

Why psychologists need to know about Lyme disease

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People with undiagnosed Lyme disease may present with chronic fatigue, mental health problems, neuropsychological impairments and autistic spectrum disorders. This article considers the evidence across each of these areas, before discussing how psychologists can recognise and support people with Lyme disease.

LYME DISEASE is a bacterial illness spread by ticks. It is found all over Europe and North America. It is relatively rare in the UK, but the number of reported cases is increasing (HPA, 2008). It can be complicated by co-infections, as ticks often carry other bacteria and parasites that make the disease more difficult to treat. People with undiagnosed Lyme disease may end up in psychological services either because of the psychological consequences of the illness or because the symptoms are mistaken for those of other disorders. People may be referred for cognitive behaviour therapy for chronic fatigue syndrome, for the psychological manifestations of Lyme disease, for neuropsychological investigation of their cognitive impairments or for assessment of autistic spectrum disorders. A purely psychological approach will not be enough to help those with Lyme disease receive appropriate treatment. Psychologists can play a crucial role in identifying these people and referring them for the antibiotic treatment that may transform their lives.

Lyme disease is caused by spirochete bacteria similar to the bacteria that causes syphilis. In the early stages of infection, around 30–60 per cent will have a characteristic bulls-eye rash (Stricker et al., 2005). This may be followed by mild to severe flu-like symptoms. If untreated, the bacteria can disseminate to the central nervous system and

cause a wide range of symptoms, including fatigue, nerve, joint and muscle pain, cardiac problems, neurological problems, difficulties with mood, concentration and sleep, and other psychiatric problems. The course can be fluctuating, with periods of improvement and periods of relapse. If Lyme disease is not adequately treated, infection often persists and affects a wide range of systems within the body.

Chronic fatigue syndrome

Donta (2002) argues that Lyme disease is one of several infectious causes of chronic fatigue syndrome (CFS). He points out the large symptom overlap between the two disorders: both consist of fatigue, neurocognitive dysfunction, muscle and joint pain. There is evidence that Lyme disease can lead to a chronic fatigue-type illness. Gustaw (2003) found that over 70 per cent of people with a history of Lyme disease met criteria for CFS. Treib et al. (2000) tested the blood of over 1000 healthy young males and found that men who tested positive for the bacteria that causes Lyme disease showed significantly more chronic fatigue than those whose tests were negative. However, other studies comparing people with CFS and healthy controls did not find that the CFS group are more likely to test positive for Lyme disease (MacDonald et al., 1996; Schutzer & Natelson, 1999).

Mental health problems

Hájek et al. (2002) screened over 900 people who were admitted to a psychiatric centre for antibodies to Lyme disease. They found that 33 per cent of the psychiatric population tested positive for Lyme disease, compared to 19 per cent of a similar sized control group.

In a review article, Fallon and Nields (1994) reported studies linking Lyme disease

with major depression, panic attacks, paranoia, schizophrenia, bipolar disorder, dementia, anorexia nervosa and obsessive-compulsive disorder. Of course, these problems may simply be comorbid, or develop as a result of dealing with an unpredictable complex illness. However, there is reason to believe that mental health problems can arise as a direct consequence of Lyme disease. Fallon et al. (1997) outline three strands of evidence supporting this view: the frequency of psychiatric disorders is greater in people with Lyme disease than amongst other medical conditions; many people with Lyme disease develop mental health problems without a prior psychiatric history; and these mental health problems may improve after antibiotic treatment alone. Moreover, single photon emission tomography (SPECT) studies have shown that people with Lyme disease typically show multifocal areas of decreased perfusion in the cortex and subcortical white matter (see Fallon et al., 1997, for a review).

Autistic spectrum disorders

Bransfield et al. (2007) have argued that Lyme disease may increase vulnerability for the development of autistic spectrum disorders. They draw on evidence that shows that Lyme disease can be passed from an infected mother to her unborn child and cause neurological problems as well as vulnerability to other infections. These effects on the developing body and brain may lead to autistic spectrum disorders. They provide some evi-

dence for this theory, reporting several studies that show 20–30 per cent of people with autistic spectrum disorders are positive on blood tests for the Lyme disease bacteria.

Neuropsychological impairments

Westervelt and McCaffrey (2002) reviewed the literature and found evidence of mostly mild deficits in verbal memory (particularly list learning), verbal fluency, upper extremity fine motor speed/coordination and oral agility, and speed of processing – problems that are consistent with primarily frontal systems involvement. However, people with Lyme disease have an idiosyncratic neuropsychological profile and thus there may not be a classic neuropsychological pattern associated with Lyme disease. These impairments seem to be unrelated to the depression often found in people with chronic Lyme disease, and evidence suggests that they can improve with antibiotic treatment (Westervelt & McCaffrey, 2002).

In rare cases, Lyme disease can be associated with other neurological problems such as dementia, demyelinating disorders mimicking multiple sclerosis, seizure disorders, hemiparesis, aphasia, ataxia and stroke (Westervelt & McCaffrey, 2002).

