


Motivations and Experiences of Canadians Seeking Treatment for Lyme Disease Outside of the Conventional Canadian Health-Care System

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Abstract

Objective: We aimed to describe the experiences of Canadians who seek diagnosis and treatment for Lyme disease outside of the conventional Canadian health-care system. **Methods:** Forty-five individuals who had sought treatment for Lyme disease outside of the conventional Canadian health-care system were recruited from Lyme support and advocacy groups across Canada to answer open-ended questions about their experiences. **Results:** Respondents sought treatment outside of the conventional medical system due to extensive diagnostic procedures and treatments that did not resolve symptoms. Escalating health concerns, lack of effective treatment, and stigma produced a sense of abandonment and desperation. Respondents accessed alternative forms of care based on the recommendations of peers, yet considerable financial and emotional stress was experienced. **Conclusions:** Many individuals with Lyme or Lyme-like diseases are deeply dissatisfied with the care received within the conventional Canadian health-care system and therefore felt both pushed and pulled to seek treatments either from international physicians using different treatment protocols or from alternative medicine providers in Canada.

Keywords

Lyme disease, patient perspectives/narratives, medical tourism, complementary/alternative medicine, Lyme treatment, Lyme diagnosis, Canada

Lyme disease is an infection with *Borrelia* sp. spirochete bacteria and is the most common tick-borne illness in North America and Europe (1,2). Due to climate change, Lyme disease is becoming increasingly frequent (3,4), particularly in areas where it was rare a few decades ago such as in Canada, with increasing incidences throughout the country and documented cases in every province (5,6). Although the Public Health Agency of Canada reported only 917 cases of Lyme disease in Canada in 2015, (7) it is highly likely that the Canadian statistics dramatically underrepresent the incidence of Lyme disease. Indeed, Zubek (8) found that 221 Lyme cases were diagnosed in British Columbia, but only 13 were reported.

Diagnosis of early Lyme disease relies on the presence of erythema migrans (bull's eye or target rash) and a history of possible exposure to infected ticks (9). Immediate antibiotic treatment for acute early infection has been shown to prevent further illness, but when untreated, the bacteria affect multiple organ systems, often producing serious joint, neurologic, cardiac, and other disease (2,10). Although diagnosis of late or disseminated Lyme disease is possible within the

conventional Canadian health-care system, it relies on a 2-tiered system of serological tests in which only samples positive by an enzyme-linked immunosorbent assay (ELISA) test are sent for subsequent immunoblot testing and only those samples positive by both criteria are considered to indicate *Borrelia* exposure (11). Thus, underreporting in Canada could be due to unfamiliarity of physicians with an emerging disease, geographically specific *Borrelia* genospecies that may not generate positive 2-tiered serological results (12,13), or failure of 2-tiered serology tests to detect infections (14).

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Frustrations with the conventional health-care response to Lyme disease have been documented, even in the United States where the disease is more frequently diagnosed. Drew and Hewitt (15) reported negative experiences with conventional Lyme health care in the United States, particularly frustration over visits with multiple health-care providers, lengthy diagnosis processes, financial stressors, and the need for self-advocacy among patients struggling with unresolved symptoms following treatment. Similar experiences were again reported a decade later, where negative experiences with conventional health care were contrasted with the sympathetic and engaged care received from alternative health-care providers (16,17). Such frustrations are also commonly discussed in the Lyme patient community in Canada, where recommendations to seek care outside of the Canadian health-care system are frequent (18,19).

Little is known about the use of alternative health care and medical tourism by patients with Lyme disease, but it is well established that many Canadians access care outside of the conventional Canadian health-care system. Up to 20% of Canadians, particularly those with chronic diseases and chronic pain, access alternative health-care treatments instead of, or complementary to, conventional medical care (20,21). Additionally, more than 62 000 Canadians left Canada for medical treatment in 2016 (22). A scoping review of the medical tourism literature found a lack of credible research on medical tourism overall. Nonetheless, existing work suggests that the main reasons why Canadians travel internationally to seek medical care were reducing wait times and accessing care not readily available in Canada (23). The latter issue may be particularly relevant to Lyme disease, given the lack of expertise in the diagnosis and treatment implied by the rates of underdiagnosis in Canada. Although Canadian researchers have examined the increasing risk of contracting Lyme disease (24) and barriers to diagnosis and treatment (25), little is known about how and why Canadians seek medical diagnosis and care out of country and outside the publically funded health-care system. Thus, our study represents the first formal evaluation of the motivations, perceptions, and experiences of individuals seeking care for Lyme disease outside the Canadian conventional health-care system (CCHS).

