

Points of view: Lyme disease patients and physicians

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The authors looked at the perceptions, representations, and experiences of patients who had Lyme disease with nonspecific symptoms and no objective manifestations of the disease. [This small study included 12 patients](#) with confirmed and non-confirmed Lyme disease or unexplained symptoms.

“Our study highlights that some physicians may also experience a lack of knowledge and information about [Lyme Borreliosis], increasing the difficulty to answer the patient’s needs,” wrote Raffetin et al. ¹

The investigators described several themes from their interviews with patients, along with patient statements expressing their frustrations.

Painful Experience with the Disease, Leading to Confusion and Fear

- “Nothing could bring me relief ..., the pain was almost unbearable.”
- “Always tired, tired ... tired, tired.”

Incomprehension, Fear, and Doubt when Faced with the Lack of Explanation for the Symptoms

- “We kept doing the analyses, we didn’t understand.”
- “The patients expressed a feeling of fear of unpredictable ?are-ups, of not being cured, etc.”
- “I was afraid of not knowing how I would end up.”

Long and Difficult Treatment Path, Experienced as an Obstacle Course

Fight against the Medical World

- “My GP, I am reluctant to ask him, he doesn’t want to believe me.”
- “They don’t listen, ... they look at everything medical, and as long as the tests are negative, they say that you have nothing.”
- “The absence of consensus on recommendations at the time of the study has reinforced the feeling of abandonment by the scienti?c community.”

Disease Taking a Serious Toll on the Patient’s Health

Multiple and Negative Repercussions, Experienced as an Injustice

- “At the professional level, the patients reported absences linked to multiple medical consultations, repeated leave from work, etc.”
- “Activities were impacted by the unpredictability of the symptoms, leading to the feeling of being overwhelmed by the disease.”

- “The patients described either a lack of understanding from their relatives, or unconditional support, sometimes with the family adapting to their condition.”

Frustration expressed by doctors

The authors also described the frustration among doctors treating Lyme disease patients. “According to a survey, one-third of general practitioners experience difficulty when faced with the ‘insistent’ demands of ‘hyper-informed’ patients.”

“The major challenge for the doctor is to determine on one hand the limits of his own knowledge and his capacity to answer the patient, and on the other hand the quality of the patient’s information sources.”

Some of the problems lie in the lack of education. “The patients highlighted the poor training of physicians regarding persistent symptoms, as has also been shown in several studies on somatic symptom disorders.”

“These results are consistent with the views of the [general practitioners] interviewed in a study by Lisowski et al., 87% of whom said they were uncomfortable following up with patients who had symptoms after a full course of antibiotics due to having failed to provide codi?ed management.”

The authors emphasized the need for a “coordinated care pathway and careful listening and recognition.” They also suggested that specialized reference centers might help meet these expectations.

Related Articles:

[How concerned are people about tick bites and tick-borne diseases?](#)
[COVID-19 long-haulers and lyme disease patients share similar frustrations](#)
[Lyme disease myths lead to frustrations for doctors](#)

References:

1. Raffetin A, Barquin A, Nguala S, et al. Perceptions, Representations, and Experiences of Patients Presenting Nonspecific Symptoms in the Context of Suspected Lyme Borreliosis. *Microorganisms*. Jul 15 2021;9(7)doi:10.3390/microorganisms9071515

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