



Article

“I Can Do Anything if I’ve Overcome That”: A Collaborative Case Study of an Adolescent with Symptoms of Lyme Disease in Canada

Sarah Ciotti * , Shannon A. Moore and Christine Tardif-Williams

Department of Child & Youth Studies, Brock University, 1812 Sir Isaac Brock Way, St. Catharines, ON L2S 3A, Canada; smoore@brocku.ca (S.A.M.); ctardifwilliams@brocku.ca (C.T.-W.)

* Correspondence: sc17kx@brocku.ca

Abstract: This qualitative case study explored the experiences of one Canadian adolescent with symptom-persistent Lyme disease. Lyme disease is the most prevalent vector-borne illness in North America, and infection rates are rising across Canada. Peak incidence occurs in children aged 5–9 years, making it a significant childhood infectious disease. This involves collaboration with an adolescent with symptom-persistent Lyme disease in Canada to address a gap in the literature. This empirical research was guided by the central research question: “What is the experience of an adolescent with symptom-persistent Lyme disease in Canada?” The purpose of this study was to understand the unique experiences of symptom-persistent Lyme disease in Canada by emphasizing one adolescent’s unique voice. The findings of this case study demonstrate the challenges this adolescent faced in receiving appropriate diagnosis and treatment for Lyme disease, pointing to a need for increased awareness among health professionals regarding the impact and prevalence of tick-borne illnesses for young people, their caregivers, and their healthcare providers. Additional findings suggest that collaborative healthcare may be beneficial for patients with symptom-persistent Lyme disease, and health researchers should continue to engage young people to ensure accurate representation of their experiences.

Keywords: adolescent; Canada; case study; collaborative healthcare; Lyme disease



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1. Background

Lyme disease (LD), the most prevalent vector-borne illness in North America, is an important children’s health issue worthy of investigation in childhood studies. Infection rates are rising across the country, and peak incidence occurs in children aged 5–9 years [1]. This study addresses a gap in current health research regarding the experiences of young people with symptom-persistent Lyme disease in Canada [2]. Contemporary notions of childhood perpetuate the viewpoint that illness and chronic pain in childhood are unnatural and anomalous. In recognition of the importance of the inclusion of children in research, opportunities for children and adolescents to engage in research have intensified in recent years [3], and previous scholarship has explored adolescent experiences with chronic illness/chronic disease [4–6]. Importantly, with respect to representations of children in the context of health research on LD, “few clinical trials of treatment for Lyme disease have been conducted in children. Most recommendations for the treatment of children are extrapolated from studies of adults” [7]. Exploring childhood health and illness through children’s participation in academic empirical research is key to advancing knowledge in this area.

1.1. Lyme Disease: Controversy and Opposing Perspectives

Over the past decade, researchers have questioned the classification of symptom-persistent Lyme disease in academic literature [7–9] and debated whether symptom-

persistent Lyme disease can be attributed to active infection [10,11]. In most cases, Lyme disease, when diagnosed in the acute stage, can be successfully treated with a short-term dose of antibiotics; however, a small minority of individuals develop significant long-term health consequences post-infection [12]. Symptom-persistent Lyme disease is commonly referred to as post-Lyme disease syndrome [7] or late disseminated Lyme disease [8] in the academic literature. The label chronic Lyme disease (CLD) has recently emerged in the academic literature, although the conventional health system does not recognize its existence [9,13,14]. Some researchers [15] argue that chronic Lyme disease is a construction of Lyme disease advocacy groups, pseudoscientists, and activists who are antiscience. Notwithstanding, patients with symptom-persistent LD have reported insufficient care within the conventional health system [9,13,16–20]. Patients face “Lyme denialism” because the conventional health system endorses a diagnostic approach that is not suitable for the clinical diagnosis of the disease [21]. Patients with previous Lyme borreliosis infections experience higher rates of mental health disorders and suicidal ideation [22], and higher rates of neuropsychiatric symptoms (although self-reported by patients) are not well-recognized by public health officials [23]. This points to some of the ongoing health challenges that patients with LD experience.

1.2. Children’s Experiences with Lyme Disease

In children, early LD symptoms include developmental, psychological, neurological, cognitive, and diverse physical symptoms [2]. Arthritis is the most common clinical presentation for children in the late disseminated stage of LD, which suggests the need for early-onset interventions and treatment of the disease [24]. “The prognosis for children with early Lyme disease who are treated with appropriate antimicrobial therapy is excellent” [25]. However, a Canadian qualitative research study found that “for many parents, their experiences within the Canadian healthcare system while seeking care for Lyme disease for their children was an intensively negative experience that led them to lose trust in mainstream doctors” [2]. The authors reported that parents of children with LD described their experiences in four stages: symptoms that were wide-ranging and difficult to manage, extensive testing and consultations with medical specialists, dismissal from doctors and suggestions of mental health diagnoses, and, finally, seeking care outside of the conventional healthcare system [2].