Methods

Study Sample

Participants were recruited from Lyme disease support groups in New Brunswick and Nova Scotia during the summer of 2014, and in-person or telephone interviews were carried out and audio-recorded. In January 2015, respondents from the rest of Canada were recruited through a notice on the Canadian Lyme Disease Foundation website. A written survey containing the same questions used in the in-person interview was made available to respondents in

Table 1. Demographic Characteristics of Participants.

Participant Characteristics	Number of Participants, N = 45	Percentage of Sample
Gender		
Male	8	18%
Female	37	82%
Region		
New Brunswick/ Nova Scotia	20	44.4%
Ontario	11	24.4%
Quebec	5	11.1%
British Columbia	9	20.0%
Age	Mean = 50	Range = 14-73

English or French. Most respondents responded in writing but some with health limitations were interviewed via telephone. Verbatim transcriptions of all interviews were produced. In all cases, we recruited individuals who self-identified as suffering from Lyme disease and who had sought treatment outside of the CCHS. Oral informed consent was obtained for all telephone interviews and written consent for participants who responded in writing. Demographic characteristics of the sample are shown in Table 1.

Measures

The interviews were semi-structured and all participants were asked 4 open-ended questions: (a) What prompted your pursuit of alternative treatment for your condition? (b) Did you encounter difficulties in accessing alternative care? (c) In an ideal world, what form of treatment would you want available for people suffering from Lyme disease? and (d) If you could recommend any specific changes to the Canadian health-care system with respect to its approach to treatment of Lyme disease, what would those changes be? Basic demographic and diagnosis information was also collected. This research project was reviewed and approved by the university research ethics board.

Data Analysis

An exploratory descriptive design was used. The extraction and organization of salient themes was carried out using a multistep thematic networks analysis (26): Lowest order (ie, text-based) themes were first identified independently by the first 2 authors, organizing themes summarizing several basic themes were then identified, and finally global themes that summarized and united groups of lower order themes abstracted from the data were determined. As a final step, we revisited the original transcripts in relation to the context provided by the thematic networks identified to confirm conclusions and to identify quotations for data presentation.