In children, deficits in memory, reading comprehension, handwriting skills, speech fluency, mathematics, visual skills and executive functioning can all be a result of Lyme disease. Alarm bells may be rung if one or more of these problems occurs alongside physical symptoms of the illness (e.g. fatigue and headaches) or uncharacteristic emotional or behavioural presentations. Hamlen and Kliman (2007) note that symptoms often develop in a previously well-functioning child, onset may be gradual, symptoms may fluctuate over time and problems can be confused with attention deficit disorder or oppositional defiant disorder.

The experience of Lyme disease

The experience of having such a complex and controversial illness can be devastating to people and their families. Fallon et al. (1992) conducted clinical interviews and obtained written descriptions from around

Resources

Lyme Disease Action – UK based charity:
www.lymisediseaseaction.org.uk

International Lyme and Associated
Diseases Society:
www.ilads.org

Leaflet – What psychiatrists should know
about Lyme disease:
www.ilads.org/PsychiatristBrochure.pdf

Eurolyme – Support group:
[http://health.groups.yahoo.com/
group/EuroLyme/](http://health.groups.yahoo.com/group/EuroLyme/)

200 people with chronic Lyme disease. They found that respondents reported that the fluctuating nature of the illness made it difficult for people to make plans, for example to try to return to employment. It can confuse other people as it may seem as though the symptoms are under voluntary control or of psychological origin. Many people are not diagnosed for several years, and during this period they may believe that they are going mad. This view is often confirmed by a referral to psychiatry.

There is great controversy in the medical field as to how to treat Lyme disease, with the Infectious Diseases Society of America (IDSA) producing guidelines that claim that a short course of antibiotics always cures the illness (Wormser et al., 2000). However, symptoms can persist or return many years later (Logigian et al., 1990), leading other doctors to produce guidelines that state that longer term antibiotic treatment is necessary for some people (Cameron et al., 2004).

What psychologists can do

Psychologists are likely to encounter Lyme disease before it is diagnosed, and recognition of the disease could radically alter someone's life. Therefore psychologists should:

Have basic knowledge about Lyme disease

- Lyme disease is a bacterial infection carried by ticks.
- People may not remember the tick bite or show the bulls-eye rash.
- It has a fluctuating course, and symptoms may not appear for months or years.
- It can cause a wide variety of physical, cognitive, and psychological symptoms.
- Diagnosis is primarily based on clinical symptoms, as laboratory tests produce many false negatives.
- Treatment is through antibiotics, but the duration of this is fiercely disputed.
- People may worsen on initial treatment with antibiotics, before improving.
- People may continue to have symptoms after a short course (2–4 weeks) of treatment.

Know what to look for

The questions below represent a summary of issues raised in an educational leaflet aimed at psychiatrists (Sherr & Solomon, 2004). This is not an evidence-based diagnostic measure; the aim is to aid psychologists in their consideration of Lyme disease. Answering yes to several of the questions below suggests that it may be worth referring this person on for further assessment for Lyme disease. However, every person with Lyme disease has a different constellation of symptoms, and few will answer yes to all of these questions:

- *Exposure:* Do they enjoy outdoor activities where they may have been bitten by a tick? Do they have a dog or cat?
- *Medical history:* Do they have a history of many different physical symptoms, perhaps with a fluctuating course? Have they experienced a bulls-eye rash, fatigue, joint or muscle pain, severe headaches, sound or light sensitivity, burning or pricking pain, twitches, heart problems, word-finding problems, short-term memory loss, tremors, Bell's palsy (temporary paralysis of half of the face), shooting pains?
- *Psychological problems:* Are these unusual or atypical? Is there a lack of a clear stressor or psychological precipitant? Is there a lack of personal or family history of psychological problems? Were they over 40 years old when problems first emerged? If panic attacks are present, do these last longer than half an hour? If depression is present, is there marked mood lability?
- *Cognitive problems:* Do they report problems with memory, attention, or concentration? Do they have problems with conversation, reading, problem-solving, decision making? Do they have slower processing speed?

How to support people with Lyme disease

Psychologists can help other professionals consider whether a psychological formulation makes sense or whether a psychological origin has been proposed just because a physical disease is not immediately apparent.

If Lyme disease is suspected, then the person can be referred to an Infectious diseases specialist for further assessment. However, it is important to note that Lyme disease is not yet well known amongst the medical profession in the UK, and so it cannot be assumed that all doctors will be aware of the illness and the issues around diagnosis and treatment.

After a diagnosis is made, people may continue to require support as the illness is often long and medical advice is conflicting. Some people may benefit from being pointed towards support groups on the internet (see the Resources box). Psychologists may also be able to work with other professionals who see people with Lyme disease or to work directly with groups of people with Lyme disease. In this way they could help others to provide support and teach psychological techniques to help people cope with a long and variable illness.

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Conclusion

Psychologists might see people with undiagnosed Lyme disease referred for help with CFS, mental health problems, neuropsychological assessment or autistic spectrum disorders. If Lyme disease is suspected, people can be referred to the infectious diseases speciality for further assessment. As there are many controversial aspects around the diagnosis and treatment of Lyme disease, people may benefit from support from other people with Lyme disease via internet support groups or from other professionals who may require education about Lyme disease.

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