1.3. Research Aims and Objectives

This qualitative research study utilized a case study methodological approach [26,27] to explore one adolescent’s experience with symptom-persistent Lyme disease in health and social contexts. This empirical research was guided by the central research question: “What are the experiences of a young patient with symptom-persistent Lyme disease in Canada?” The purpose of this study was to understand the unique experiences of symptom-persistent Lyme disease in Canada by emphasizing one adolescent’s unique voice. This builds upon previous research, including Canadian research [2], that has explored the impact of Lyme disease on children in Canada from the perspectives of their adult caregivers. Understanding the perspectives of child patients with symptom-persistent Lyme disease is critical in advancing an understanding of this important children’s health issue. “Childhood studies has long advocated for an analysis that is focused on children’s lived experiences, views, and agency” [28]. This empirical research involves collaboration between the researcher and the adolescent patient to ensure equity and inclusion in the co-construction of new knowledge. The participant in this study was invited (and agreed) to review the data as they were collected and analyzed to ensure accuracy in the representation of his voice and experiences. This research holds the research participant as an important collaborator and stakeholder in the co-construction of new knowledge regarding child patient experiences with symptom-persistent Lyme disease in Canada.

1.4. Conceptual Framework

This research is rooted in a transdisciplinary theoretical framework, which seeks to address complex social issues by engaging multiple disciplinary perspectives to advance knowledge and improve social conditions [29–35]. Transdisciplinarity is interested in social action [36]. This study is multifaceted in that it explores issues related to children's health and illness, specifically children's experiences with symptom-persistent Lyme disease. Lyme disease is a complex and controversial illness that has real consequences for children and their families. In the co-construction of knowledge between the adolescent participant and the researchers, the adolescent participant was invited to share his experiences with symptom-persistent Lyme disease in ways that were meaningful to him in his own voice. Collaboration is a fundamental concept in transdisciplinary research [32]. Moving beyond children as subjects, this research involved a young participant in data collection, analysis, and the reporting of findings. "Transdisciplinary involves scientists from different disciplines as well as non-scientists and other stakeholders and, through role release and role expansion, transcends (hence "trans") the disciplinary boundaries to look at the dynamics of whole systems in a holistic way" [30]. In this study, the adolescent participant was a key stakeholder in the co-creation and production of new knowledge regarding (child) patient experiences with symptom-persistent Lyme disease in Canada.

2. Materials and Methods

The methodology guiding the design and methods of this investigation was case study methodology [26,27,37–39]. Case studies are used widely in small-scale social research to study an individual case in a natural setting [38] and offer an "in-depth investigation of a phenomenon" [27]. Data are collected from multiple sources [26], such as "interviews, documentation, archival records, direct observations, participant-observation, and physical artifacts" [37]. There have been several studies on pediatric cases of Lyme disease reported in the literature [40–44]; however, these studies have not included participants' experiences in their own voices, instead focusing on their experiences as told by adults (their caregivers and health providers). Idiosyncratically, "case study research encompasses a great deal more complexity than a typical case report and often incorporates multiple streams of data combined in creative ways" [37]. This case study provides a detailed representation of a young patient's experiences with symptom-persistent Lyme disease in Canada, drawing data from multiple sources: (i) semi-structured interviews with the youth; (ii) an online video created and uploaded by the family's provincial health authority that described the health care experiences of the patient and his family; (iii) photos of the patient when he was sick, including photos of an erythema migrans rash on his chest; and (iv) contributions from his mother who, at the request of the patient, was present during the interviews to add additional context to his experiences, given the length of time that had passed since he first became sick and because he was not privy to all of the healthcare decisions as a minor. Interview (textual) data were prioritized for their importance in highlighting this young person's experiences with symptom-persistent Lyme disease in his own voice. He exercised agency and voice by choosing to have his mother present in the interviews to provide supplemental information in telling his story. Additionally, photographs and video data sources were provided as supplemental information by the participant's mother.