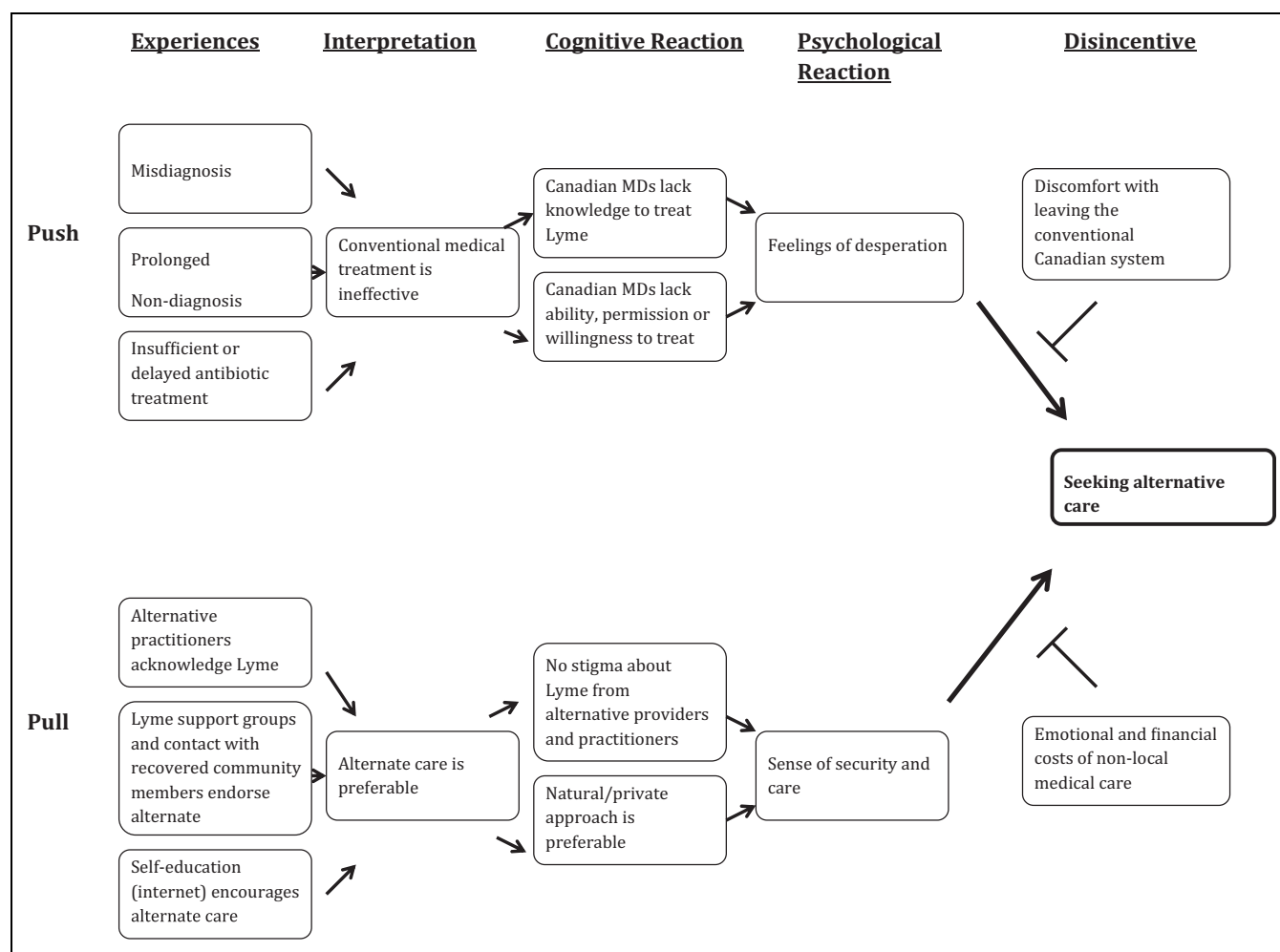


Figure 1. The Push-Pull Model of Patient Experiences with Lyme Disease Care.

Results

Respondents reported a complex series of experiences, interpretations, and emotional reactions that led them to the decision to seek health care outside of the CCHS. As shown in Figure 1, respondents could be seen as being pushed away from traditional care, while simultaneously being attracted to forms of alternative care. Nonetheless, both pathways are accompanied by economic and emotional barriers. Quotes illustrating the themes highlighted in Figure 1 are provided below.

Push: Experiences Within Conventional Canadian Health Care

All participants had first sought assistance for their health-care concerns within the CCHS before turning to other options. The participants described negative experiences within the CCHS including (a) perceived misdiagnoses, (b) failure to obtain a diagnosis or improvement in symptoms, often after years of multiple specialist consultations (R12: I knew there was something drastically wrong with me and

had tried everything I could with our own health [care] system, [...] got laughed at and told that my symptoms were all nonspecific, and there's nothing wrong with you), and (c) insufficient or delayed antibiotic treatment (R27: My own family MD gave me a clinical diagnosis of Lyme disease but was reluctant to offer me any antibiotic treatment. He was willing to prescribe (...) drugs to treat my symptoms, but because of the political climate surrounding Lyme disease, he refused to prescribe conventional antibiotics).

Push: Cognitive and Psychological Reactions to Experiences

Negative experiences with the CCHS were associated with the failure to offer effective treatment. (R8: They just made it sound like "go home and live with it.") Respondents questioned physicians' knowledge of Lyme disease, particularly when their statements were unsupported by other physicians or by biological research. (R30: I was finally prompted to pursue treatment [outside of CCHS] when my [American] blood test came back CDC positive and, with ongoing undiagnosed symptoms, the infectious disease doctor would

not acknowledge that I could have Lyme disease. [The doctor] told me even if I did have Lyme disease, I wouldn't need treatment because my immune system would take care of it.) In many cases, patients felt belittled by health-care practitioners. (R12: "My doctor has rolled his eyes at me for saying I suspect I have Lyme. He was scared to death to deal with [Lyme], and he knows nothing about it.") When Lyme disease was discussed, respondents encountered limitations as to what type of care was offered by the CCHS, with long-term antibiotic treatment being unavailable. (R27: Despite getting a clinical diagnosis of late-stage Lyme disease from my doctor, no antibiotic treatment was offered to me here in [Canada] (because of [my] negative Canadian ELISA.)

