van der Horst HE, Hovius JW, Sanders JM. Knowing the entire story - a focus group study on patient experiences with chronic Lyme-associated symptoms (chronic Lyme disease). BMC Prim Care. Jun 2 2022;23(1):139. doi:10.1186/s12875-022-01736-5

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