2.1. Sampling and Recruitment

The research ethics board approval was received prior to commencement (REB #21-144-MOORE). Attempts were made to broadly recruit participants from across Canada to address regional variations in healthcare (provincial/territorial jurisdiction). Selective sampling occurred through outreach to Lyme disease research and advocacy organizations (i.e., the G. Magnotta Foundation for Vector-Borne Diseases, CanLyme, and Lyme Ontario). Parents were screened through an online survey, which also included a parental consent form. The adolescent who was the subject of this case study was recruited via an online screening survey. His mother completed the online screening survey (and parental con-

sent form) and then was contacted via email by the researcher. The participant and his mother were invited to take part in a virtual (online) semi-structured interview, and the informed assent form was sent to the participant and his mother for review prior to the interview. Written and verbal assent were provided by the participant. Figure 1 outlines the recruitment and data collection process:

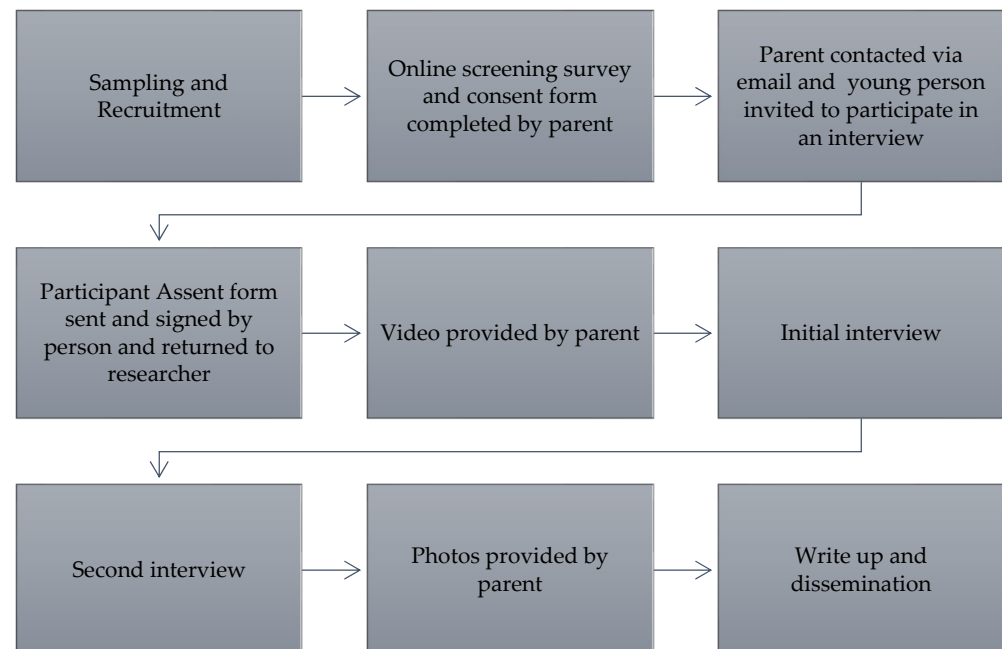


Figure 1. Recruitment and data collection process.

2.2. The Participant

The participant was a 15-year-old male patient who had symptom-persistent Lyme disease. He became infected with Lyme disease in Canada and sought medical treatment in Canada. He was diagnosed with Lyme disease in 2016 and received treatment from a pediatrician in collaboration with a naturopathic doctor specializing in Lyme disease out of province (but still in Canada). He was 8 years old when he first experienced symptoms of Lyme disease, and his symptoms escalated over the course of one year post-infection. He had been in remission (symptom-free) for over one year prior to participating in this research. The data collected are a retrospective of his experiences with the disease over the past seven years.

2.3. Methods and Procedures

The interview guide used in this research followed a semi-structured interview format that was developed to explore patient experiences with chronic illness [45]. The two interviews (initial and member checking) were conducted virtually online and with the participant's permission, and the interviews were recorded and transcribed. Prior to the initial interview, the patient's mother also shared a video for the research via email, which summarized the patient's and his family's experiences with the healthcare system. At his request, the patient's mother was present during the initial interview. A follow-up meeting was conducted to member-check the data with the participant [46] and review the findings/themes that emerged from the initial interview to ensure the accuracy of the findings. The initial findings and themes were sent to the patient and his mother prior to the follow-up meeting.

