

## Abstract

In this article, we examine the arguments made by authors of published academic articles concerning the debates surrounding chronic Lyme disease. Chronic Lyme disease is an example of a contested condition and shares problems of legitimacy with other medically unexplained conditions such as chronic fatigue syndrome. We use a critical discourse analysis approach to understand the arguments of the authors to establish the legitimacy, or not, of a chronic Lyme disease diagnosis. This enabled us to make sense of the nature of the stalemate between patient groups and advocates of the medical establishment, as performed by authors of academic articles. In this article, we bring together the arguments in order to explain the polemical debate and to support accounts that avoid the impasse to give us greater insight into the experience of chronic illness.

## Introduction

Lyme disease has the distinction of being both a bio-medically described bacterial infection, contracted from a tick bite, and a disputed chronic condition. This makes it an interesting case to study from the perspective of diagnosis. The majority of patients are successfully treated after satisfying clinical and sometimes serological tests (Kowalski, Tata, Berth, Mathiason & Agger, 2010). However, a minority report suffering from a variety of ongoing symptoms which they attribute to Lyme disease, either after diagnosis (Wormser et al., 2006) or without diagnosis (Borgermans, Goderis, Vandevoorde & Devroey, 2014). Thus Lyme disease in its chronic form has the characteristics of a medically unexplained symptoms (MUS) condition. However, unlike other MUS conditions, such as chronic fatigue syndrome, the chronic manifestation of Lyme disease has the potential to affect the diagnosis and treatment of the medically recognised infection (Aronowitz, 2012).

Due to the contested nature of the diagnosis, chronic Lyme disease (CLD) patients have organized themselves into a social movement to campaign for greater access to health care. Generally, health social movements are formed with several objectives; first to improve access to services, second to draw attention to health inequality and third to address illness experience by challenging science on aetiology, diagnosis and treatment (Brown et al., 2004). It is the third objective, characterised by Brown et al. (2004) as embodied health movements (EHM), that we examine in this article. We are interested in the effects on academic literature of the social movement connected with CLD patients, both as perpetuated by the patient movement and in the responses of the medical establishment. In order to examine how EHMs impact on academic literature we employ critical discourse analysis to examine the positions and legitimating strategies used by authors of six articles on the experiences of patients with Lyme disease included in a systematic review on patient experiences of Lyme disease diagnosis (Brunton et al., 2017).

Campaigns for contested illnesses, such as CLD, focus on diagnosis since it is through diagnosis that an illness gains legitimacy and entry into the medical system (Zavestoski et al., 2004). Chronic Lyme patients' groups also exhibit the characteristics of evidence based activism. This type of EHM brings together experiences of a disputed illness with scientific knowledge to challenge orthodox medical opinion, in order to open up a political debate about the condition. Thus it combines the politics of knowledge with the politics of health (Rabeharisoa, Moreirab & Akricha, 2014). In this case, patients' groups have set up their own medical guidelines in America for the diagnosis and treatment of CLD, based on the experiences and knowledge of community care professionals (Johnson, Aylward & Stricker, 2011). Thus patient groups challenge the medically endorsed guidelines through the production of their own artefact of evidence based medicine. The same strategic process is accomplished in the articles examined for this article, as patients' groups sponsor and support research into the experience of CLD, using scientific processes, namely research methods and publication, to legitimise their experiences. This contributes to the 'proto-professionalization' of patients and increases their expectation of a bio-medical explanation (Dent 2006; Greco 2017, p. 120).

EHMs are also a product of the democratization of knowledge, seen in the health context as the incorporation of the patient experience into the management of health problems. Patients and doctors are encouraged to work together, the patient as a citizen owning the problem and the doctor using knowledge to shape the problem (Greco, 2017). Doctors are often anxious about dealing with an illness they cannot explain (Yon, Nettleton, Walters, Lamahewa & Buszewicz, 2017), a feeling heightened by the perceived changing power relations between them and their patients (Greco, 2017).

Thus relations between doctors and MUS patients can be troubled. In particular, the patient is put in a difficult position of having no choice about engaging with medical science

to access care and being forced to appear as a credible patient in a system that regards their condition as illegitimate (Dumit, 2006). In response to a lack of a linear causal narrative, doctors may resort to psychosomatic explanations. Patients react against these explanations because of the stigma associated with them and thus the result of the therapeutic encounter can be a polemical polarization (Greco, 2017).

