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Lyme Disease, Trauma, and Disenfranchised Grief: A Brief Guide for Clinicians

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Abstract Lyme disease has become a contentious issue within both medical and public spheres. While initially recognized for its characteristic rash and flu-like symptoms, Lyme disease has evolved into a complex and controversial diagnosis, intertwining medical uncertainty with profound personal and societal implications. This conceptual paper explores Lyme disease as a contested illness, the trauma it can cause, and the phenomenon of disenfranchised grief experiences by those affected.

Keywords Lyme disease, contested illness, trauma, disenfranchised grief

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1. Introduction

The Center for Disease Control (CDC) reported that there were 63,000 cases of Lyme disease reported in 2022. However, they estimate that the numbers were actually higher. Based on medical claim data, the incidence rates of new cases of Lyme disease were at least 6 to 8 times higher than the 63,000 cases reported to the state health departments. This means that there were possibly over 500,000 new cases of Lyme disease in 2022 (CDC, 2024; Fagen, Shelton, & Luche-Thayer, 2023). The number of new Lyme disease cases in 2022 far exceeds the number of new breast cancer cases, 287,850 (Giaquinta et al., 2022) and new HIV cases, 38,043 (CDC, 2024). Although the numbers of Lyme disease cases have risen exponentially, treatment for the disease lags behind treatments for other mainstream medical conditions (Ferguson, 2012; Johnson, Aylward, & Stricker, 2011). This is due in part to Lyme disease being characterized as a contested illness (Dumes, 2020; Fagen et al., 2023; Ferguson, 2012; Kulkin, 2019; Rebman, Aucott, Weinstein, Bechtold, Smith, & Leonard, 2017).

2. Lyme disease a contested illness

Lyme disease is often described as a contested illness due to its complex presentation and the ongoing debate over its diagnosis and treatment. The disease's recognition varies widely, with some medical professionals firmly asserting its existence and others questioning its validity (Fagen et al., 2023). This controversy is fueled by the variability of symptoms, which can range from classic signs such as the erythema migrans rash to less specific complaints such as fatigue, joint pain, and cognitive difficulties. The broad spectrum of symptoms contributes to the diagnostic challenge and polarized opinions within the medical community (Ciotti, 2023; Fagen et al., 2023; Ferguson, 2012; Johnson et al., 2011; Kulkin 2019; Rebman et al., 2017).

In 2006, the Infectious Diseases Society of America (IDSA) published practice guidelines for the assessment, treatment, and prevention of Lyme disease. These guidelines discredited the existence of chronic Lyme disease, a condition that develops from persistent Lyme infection after the standard courses of antibiotic treatment (Ferguson, 2012, p. 196). It was later uncovered that the IDSA's guideline promulgation process was tainted. The IDSA did not organize any screening for conflicts of interest for its panel members. Some panel members had associations to drug companies and Lyme diagnostic tests and patents, as well as consulting arrangements with insurance companies. Some panel members obtained fees for acting as expert witnesses in medical malpractice suits related to Lyme disease. These panel members all stood to benefit financially if the restricted definition of Lyme disease remained the same (Ferguson, 2012, p. 215).

The aforementioned conflicts of interest paled in comparison to some of the actions that were taken by the IDSA panel members. The IDSA did not follow its own conflict of interest procedures, which allowed the panel chairperson, who held a bias against the existence of chronic Lyme disease, to choose a like-minded panel. The selection process was discharged without the careful examination of the IDSA oversight committee. The panel refused to accept any potential panel member who believed in the existence of chronic Lyme disease. Additionally, patients who attempted to have a voice in the guideline process were turned away (Ferguson, 2012, p. 215).