2.4. Data Analysis

Interview data were transcribed verbatim and analyzed using inductive thematic analysis [47,48]. The videos and photos provided were analyzed alongside the text data. A

key objective of thematic analysis is to provide “a rich thematic description of your entire data set, so that the reader gets a sense of the predominant or important themes” [47]. In this case study, it was important that the participant’s *voice* was represented. The codes and interpreted themes identified were present across the data set (videos, photos, and interviews with the participant and his mother). Examples of initial codes included opinions about the healthcare system (lack of trust in doctors, not being believed, frustration, not healing/seeing improvement in symptoms with treatments offered), thoughts/feelings about Lyme disease (initial confusion, then sadness and grief with persistent symptoms, and, finally, comprehensive knowledge regarding the severity of the disease), and experiences with chronic illness (mainly symptoms of pain, decreased mobility and fatigue, and impact on quality of life/overall functioning). Figure 2 outlines the data analysis process:

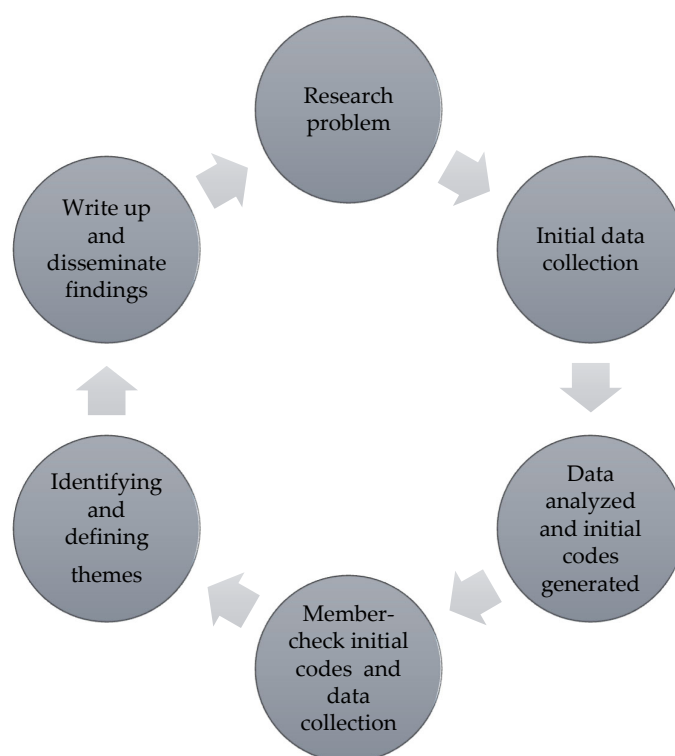


Figure 2. Data analysis process.

3. Findings

The findings of this case study provide a detailed account of the experiences of one adolescent who is a patient with symptom-persistent Lyme disease in Canada, additionally contextualized through the viewpoints of his mother and with visual representations (photos) of his illness at the time he was sick and receiving treatment. This young patient became ill, sought treatment and diagnosis within the conventional Canadian healthcare system, and then, after almost a year of failing to make progress within the conventional healthcare system, sought healthcare from a naturopathic doctor in collaboration with a pediatrician in Canada. Through analysis, one primary theme emerged from the data, 1. illness, healthcare experiences, and process, with the following subcategories: 1.1 initial infection, early localized symptoms, and preliminary knowledge of the tick-borne illness; 1.2 disseminated symptoms (early disseminated and late disseminated); 1.3 conventional healthcare experiences; and 1.4 health improvement through collaborative healthcare and naturopathic medicine. These findings are presented with quotations from the patient (and his mother) to ensure that his experiences are represented through his voice. Table 1 outlines the sources of data & themes that emerged through analysis:

Table 1. Sources of data and themes that emerged through analysis.

Theme		Sources of Data
1. Illness, Healthcare Experiences, and Process		
i	Initial infection, early localized symptoms, and preliminary knowledge of the tick-borne illness	Online screening video by a public healthcare provider
ii	Disseminated symptoms (early disseminated and late disseminated)	Initial interview (1.5 h) Member checking interview (1 h)
iii	Conventional healthcare experiences	Photos
iv	Health improvement through collaborative healthcare and naturopathic medicine.	

3.1. Illness, Healthcare Experiences, and Process

The participant was infected with Lyme disease, which was not immediately diagnosed. His symptoms progressed and manifested in variable ways. The experience navigating the conventional health system with Lyme disease was very challenging for the family, and they had several other experiences accessing conventional healthcare as points of comparison. Both the patient and his mother acknowledged their belief that doctors do their best to help patients and that they genuinely care but that there were challenges in treating Lyme disease. As his mother, who was diagnosed with cancer after her child's illness, poignantly stated:

I've always said that being diagnosed with cancer was like night and day to his Lyme disease because no one argued with me that we don't have cancer in [the province] or we don't have this type of cancer here or cancer can't come back once you've been treated. . . It was such a strange relief in some ways to be diagnosed with a disease that you knew that you were going to be able to get treatment for and there was no stigma and people aren't going to argue with you and professionals. (Mother)

Figure 3 outlines the patient's disease symptoms and timeline of illness.