Our aim in considering these articles as arguments for the biomedical and the EHM positions on CLD is to understand the persuasive approaches used by authors rather than to adjudicate between the different perspectives. Simply describing the patient experience and the response of the medical establishment would repeat the polemical divisions that exist between them (Greco, 2012). We argue that an analysis of author arguments and strategies of persuasion might offer a way forward to bridge the divide between those promoting patient experience and those defending the primacy of biomedical evidence. To this end, we use critical discourse analysis (Fairclough, 2003; Mullet, 2018) to examine how both parties legitimate their positions concerning diagnosis.

## Method

Critical discourse analysis (CDA) is an inductive analytical approach that seeks to reveal hidden power relations through examining the persuasive techniques in texts (Fairclough, 2003; Mullet, 2018). We employ the seven stage 'General Analytic Framework for CDA' as outlined by Mullett (2018). In brief, the seven stages of analysis are 1) selecting the discourse, 2) locating and preparing texts, 3) exploring the background of each text, 4) coding the texts and identifying overarching themes, 5) analysing external relations, 6) analysing internal relations and finally 7) interpreting the data. The specific steps we undertook in relation to each of these stages are outlined below.

### 1) Selecting the discourse

The discourse of interest, i.e. the patients' experience of Lyme disease, was identified during

the course of our systematic review on Lyme disease (Brunton et al., 2017). We wanted to understand whether examination of the persuasive approaches used by authors could assist in the interpretation of our review findings and whether the approach may be useful in reviews on other contested issues. In preparation for the discourse analysis, we read background material and commentary about the debates surrounding Lyme disease (e.g. Aronowitz 1991, 2012; Auwaerter & Melia, 2012; Borgermans et al., 2014). This enabled us to understand references to the different medical guidelines and be aware of heterodox sources of diagnosis and treatment, such as the Lyme literate physicians in the USA. We also read articles written from the MUS perspective (e.g. Nettleton, 2006; Yon et al., 2017; Barker, 2008) since these provided us with a critical and theoretical vocabulary to identify the underlying arguments of the heterodoxy (Aronowitz, 2012) and the orthodoxy (Greco, 2017).

## 2) Locating and preparing texts

In order to examine how various authors constructed the legitimacy of patients' illness experiences, we analysed articles reporting on patients' experiences of Lyme disease diagnosis and subsequent treatment. We considered articles using either qualitative methods or quantitative approaches. We located the articles through extensive searching as part of our systematic review (Brunton et al., 2017). In extracting data for the analysis, we gathered information from the background, methods, findings and discussion.

## 3) Exploring the background of the texts

To understand the social and historical context of the texts (Fairclough, 2003), we noted the aims of the journals they were published in as well as their intended audiences. To appreciate the background of the authors we examined their affiliations and professional roles. We identified statements from the articles with respect to the legitimacy of CLD to understand the authors' position or 'general slant' (Mullett, 2018, p. 124). We used these statements to categorise the articles as broadly taking an orthodox or a heterodox position in

order to explore whether the arguments made differed according to the position taken.

#### 4) Coding the texts and identifying overarching themes

Rather than taking a purely inductive thematic analysis approach to developing themes as suggested by Mullet (2018) we drew on the framework synthesis approach described by Carroll, Booth & Cooper (2011). Their approach is ‘augmentative and deductive (building on an existing model or framework), rather than grounded or inductive (starting with a completely blank sheet)’ (p.2). Since we were concerned with how the texts established the legitimacy of either the patients’ experience or the bio-medical diagnosis, we developed a framework based on the health social movement literature to guide our analysis of the text. The framework included three broad themes in relation to the persuasive strategies used: evidence based activism (legitimacy based on rationality) (Rabeharisoa et al., 2014); the sick role (legitimacy based on moral criteria of the good patient) (Parsons, 1951); and the proto-professionalization of patients (legitimacy based on economic values) (Dent, 2006).

#### 5) Analysing external relations in the texts

To examine each theme we employed two analytic strategies from critical discourse analysis. First, we examined relations or interactions between the selected articles and other sources of discourse. That is to say, we explored reference within the texts to social practices, such as help seeking, and structures, such as relations with health services, or to other texts such as evidence guidelines (Mullet, 2018).

#### 6) Analysing internal relations in the texts

We then considered ‘internal relations’ of the texts. These are described by Mullet (2018) as the ‘linguistic devices’ used to persuade us of the legitimacy of the authors’ positions. This analysis examined vocabulary, such as the terms used to designate CLD, and grammar, such as the use of the passive and active voice.

#### 7) Interpreting the data

To interpret the data for each of the internal and external strategies employed within the three themes in our framework we compared and contrasted the approach of the heterodox and the orthodox articles. To be included in our analysis, each strategy needed to be used by at least one of the heterodox articles and the orthodox article. This helped us to see the extent to which the same strategies were being employed to make opposing arguments. In our final analysis (reported in the discussion section of this article) we also revisited the wider context to understand what this analysis tells us about the construction of legitimacy by health social movements in the context of peer reviewed journal articles.

