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Obsessive-compulsive symptoms in adults with Lyme disease

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ABSTRACT

Objective: This study examined the phenomenology and clinical characteristics of obsessive compulsive symptoms (OCS) in adults diagnosed with Lyme disease.

Method: Participants were 147 adults aged 18–82 years (M = 43.81, SD = 12.98) who reported having been diagnosed with Lyme disease. Participants were recruited from online support groups for individuals with Lyme disease, and completed an online questionnaire about their experience of OCS, Lyme disease characteristics, and the temporal relationship between these symptoms.

Results: OCS were common, with 84% endorsing clinically significant symptoms, 26% of which endorsed symptoms onset during the six months following their Lyme disease diagnosis and another 51% believed their symptoms were temporally related. Despite the common occurrence of OCS, only 44% of these participants self-identified these symptoms as problematic. Greater frequency of Lyme disease symptoms and disease-related impairment was related to greater OCS. In the majority of cases, symptom onset was gradual, and responded well to psychological and pharmacological treatment. Around half of participants (51%) reported at least some improvement in OCS following antibiotic treatment.

Conclusions: This study highlights the common co-occurrence of OCS in patients with Lyme disease. It is unclear whether OCS are due to the direct physiological effects of Lyme disease or associated immunologic response, a psychological response to illness, a functional somatic syndrome, or some combination of these.

1. Introduction

Lyme disease (LD) is the most common vector borne illness in the United States [1]. LD is an infection caused by the *Borrelia burgdorfi* bacteria, and is transmitted primarily via tick bites [2]. Typical manifestations usually emerge within days or weeks following the bite, and include a localized skin rash, followed by some flu-like symptoms (e.g., fatigue, fever/chills, headache, stiff neck and joint pain) [3]. Diagnosis is usually confirmed via physician observations of clinical manifestation (e.g., erythema migrans rash of at least 5 cm in diameter) and often includes laboratory confirmation of exposure to the *Borrelia burgdorfi* bacteria (e.g., serological tests such as the enzyme-linked immunosorbent assay (ELISA) or the Western Blot test) [1]. The Centre for Disease Control requires a two-tier approach to serologic confirmation of LD infection, with positive results on both the enzyme immunoassay (e.g., ELISA) and immunoblot (e.g., Western Blot) tests. In addition to infecting the host with LD, coinfections such as babesiosis and ehrlichiosis are common [4,5]. Symptoms of LD vary greatly, and can include musculoskeletal symptom (e.g., arthritis), neurological symptoms (e.g., lymphocytic meningitis, cranial neuritis, radiculopathy, encephalomyelitis with intrathecal antibody production), or cardiac symptoms (e.g., second or third degree atrioventricular conduction delays). If treated early, symptoms can be transient and mild, and remit. However if left untreated, the course can be characterised by a waxing and waning course of symptoms. In addition to these physiological and neurological symptoms, neuropsychological studies have found some cognitive impairments in a portion of patients with LD, namely in memory, concentration, learning and conceptual ability [6–9]. Many of these cognitive impairments associated with Lyme encephalopathy improve following antibiotic treatment [2,7,8].

Neurological symptoms are well-recognised symptoms of LD and occur in approximately 15–40% of patients [2]; however there is less

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understanding about the neuropsychiatric effects. Conditions including depression, mania, delirium, dementia, psychosis, obsessions and compulsions, and panic attacks have all been reported to occur after infection with LD [2,10], however causality has not been established [3]. For example, although elevated rates of depression have been noted in LD patients, greater rates of depression are commonly noted in a range of medical populations compared with controls [3]. Positive serological tests alone are not sufficient for diagnosis, or for symptoms to be attributable to LD. LD has often been presumed to be a functional or psychogenic disorder as a result of inadequate sensitivity and specificity of serologic tests [11] and both underdiagnosis and overdiagnosis of Lyme disease has been reported in the context of primary or prominent neuropsychiatric symptoms [3,11]. Late stage manifestations of LD often include mild to severe encephalopathy, polyneuropathy and profound fatigue. These symptoms can often be complex to differentiate from psychiatric symptoms, as patients commonly present with irritability, tearfulness, depressed mood, and concentration and sleep problems [9]. Memory loss, word finding problems and polyneuropathy may assist with differential diagnosis in favour of LD [9]. Other psychiatric symptoms such as paranoia, hallucinations, panic attacks, bipolar disorder, dementia, agitation, and anorexia have also been noted [9,12–14]. In a study of 200 seropositive patients, Fallon, Nields, Burrascano, Liegner, DelBene and Liebowitz [9] found that neuropsychiatric symptoms were common, with 94% of patients experiencing fatigue, 83% experiencing memory problems, 70% experiencing photophobia, 69% experiencing word reversal when speaking or letter reversals when writing, 57% experiencing spatial disorientation, 48% experiencing auditory hypersensitivities, 33% experiencing taste hypersensitivities, and 25% experiencing olfactory hypersensitivity. This study also found that psychiatric symptoms were common, with 64% reporting irritability and/or emotional lability.