3.1.1. Initial Infection, Early Localized Symptoms, and Preliminary Knowledge of Tick-Borne Illness

The patient recalled becoming ill after a family camping trip in May 2016. He described falling to the ground into a leaf pile after being hit in the head by a stick, and then within a couple of days of returning home from the trip, he discovered an erythema migrans (bullseye-shaped) rash on his chest. He explained:

I had this big red bullseye rash. . . I didn't think anything about it. I just thought it was a rash and so mom took a few pictures and then. We kind of forgot about it. . . (later) I got a like, a very, very stiff neck. Like, I couldn't turn my head. I got achy joints. (Patient)

With little prior knowledge of tick-borne illness, he shared that he thought little of the rash at the time because it had no meaning or significance. Importantly, he did not find an embedded tick, nor did he see a tick on his body. He did, however, see a tick crawling on the wall of the family home when they returned from the trip, and brought this to his mother's attention. He and his mother shared that it was not uncommon for the family to see ticks, as they spent a lot of time outdoors, but it was unusual to see them in the family home. Given that the family was not aware of the risks associated with tick bites, the presence of an EM rash was of no significance to them, and they did not seek treatment in the early stage of the disease.

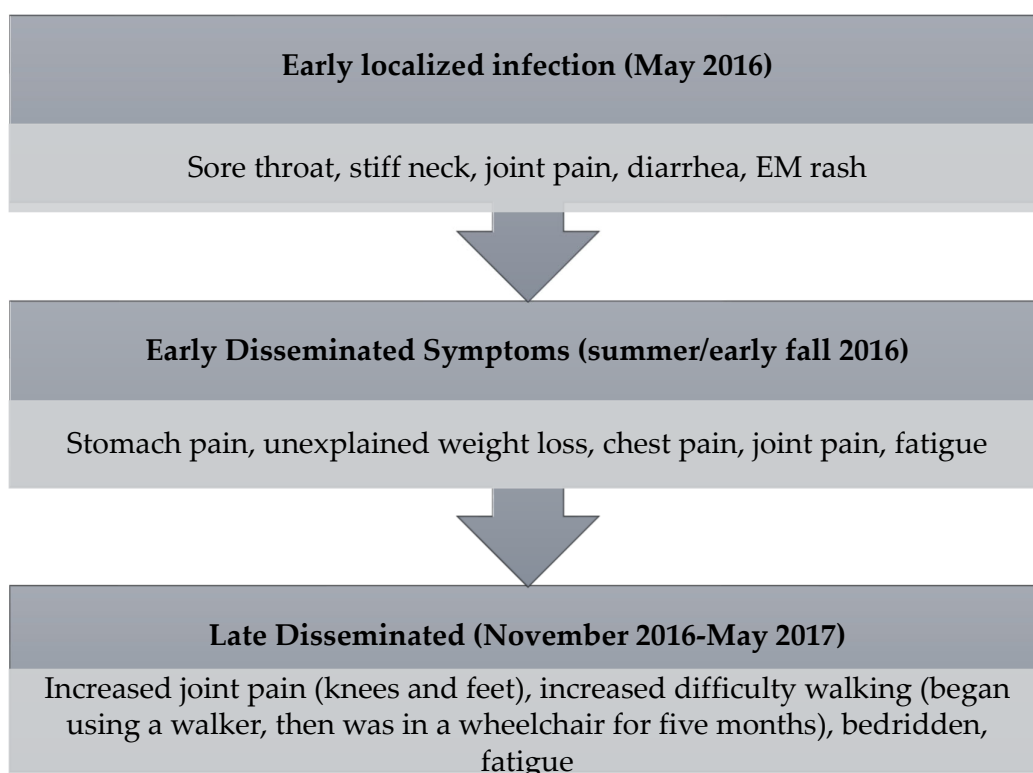


Figure 3. Disease symptoms a timeline.

3.1.2. Disseminated Symptoms (Early Disseminated and Late Disseminated)

Following the initial infection and early localized symptoms (stage 1), the patient experienced early disseminated (stage 2) and late disseminated symptoms (stage 3). The disease manifested through a variety of symptomology over the course of several months. He described his early experiences of the disease and associated pain, including stomach pain, chest pain, allergies, and fatigue.