Other respondents, however, acknowledged limitations faced by their family/primary care physicians. (R17: I guess it's a new disease in Canada [.]. Once we get some Lyme literate doctors here and governments and government bodies willing to support them, then we will hopefully get some treatment.) Respondents often drew a distinction between "Lyme literate MDs" who were seen as very helpful and other physicians. In the 1 province where naturopathic doctors are able to prescribe long-term antibiotics, they were seen as providing the most help. Specialists, in particular neurology and infectious disease, were not perceived as being helpful.

Ultimately, a lack of effective treatment resulting in worsening symptoms and reduced quality of life prompted a search for treatment outside the CCHS. (R27: I was not functioning well, I lived with chronic pain and symptoms and was unable to work or care for my children. I sought alternative treatment in the United States to improve my functioning, reduce my pain, and to improve my symptoms and my quality of life.) Feelings of desperation were also at the root of this decision. (R5: The last straw was when my last neurologist told me there was nothing more that could be done for me and that I would have this unexplained pain for the rest of my life [. . .] I felt like I was dying [. . .] I was feeling weak emotionally and physically, and I felt that the specialist had closed the doors on me.)

Disincentives to Leaving the Conventional Canadian Health-Care System

Despite factors pushing patients away from the CCHS and toward international and alternative health-care options, the choice to leave conventional medicine was not straightforward. Many respondents discussed the emotional costs of seeking care outside of the conventional system and the anxiety of not knowing whether the treatment was safe and effective. (R5: No consensus seems available on what is the right [treatment] to do [. . .] You don't feel that security of knowing a certain treatment is endorsed by all [It's] scary when you get the list of antibiotics [. . .] I guess if they kill me, they kill me.)

Pull: Motivations for Alternative Health Care

Interactions with family members and recovered community members, as well as self-guided research, were all clearly important factors in making the decision to seek alternative forms of care. When asked what prompted them to seek care outside the CCHS, 1 respondent replied: (R18: Two things—speaking with people who had lived with Lyme and their experiences and research into treatment protocols). As seen in Figure 1, respondents reported many experiences that led them toward alternative forms of care.

Pull: Experiences in Alternative Care

Many respondents noted dramatic improvements in symptoms when they began receiving care from "Lyme literate" health providers, either in Canada or internationally. Another important consideration was that practitioners outside of the CCHS were perceived as (a) being more receptive to the possibility that Lyme disease was responsible for the symptoms experienced and (b) providing emotional support through acknowledging the suffering experienced. (R16: If you schedule an appointment with him [naturopathic doctor], you get a solid hour, a whole hour with him. And he is very calm, very supportive.)

Pull: Cognitive and Psychological Reactions to Experiences

Of particular importance to many was the relief from the stigma associated with Lyme disease experienced in the CCHS. This was highlighted by the protective attitude of participants toward their care providers. (R10: We don't want to get the doctors who are helping us in trouble. There is a stigma.) Finally, for some individuals, a general preference for alternative medicine was also expressed. (R14: I would prefer natural doctor, in order to avoid the negative side effects that often accompany Western medicine.)

Disincentives to Accessing Care Outside the Conventional Canadian Health-Care System

In addition to the emotional toll of leaving the CCHS, logistical and financial barriers were highlighted. Finding reliable and trusted information on Lyme disease was the first barrier (R28: "I had to do all the research and follow-up myself. [This was] difficult when [I was] barely able to cope with day-to-day caring for my family. [. . .] After losing my job due to the illness, treatment costs would have been impossible, if not for well-off relatives able and willing to pay for the treatments.") It should be noted, however, that a few individuals found it easy to access treatment information via the Internet and social media. (R41: "... easy to find but out of financial range for most.")

Accessing care from American physicians resulted in difficulties for many. The financial burden of travel costs, as

well as the direct cost of consultations and medications in the United States, was the most common barrier discussed. (R38: It has still been very expensive for our family — about \$25 000 so far. My husband can't retire until I am all better, but I am getting better now with [this current] care.) Geographic barriers also meant time away from work, the physical toll of travel, time away from family, and often the need for assistance when too ill or mobility impaired to travel alone. Finally, obtaining the medication in Canada that had been prescribed in the United States was problematic for some. (R45: As I lived 4 hours from the American border, it was difficult to get my medicine. I therefore had to procure them illegally and this caused me a lot of stress. My partner had to miss more than 20 days of work in order to accompany me to the doctor and get my prescription renewal.)

