

Lyme disease and persistent  
symptoms: perspectives on quality of  
life, the care experience and the  
clinical approach  
English summary

Une production de l'Institut national  
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# SUMMARY

## Lyme disease and persistent symptoms: perspectives on quality of life, the care experience and the clinical approach

### Introduction

The manifestations suggestive of Lyme disease include cutaneous, cardiac, neurological and joint involvement. Depending on the stage of the disease, general systemic symptoms may also be present. These manifestations are not well known by many, and, for various reasons, the diagnosis of Lyme disease is complex. In addition to augmenting disease burden, increased time to diagnosis from the onset of symptoms affects the risk that the patient will experience residual symptoms after antibiotic therapy. Furthermore, the medical community is divided on the plausibility that Lyme disease can cause persistent, general systemic symptoms, such as fatigue, memory or concentration problems, headaches, and muscle or joint pain. However, these symptoms are a reality for many people and result in a large number of medical visits and requests for laboratory tests or specialized examinations. Furthermore, some patients struggling with such symptoms and looking for their cause step outside Québec's conventional healthcare system. They turn to clinicians who specialize in managing such patients, or they resort to tests performed by certain private laboratories and to empirical treatments, whether pharmacological or otherwise.

In May 2019, at the request of three branches of the Ministère de la Santé et des Services sociaux (MSSS), INESSS published clinical and implementation recommendations regarding the diagnosis, treatment and management of patients with localized or disseminated Lyme disease to equip health professionals, especially front-liners, given the increase in this illness. As a continuation of this work, MSSS asked INESSS to shed scientific light on the plausibility that Lyme disease can cause persistent, general systemic symptoms, to provide a portrait of the experience of patients with suspected or confirmed Lyme disease, and to make recommendations concerning their management. The purpose of this report is to present the information gathered during this work regarding:

- the quality of life and the care experience of patients with suspected or confirmed Lyme disease;
- the clinical approach used by health care professionals with these patients and their preferred means of staying informed or updating their knowledge of the disease.

The gathering of this information helped in preparing two reports and recommendations stemming from this work.

## Methodology

To prepare this state-of-knowledge report, INESSS gathered scientific data and the perspectives of different stakeholders, including patients and clinicians with varied practices regarding Lyme disease. For this purpose, it carried out a systematic search of the scientific literature published in French and English on the aspects to be documented.

To gather the perspectives of the different parties concerned, INESSS created an advisory committee consisting of clinicians; experts in laboratory tests, acarological surveillance and public health; and patient partners with Lyme disease. In addition, clinicians with expertise in managing patients with persistent, general systemic symptoms attributed to Lyme disease were consulted through interviews or a survey to obtain the perspectives of clinicians with differing viewpoints. Further consultations were held with representatives from the Association québécoise de la maladie de Lyme and Enfance Lyme Québec, and interviews were conducted with patients with localized or disseminated Lyme disease, patients with persistent, general systemic symptoms attributed to this illness, and parents of children with such symptoms. The patient perspective was supplemented with case histories described in documents provided by patient associations and those mentioned by the various persons consulted.

## Results

Of the patients who say they suffer from Lyme disease, there are those who have symptoms associated with its main types of involvement that lead to a confirmed diagnosis of this illness (diagnosis made with a high degree of certainty) and those who have persistent, general systemic symptoms with or without a history of confirmed Lyme disease. Work showed that the condition of the latter group of patients is poorly defined. Since bacteria belonging to the *B. burgdorferi s.l.* complex are seemingly not the only possible etiological agents in this context, and since noninfectious mechanisms, as well as other clinical conditions, might also be involved, the data collected on these patients were analyzed separately from those concerning patients with confirmed Lyme disease.

Data from the scientific literature and the consultations suggest that there are significant differences in quality of life and the care experience, depending on whether the patient has confirmed localized or disseminated Lyme disease or has persistent, general systemic symptoms attributed to this illness with or without a history of confirmed Lyme disease. Indeed, in the latter case, the patient seems to have a much more compromised quality of life and a less satisfactory care experience. Furthermore, the consultations with patients and patient association representatives suggest that diagnosis-seeking is common among both patients with disseminated Lyme disease and those with persistent, general systemic symptoms attributed to Lyme disease, but the period of diagnosis-seeking appears to be longer for the latter group.

As regards the clinical approach used by health professionals, the comments collected from the clinicians show that they are divided on the plausibility that Lyme disease can cause persistent, general systemic symptoms, which, in some cases, seem to influence their conduct towards their patients and the way they manage them. Although some clinicians appear to be more reluctant to follow patients with persistent, general systemic

symptoms attributed to Lyme disease, whether they have a history of confirmed Lyme disease or not, all the clinicians consulted felt that open-mindedness, attentive listening and empathy should be exercised with these patients to avoid a breakdown in the clinician-patient relationship. In addition, the ways in which clinicians prefer to stay informed or update their knowledge of Lyme disease appear to vary from one to another. Diversifying methods used to disseminate information could therefore make it possible to reach a larger number of health professionals.

Taken together, the results of this state-of-knowledge document suggest that enhancing health professionals' knowledge of the Lyme disease diagnostic process and working in an interprofessional and multidisciplinary manner on more complex cases would help improve patient management and the patient care experience. However, the scientific uncertainty regarding the clinical condition of patients with persistent, general systemic symptoms attributed to Lyme disease is a major obstacle that should be addressed and examined through research.

## **Conclusion**

The integration of the results from the scientific literature added a scientific dimension to the contextual data and the perspectives of the various stakeholders consulted. This work shows considerable differences between the reality of patients with localized or disseminated Lyme disease and that of patients with persistent, general systemic symptoms attributed to this illness, whether they have a history of confirmed Lyme disease or not. In addition to the scientific uncertainty surrounding the clinical condition of patients with persistent, general systemic symptoms attributed to Lyme disease, several barriers and facilitators identified during this work guided the development of the recommendations for improving access to care and patient flow and satisfaction in the care continuum.

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