In September 2016, I started getting like really bad chest pain, so, I called it striking. It felt like electrical bolts were going through my chest and then it started like a week or two later, it started moving through my body. I started getting that and soon it went through almost everywhere like sometimes I'd even have it in my teeth, it felt like... and it was like it wasn't a dull pain, it was a very sharp, painful pain and would, I would get a strike every 5 s almost. So, it was a really like there wasn't really any break in between it. (Patient)

These symptoms were very distressing and debilitating, and their presence was unexpected and confusing for the adolescent and his caregivers. The family sought healthcare for him; however, his disease continued to progress over the next several months and included increased pain throughout his body. He experienced various allergies and was diagnosed with oral allergy syndrome in the summer of 2016. Eventually, he noted that he was unable to walk unassisted due to the pain in his feet and knees.

I had sore muscles plus flushed cheeks, sore chest, the striking, a low-grade fever, sore joints, and I didn't want to bend my knees cause like it hurts so much to bend my knees... I wasn't able to walk on my feet because... that was the burning. So, it felt like if I was lying in bed, it would feel okay, but as soon as anything touched it, my feet just felt like they're burning. (Patient)

This was a pivotal point in his illness (and care) because he was a very active and athletic child prior to becoming sick. While seeking treatment at a children's hospital, he

happened upon a photo of the rash on his chest that his mother had taken shortly after he was infected (and initial symptoms occurred).

I knew Mom said she took a photo of a rash, but we did not know where it was, so I was like, is this a rash that you were looking for? (Patient)

The discovery of this photo provided a potential answer as to the cause of his mystery illness and debilitating symptoms. The family shared this with the treating health team as a source of information for a potential clinical diagnosis. They were met with skepticism, and a healthcare provider even told them that there was no Lyme disease in the province in which they resided. This was a very challenging time for the family. Importantly, there was something different about this disease—some in the family had experienced other diseases (autoimmune conditions, cancer, and stroke) and were treated very differently within the healthcare system.

3.1.3. Conventional Healthcare Experiences

The family experienced several challenges navigating the conventional healthcare system for this adolescent. Given his age and the severity of his symptoms, healthcare providers did not include him in many conversations regarding his care. Instead, his parents primarily dealt with the healthcare professionals to make decisions.

[He] was kept in the dark a lot about the stuff behind the scenes about who maybe was believing and not believing for lack of a better word. To put it simply, he didn't need to know about any of that. I'm sure that he picked up on some things, but it was people who believed us that knew that our son was sick. (Mother)

Although his mother identified that she was traumatized by her son's healthcare experience, he shared that he was not traumatized. He expressed feelings of gratitude that his parents kept him out of contentious discussions with healthcare providers. While he was excluded from the conversations regarding his healthcare, he did not experience this as disempowering, and in a way, this allowed him to maintain a sense of agency and power over his own story and experience by not making meaning from the adults who did not believe him. "For me, it doesn't bring back, like it brings back memories, but it's not like trauma like mom had" (Patient). At the same time, he did express that he experienced frustration with his doctors and the conventional treatment options offered to him after the treatments did not improve his symptoms. This is an example of how he asserted his agency and power within his position as a patient—by expressing his frustrations with his care to his parents. His goal was to feel better so that he could resume his normal activities, which included engaging in physical activities, like sports. He described his experiences with medication trials, wondering if he would see results but being disappointed on several occasions. This led to a lack of trust in the healthcare providers and doubt regarding their motivation, skills, and ability to help him improve his symptoms and quality of life. Although he experienced marginalization by not being included in his treatment decisions, he experienced empowerment in his trust and belief in himself that his health would improve despite his lack of confidence in the doctors (i.e., adults) treating him.

Honestly, I didn't know if I was going to get better, but I didn't, but I trusted I was gonna get better. Like, I didn't know really what they were doing. I knew, like a lot of the doctors, didn't believe me. Umm. Which kind of I was like, 'how can you not believe me?' (Patient)

The family was open to all diagnostic possibilities but did not want him to think that the adults treating him did not believe his account of his pain. A psychologist on the healthcare team quickly ruled out a psychosomatic diagnosis, but this turned into an inter-professional conflict that he was not aware of but that his parents were privy to.

3.1.4. Health Improvement through Collaborative Healthcare and Naturopathic Medicine

The patient eventually sought treatment from a naturopathic doctor (out of province) who specialized in treating symptom-persistent LD. His mother explained that the pediatrician (after seeing the patient's marked improvement in health symptoms and functioning) worked collaboratively with the naturopathic doctor. This collaborative care included consultations regarding therapeutic interventions (such as IV antibiotics through a peripherally inserted central catheter or PICC). The treatment he received from the collaborative care of the physician and the naturopathic doctor was arguably unconventional; however, it led to a significant improvement in his symptoms.