There has been an ongoing interest in the relationship between immune mechanisms and Obsessive Compulsive Symptoms (OCS) [15]. For example, elevated rates of OCS have been noted in adults with lupus [16]. Obsessions are characterised by recurrent and persistent thoughts, urges or images that are experienced as unwanted and distressing [17]. Compulsions are stereotyped patterns of repetitive behaviours and rituals (e.g., handwashing, ordering, checking) or mental acts (e.g., counting, repeating words) [17]. LD has been identified as a potential trigger for OCS and tic symptoms in children with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS), with remission of symptoms following antibiotic treatment [5,18–21]. The presence of obsessional thoughts and checking compulsions along with sudden onset anxiety were noted in one case study of a patient with LD [12].

To our knowledge, this is the first systematic study of OCS amongst patients that self-report chronic LD. This study aimed to examine the phenomenology and clinical characteristics of OCS in adults self-reporting as diagnosed with LD.

2. Method

2.1. Participants

Participants were 147 adults aged 18–82 years (M = 43.81, SD = 12.98) with LD recruited from online forums. Participants were primarily female (n = 117; 79.59%) and Caucasian (n = 146; 99.32%). Participants were recruited via online support groups for individuals with Lyme disease (Lymenet, MDJunction: Lyme Support and Lyme Connect) to participate in a study about “Lyme disease and associated problems”. Participants were excluded if their LD diagnosis had not been confirmed by a physician (per patient report) or if they did not complete the Obsessive–Compulsive Inventory – Revised [22]. Demographic information is reported in Table 1.

Table 1
Participant demographics and Lyme disease characteristics (N = 147).

	N	%
Marital status		
Single	37	25.2
Married	82	55.8
Cohabitating	8	5.4
Divorced	16	10.9
Widowed	4	2.7
Highest level of education		
Did not complete high school	6	4.1
High school	19	12.9
Some college	40	27.2
Completed college	22	15.0
Graduate school or professional training	59	40.1
Missing	1	0.4
Income (USD$)		
< $30,000	33	22.4
$30,001–$50,000	34	23.1
$50,001–$80,000	30	20.4
$80,001–$110,000	23	15.6
> $110,000	25	17.0
Missing	2	1.4
Lyme disease diagnostic method[a]		
Positive Western blot (IgM or IgG)	86	58.5
Clinical diagnosis	81	55.1
CDC Positive Western blot (IgM or IgG)	49	33.3
ELISA blood test	29	19.7
PCR	8	5.4
Antigen capture	2	1.4
Lumbar puncture	2	1.4
Other	18	12.2
Coinfections		
Bartonella	73	49.7
Babesiosis/babesia microti	60	40.8
Ehrlichiosis/Anaplasmosis	21	14.3
Other	30	20.4
Lyme disease treatment status		
Current symptoms in active treatment	101	68.7
Symptom free and in active treatment	3	2.0
Current symptoms and no current treatment	31	21.1
In remission	12	8.2

[a] Participants could endorse multiple diagnostic tests.

2.2. Measures

2.2.1. Disease characteristics

Participants endorsed the presence and mode of physician confirmed LD diagnosis, the presence of coinfections (bartonella, babseiosis, ehrlichiosis/anaplasmosis), whether their symptoms were active or in remission, their current treatments, and the presence/absence of current psychiatric and neurological symptoms.

2.2.2. Obsessive–Compulsive Inventory – Revised (OCI-R) [22]

The OCI-R is an 18-item self-report measure of distress associated with common obsessions and compulsions over the past month, including washing, checking, ordering, obsessing, hoarding, and neutralizing. This measure has shown good convergent validity, and is able to discriminate OCD from other anxiety disorders [22,23].

2.2.3. Sheehan Disability Scale (SDS) [24]

The SDS is a 3-item measure of functional impairment across three domains: work, social/leisure and family/home responsibilities. This scale was rated twice: once to assess the level of impairment caused by OC symptoms, and a second time to assess the level of impairment caused by Lyme disease symptoms and symptoms of coinfection.

2.2.4. Lyme and Obsessive-Compulsive Symptoms Scale (LOCSS)

This 18-item self-report questionnaire was created for this study. Participants answered a dichotomous yes/no question about whether they believed that experience OCS. This measure included questions