When asked how care for Lyme disease could be improved within Canada, there was a clear consensus. Respondents wanted (a) an effective treatment protocol (ie, long-term antibiotic treatment) along with supplements and lifestyle change recommendations; (b) an effective diagnostic test, as well as clinical diagnoses based on symptoms; (c) more knowledgeable physicians; (d) prescribing rights for naturopaths across the country; (e) financial coverage for alternative treatments by the Canadian health-care system; and (f) increased respect toward patients with Lyme disease, through the acknowledgment of the existence of the disease and the suffering of patients.

Discussion

We sought to document the lived experiences and motivations of Canadians leaving the CCHS to obtain diagnosis and care for Lyme disease. Respondents felt “pushed” out of the health-care system by their negative experiences and “pulled” into alternative care and medical tourism by positive experiences outside the system.

Respondents across the country reported difficulties attaining an initial diagnosis for Lyme disease and struggles to find care. These experiences are similar to those of American patients (15-17), suggesting that negative experiences within conventional health-care systems are shared between countries and between socialized and private health-care systems. Complex chronic conditions, medically or contested conditions and those resistant to treatment, have been well described as posing an exceptional strain on the health-care system and both physicians and patients (27-32). Others have also found that the burden of illness in unresolved conditions such as posttreatment Lyme disease syndrome is high and affects physical, emotional, and social function (33,34). Indeed, Lyme disease has been found to lead to disenfranchisement from the conventional health-care system at higher levels than other complex medical conditions (17,35). Our results suggest that patients with Lyme disease experience the delays in getting adequate treatment and the inadequate treatment options that characterize medical tourists (24), as well as the chronic pain and complex

chronic conditions that drive patients to access alternative health care (20,21).

Our respondents interpreted the unwillingness to diagnose Lyme disease as due to a lack of physician knowledge and experience, even in areas where Lyme disease is endemic and greater knowledge of the disease by physicians could be expected. Similarly, patients frequently described infectious disease specialists and neurologists as unhelpful, even though these specialists should be particularly equipped to recognize Lyme and Lyme-like illnesses. Of particular frustration was the reliance on a problematic (10,35,36) 2-tiered serological testing protocol for diagnosis of late-stage Lyme disease in Canada.

Many respondents were distressed when compelled to act outside of the recommendations of their Canadian physicians, illustrating the value they place on their relationship with family doctors, but also raising the concern that individuals may choose to withhold information regarding alternative treatments and medications from physicians. Among the factors “pulling” Canadians toward care outside of the CCHS was vigorous care-seeking, self-advocacy, and self-education, as in American patients (16,17). Although our respondents frequently cited the benefits of online resources, the quality of this information is unknown and may merit future research.

The attraction of Lyme support groups was presumably heightened by the perception of a stigma surrounding the disease. Indeed, respondents described physicians refusing to treat their condition for fear of repercussions from colleagues and professional associations. Selection of antibiotic(s) and treatment duration is controversial, with sparse and relatively low-quality (37) evidence supporting the 2 main treatment approaches. Nevertheless, positive responses to the treatments available only outside of the CCHS are reported here and elsewhere (15,24). One effect of the differing treatment protocols across countries is the significant psychological and financial burdens that many Canadian patients experience in accessing care for Lyme disease. Barriers to accessing care have been described previously (25,33), but the financial and psychological burden of Lyme disease in Canada remains relatively unexplored.

Clearly, this study has many limitations. Beyond the common challenges of using qualitative data, we recruited a disenfranchised group having actively sought treatment outside the CCHS and our results therefore do not necessarily reflect the experiences of all Canadians with Lyme disease. Those who received prompt and effective care for acute manifestations of the disease and those who were not affiliated with Lyme support groups are likely to have different experiences from this sample.

In conclusion, our results show that many individuals with Lyme or Lyme-like diseases are deeply dissatisfied with the care they received within the conventional health-care system in Canada. Perhaps more importantly, our results also describe the qualities that attracted patients to other forms of care—qualities that led to improvements in

both physical and emotional well-being. Research to improve diagnostics and treatment is needed and is actively underway. However, as our study participants made clear, ill Canadians deserve timely, effective, and compassionate care now and should not have to wait until more data are collected to receive it.

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Declaration of Conflicting Interests

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