So, he worked with the physician [in the province he practiced], and they put a PICC-line in [him]. And so, yeah, to this day, I don't know any other patient, let alone a pediatric patient in the mainstream medical health system that had a PICC-line put in for Lyme disease treatment. So [he] went on, had a PICC-line for five or six weeks. I think of IV antibiotics and he dramatically got better, he was able to get out of the wheelchair. . . Umm, but they eventually agreed to treat him and after three months of being bedridden within 48 h, [he] started getting up and playing basketball again. Like it was like a dramatic difference again. (Mother)

Beginning naturopathic treatments marked a turning point in his health. He explained that he felt some assurance from the care he received from the naturopathic doctor. This care was meaningful and empowering for him—he felt seen and heard by this healthcare provider, and this restored his faith in the medical system.

I feel like he was the game changer, like because he started me on the meds, and I was like, no way, these are actually helping me! I was like, 'we actually found something that's going to help me'. (Patient)

Collaborative care proved beneficial for this patient. Shared power and knowledge production between his naturopath and pediatrician had a significantly positive impact on his symptoms and improved his overall functioning and quality of life. He experienced significant improvement in functioning and quality of life and a significant reduction in symptoms after beginning antibiotics and following the care and treatment plan offered by the naturopathic doctor in collaboration with the pediatrician. However, it is worth noting that he did experience relapses in symptoms and subsequently developed another condition called mast cell activation syndrome (MCAS), which required ongoing treatment to manage symptoms. However, with respect to his symptom-persistent Lyme disease, the patient and his mother attributed the improvement in his symptoms to the collaboration between the conventional (pediatrician) and unconventional healthcare providers (naturopathic doctor).

4. Discussion

The purpose of this case study was to investigate one adolescent's experiences with symptom-persistent Lyme disease in Canada. There is noticeable conflict within the academic literature on Lyme disease [2,7–11,13–16,49], and this case study points to the ways in which LD patients can be marginalized and caught in the middle of the so-called “Lyme wars” [50–52]. The dominant discourse in Lyme disease research has portrayed Lyme disease advocacy as ‘antiscience’ and ‘pseudoscience’ [15,53]. In this case, neither this patient nor his family was involved in LD patient advocacy, nor were they invested in seeking a specific diagnosis of Lyme disease. Rather, as demonstrated by the results of this study, this patient and his parents were focused solely on improving his health.

This young patient went from being an active, athletic child to being unable to walk unassisted within less than a year of discovering an erythema migrans (EM) rash on his chest. There was no ideological agenda motivating their choices to seek healthcare—this adolescent was suffering from pain, and he and his parents were open to all treatment options offered to them by the conventional health system. Only when his symptoms escalated and the treatment options offered failed did they seek alternative healthcare. These findings suggest that it is critical that researchers and health providers are open

to listening to the experiences of LD patients and their families who access care. Not all patients with symptom-persistent Lyme disease are taking part in ‘antiscience’ movements, and this represents a dangerous and disingenuous discourse that may perpetuate the same misinformation that it purports to critique. Importantly, outcomes for patients with LD are improved with earlier interventions of antibiotic treatments [54]; however, this patient did not receive this standard of care (despite previously having an EM rash).

4.1. Implications for Practice

The findings of this study support previous research illustrating that general practitioners (GPs) hold a significant amount of power as gatekeepers in patient care [55,56]. As Lyme disease incidence continues to rise across the country, this case supports previous research that found that individuals who spent time outdoors for work and recreation were at a higher risk of contracting Lyme disease but had low levels of knowledge about the risks of infection from ticks [57]. This study points to a continued need for improved public education and awareness of Lyme disease and the dangers of tick-borne illnesses and tick prevention. The patient and his mother expressed that they had little knowledge of the dangers of ticks prior to his illness. According to the Government of Canada [54], patients have better outcomes for Lyme disease if they receive early antibiotics. Presumably, had this patient received treatment in the early stage of the disease, it is possible that his outcomes would have been improved sooner, or perhaps they would not have progressed to such severity. This case draws attention to the continued need for physician education and training regarding the risks of tick-borne illnesses, which supports previous research findings [2] and current government interventions meant to inform the public about the risks associated with Lyme disease in Canada [54].