On the opposing side of the IDSA is the International Lyme and Associated Diseases Society (ILADS), which outlines that Lyme disease is often not recognized and may persist in many patients, requiring prolonged antibiotic therapy to eliminate persistent infection (Johnson et al., 2011, p. 65). The membership of the IDSA differs greatly from the membership of ILADS. The majority of IDSA members are infectious disease researchers, academicians, or government employees while the majority of ILADS members are primarily community healthcare providers who are attempting to address significant incapacitating illness in their patients. The controversy between the IDSA and ILADS over the diagnosis and treatment of Lyme disease has been largely uneven in terms of power and resources. The IDSA has been able to assert tremendous influence over the treatment of Lyme disease in the United States and has been the subject of an investigation by the Connecticut Attorney General (Ferguson, 2012; Hill & Holmes 2015; Horowitz, 2017; Johnson et al., 2011; Rebman, Aucott, Weinstein, Bechtold, Smith, & Leanord, 2017).

In 2008, the IDSA agreed to review its guidelines. The review board of the IDSA determined that that the guidelines were to remain unchanged. In its findings, the IDSA expressly outlined its continuing belief that there was no compelling evidence of chronic Lyme infection. As a result, many Lyme patients today continue to find themselves suffering without access to treatment (Ferguson, 2012, p. 215).

3. Trauma associated with Lyme disease

Lyme disease can inflict significant psychological and emotional trauma on patients. The trauma arises not only from the physical symptoms but also from the experience of being invalidated or dismissed by the medical community (Fagen et al., 2023). Many patients with Lyme disease face prolonged periods of uncertainty and struggle to obtain a definitive diagnosis, which can lead to feelings of frustration and despair (Boudreau, Lloyd, & Gould, 2018; Greenspan, 2019; Johnson et al., 2011). The difficulty in achieving a diagnosis often results in delayed treatment and a protracted illness course, exacerbating the psychological burden (Boudreau et al., 2018; Ciotti, 2023; Fagen et al., 2023; Greenspan, 2019).

The trauma is compounded by the often-invisible nature of the disease. Unlike more visibly apparent conditions, Lyme disease's symptomatology can be fluctuating and inconsistent, making it difficult for others to understand and empathize with the patient's experience. This invisibility can lead to additional stress and feelings of isolation as individuals may be perceived as exaggerating or fabricating their symptoms (Kulkin, 2019; Rebman et al., 2017).

Essentially, Lyme disease can be profoundly traumatizing for patients, both physically and emotionally. Here are some of the reasons why:

3.1 Physical suffering

The disease can cause a wide range of symptoms, from joint pain and fatigue to neurological issues like cognitive difficulties and numbness. The persistent and sometimes debilitating nature of these symptoms can be incredibly distressing (Fagen et al., 2023; Rebman et al., 2017).

3.2 Diagnostic challenges

Lyme disease is often difficult to diagnose because its symptoms overlap with those of many other conditions. This can lead to a prolonged period of uncertainty and frustration as patients seek answers and appropriate treatment (Ciotti, 2023; Fagen et al., 2023; Greenspan, 2019, Rebman et al., 2017).

3.3 Treatment struggles

Treatment can be complex and may involve long courses of antibiotics or other medications. Some patients experience significant side effects or find that their symptoms persist despite treatment, leading to a sense of hopelessness (Ferguson, 2012; Greenspan, 2019).

3.4 Social and occupational impact

The disease can interfere with a person's ability to work or maintain social relationships. This can lead to isolation, financial strain, and a loss of identity or purpose, all of which contribute to emotional trauma (Ciotti, 2023; Greenspan, 2019).

3.5 Emotional and psychological effects

Chronic illness often brings about feelings of anxiety, depression, and stress (Slightam, Brandt, Jenchrua, Lewis, Asch, & Zulman, 2018). The uncertainty and ongoing nature of the disease can exacerbate these feelings, leading to a sense of helplessness or despair (Fagen et al., 2023; Greenspan, 2019; Kulkin, 2019).

3.6 Stigma and misunderstanding

Some patients face skepticism or lack of understanding from others about the legitimacy or severity of their condition. This can lead to feelings of isolation or invalidation, which can be emotionally damaging (Fagen et al., 2023; Rebman et al., 2017).

Overall, the combination of physical symptoms, diagnostic and medical challenges, treatment difficulties, and the impact on daily life can make Lyme disease a deeply traumatizing experience for many people (Bransfield, 2017; Fagen et al, 2023). It is this trauma that lends itself to disenfranchised grief on the part of the Lyme patient (Greenspan, 2019; Kulkin 2019).

4. Disenfranchised grief and Lyme disease

As Doka (2002) points out, disenfranchised grief is “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (pp. 39-40). Lyme disease can cause disenfranchised grief in several ways, often related to the nature of the illness and its impact on a person’s life. Here is how Lyme disease may lead to disenfranchised grief:

4.1 Unseen or misunderstood illness

As previously mentioned, Lyme disease can be challenging to diagnose and often presents with symptoms that are not immediately visible or are misunderstood by others. This can lead to a lack of recognition and validation of the person’s suffering, making their grief feel unsupported and invalidated (Kulkin, 2019).

4.2 Chronic nature of the disease

Lyme disease can lead to long-term health issues, including chronic pain, fatigue, and cognitive difficulties. The ongoing nature of the illness can make it difficult for others to understand the full impact, and the individual may feel that their experience of loss and suffering is not fully acknowledged (Rebman et al., 2017).

4.3 Social stigma

There can be stigma associated with chronic illness or the idea that someone might be “faking” their symptoms (Fagen et al., 2023; Slightam et al., 2018). This stigma can lead to social isolation and a lack of empathy from others, further contributing to disenfranchised grief (Kulkin, 2019).

4.4 Loss of function and identity

Lyme disease can cause significant changes in a person’s ability to work, engage in hobbies, or maintain social relationships. The loss of one’s previous lifestyle and identity can be profound (Louw, Zimney, Cox, O’Hotto, & Wassinger, 2018; Nicolai et al., 2018), but if these changes are not recognized or understood by others, the individual may experience grief that feels unrecognized.

4.5 Lack of support systems

The fragmented nature of Lyme disease treatment, with varying opinions and treatment approaches, can leave individuals feeling unsupported (Greenspan, 2019). The lack of a clear path to recovery or acknowledgement of the disease’s impact can make their grief feel isolated.

4.6 Internalized grief

When external support is lacking, individuals might internalize their grief, feeling like their pain is invalid or that they should hide their suffering. This internalized grief can compound feelings of disenfranchisement (Doka, 2002).

Altogether, disenfranchised grief related to Lyme disease often stems from the intersection of the illness’s invisible nature, the chronic impact on life, and the lack of adequate social or medical support (Greenspan, 2019; Kulkin, 2019). Individuals with Lyme disease may grieve not only for their lost health but also for the normalcy of their previous lives. This grief is compounded by the lack of public awareness and empathy, leading to a sense of isolation. Friends, family, and even healthcare providers may not fully appreciate the scope of the illness, contributing to a sense of disenfranchisement. This lack of acknowledgement can hinder the grieving process, making it more challenging for patients to find closure and support (Ciotti, 2023; Doka, 2002; Rebman et al., 2017).

5. Conclusion

Lyme disease exemplifies the complexities of contested illnesses, where medical uncertainty intersects with profound personal and societal consequences (Fagen et al., 2023; Rebman et al., 2017)). The trauma associated with Lyme disease extends beyond physical symptoms to include emotional and psychological impacts arising from invalidation and isolation (Greenspan, 2019). Moreover, the phenomenon of disenfranchised grief highlights the profound losses experienced by those affected and the societal failure to fully acknowledge and support their struggles (Doka, 2002). Addressing these issues requires a more nuanced understanding of Lyme disease, greater empathy from the medical community and society, and improved support systems to validate and assist those living with the disease (Fagen et al., 2023; Ferguson, 2012; Kulkin, 2019). Only through a comprehensive approach can we hope to mitigate the trauma and grief experienced by those affected by Lyme disease and ensure that their suffering is recognized and addressed.

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