The case study is supportive of the findings of previous studies on Lyme disease that have highlighted the mistrust between patients and their healthcare providers [9,13,16] and patient dissatisfaction with the conventional healthcare system [2,16]. Previous research that investigated the experiences of parents of children with Lyme disease in the Canadian context found that parents reported dissatisfaction with their children’s healthcare [2]; however, by including the voice of a child patient (and his parent), this research adds additional context to these findings. Drawing from research on pediatric cancer, health providers are well-positioned to reduce distress and help patients and their families cope with disease [58].

Finally, this case points to the benefits of collaborative, multidisciplinary care for patients with symptom-persistent Lyme disease and, potentially, for the treatment of patients with other conditions. This supports previous research findings that interprofessional collaboration can improve healthcare [59,60]. In this case, the patient experienced improved outcomes after he received treatment from a naturopathic doctor who worked in collaboration with a pediatrician. Specifically, his quality of life dramatically improved as his symptoms were reduced—he went from being unable to walk unassisted and spending the better part of his day unable to move to playing sports at a competitive level. This speaks to the significance of a transdisciplinary approach to knowledge production that seeks to eliminate disciplinary boundaries and improve social conditions. When health professionals work collaboratively, it can lead to improved health outcomes for patients [59]. This further aligns with the biopsychosocial model of health [61,62], which seeks to understand health and well-being as multi-dimensional. Furthermore, previous studies have also argued that Lyme disease patients may seek treatment options outside of the conventional healthcare system when their healthcare experiences have been unsatisfactory [2,16].

4.2. Strengths and Limitations

A significant strength of this study is the collaboration between the researchers and the adolescent participant. This empirical study captures the unique and exceptional experiences of a 15-year-old Canadian boy who became infected with LD and then received a diagnosis and treatment for symptom-persistent Lyme disease within Canada. The findings

of this study highlight a child patient's experiences in health and social context in his own words. The procedures used (particularly the collaboration between participant and researcher) enhanced the findings by ensuring that the data analysis accurately captured the participant's experiences of health and illness, and concerted efforts were made to ensure the representation of the young patient in this research study by highlighting and member checking his voice.

The most significant limitation of this study relates to the small sample size of one participant. Although the results of this case study are not generalizable, this case contributes to the current understanding of the healthcare experiences of young people with symptom-persistent Lyme disease (and perhaps other complex diseases). This adolescent's experiences may be beneficial for health professionals and families who have children experiencing similar symptoms by offering insight into how best to engage young people in their healthcare. Furthermore, this case emphasizes the importance of health professionals working collaboratively to support children and their families within the healthcare system.

4.3. Recommendations

Although this case explored the experiences of one young patient with symptom-persistent Lyme disease in Canada, the findings suggest that further studies with large samples of national participants could be warranted. A mixed-method and multi-informant approach exploring the experiences of young patients with symptom-persistent Lyme disease in Canada might offer a deeper perspective on the research topic. Furthermore, longitudinal research could explore the unique social factors associated with young patients' short- and long-term experiences with symptom-persistent Lyme disease. This type of research could help to advance the understanding of the incidence and unique experiences of persistent Lyme disease among young people living in Canada. This might further inform clinical practices pertaining to the treatment of young people with Lyme disease across the country.

It is worth highlighting that this retrospective account of this patient's Lyme disease inflection occurred in 2016, three years prior to the emergence of SARS-CoV-2, and therefore, his experiences within the healthcare system must be understood in this context. Had he become ill post-COVID-19, his experiences would not necessarily reflect the care he would have received in the post-COVID pandemic health system. The impact of the COVID-19 pandemic on healthcare is relevant for understanding symptom-persistent Lyme disease. Interestingly, even the researchers who were the most skeptical of "chronic Lyme disease" were willing to acknowledge the existence of "post-COVID-19" conditions and the importance of learning from Lyme disease before "the vacuum will be quickly filled by pseudoscience and quackery" [53]. This is an area warranting further investigation.

5. Conclusions

Through this collaborative research, attention is drawn to a patient's embodied experiences and voice, offering a retrospective on how he and his family navigated the conventional health system (and then alternative healthcare) to treat his acute and later chronic illness. This study represents a detailed account of his health and illness and the meaning he derived from his experiences, including perseverance, hope, and resilience in the face of significant adversity. This case study serves as an example of the importance of continued participation by young people in research, policy, and institutions that impact their lives. The findings of this study suggest that governments and public health agencies across the country should continue to work toward the advancement of education on tick-borne illness for health professionals and the Canadian public at large so that Canadians can have a more accurate understanding of the associated health risks that ticks present to human health. Finally, a key finding points to the significance of collaboration between health professionals in improving health outcomes for patients.

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