## Results

Nine articles were included in the systematic review. However, this article focuses on the six articles which were published in peer reviewed journals as we are concerned specifically with the legitimising effects of peer review journal publication (Ali, Vitulano, Lee, Weiss & Colson, 2014; Csallner, Hofmann & Hausteiner-Wiehle, 2013; Drew & Hewitt, 2006; Johnson et al., 2011; Johnson, Wilcox, Mankoff & Stricker, 2014; Rebman et al. 2015). Therefore we excluded the three remaining papers not published in peer reviewed journals.

ADD TABLE 1 HERE

### Positions of the authors on Legitimacy of Chronic Lyme Disease

As noted above, we sought to understand the ‘general slant’ (Mullet, 2018) of the articles in relation to the debates surrounding chronic Lyme disease. We thus identified statements about CLD from the introductions of the articles to understand authors’ positions. As can be seen from Table 1 below, Csallner et al., (2013) are explicit in their view that CLD is not a condition arising from infection; this is the only article categorised as taking an orthodox view. Four articles (Ali et al., 2014; Drew & Hewitt, 2006; Johnson et al., 2011; 2014) argue that persistent symptoms may be present ‘without evidence of previous *Borrelia burgdorferi* infection’ (Ali et al., 2014). Whilst the final article (Rebman et al., 2017) focuses on the

experience of patients with persistent symptoms of Lyme disease, suggesting an allegiance with the heterodox view, their sample meets the orthodox diagnostic tests and they cite the accepted medical authorities in their discussion of the illness. Therefore, we categorised this paper as taking a ‘neutral’ stance which appeared to be underscored in our further analyses.

### Publication Context

In this section we consider the audiences and aims of the journals in which the six articles were published. Two heterodox articles were published in journals for primary healthcare practitioners i.e. *BMC Family Practice* (Ali et al., 2014) and *Public Health Nursing* (Drew & Hewitt, 2006). The audiences for these journals are primarily community practitioners responsible for the care of Lyme patients so a focus on patient experiences of care is unsurprising. The reason for placement of Johnson et al. (2014) in *PeerJ* is less clear. However, the selection may also be due to the legitimisation afforded by the journals academic rigour as emphasised on their website (<https://peerj.com/benefits/>) with regard to their ‘prestigious editorial board’ and emphasised by the journal name itself. The Johnson et al. (2011) article was published in *Health Policy*, a journal aimed at policy makers. The article covered policy-relevant issues such as access to healthcare and delays to treatment. The authors’ choice of a large-scale survey methodology is likely to be more convincing for policy makers, since the results would be more generalizable. As such all four of these articles attempted to reach a policy or practitioner audience relating to physical health. In contrast, by placing their article in *Psychosomatics*, a journal for clinicians in the field of psychiatry, Csallner et al. (2013) signalled their view that CLD is not a legitimate physical condition but rather a psychological one. Rebman et al. (2017) published the only article in a journal, *Qualitative Health Research*, aimed at researchers rather than practitioners. Perhaps, this suggests a desire to stimulate further discussion rather than persuade a practitioner audience of either the heterodox or orthodox position.

## Thematic Analysis

We consider each of the three themes in turn: evidence based activism; the sick role and proto-professionalization of patients. For each theme we explore the authors reference to social practices or other texts in developing their argument (external relations) and the linguistic devices they employ (internal relations). We also assess within each theme the similarities and differences between the heterodox and orthodox arguments. Table 2 below summarises this framework.

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### *Evidence-based Activism*

In this section, we discuss how the authors deployed arguments based on the rationality associated with evidence-based policy making. Determining a diagnosis has been a core role for medical authorities since it provides clinicians with descriptive information and causal explanations, (Zavestoski et al., 2004), crucial for the rational management of illness. In this theme, we examine efforts of the heterodox articles to appeal to medical authorities to embrace lay understandings of the illness, and the pushback from the authors of the orthodox article, who reassert the privileged status of bio-medical explanations.

In our external relations analysis, we consider their references to evidence guidelines and the diagnostic status of the respondents. Concerning internal relations, we discuss how the authors designate the disease, and the distinctions made between chronic and acute Lyme disease populations. We discuss how both the heterodox and orthodox texts produce the population of Lyme sufferers to conform to their argument.

### External Relations

#### Evidence Guidelines

In the introduction to the three studies using quantitative methods, i.e. Csallner et al. (2013);

Johnson et al. (2011) and Johnson et al. (2014), the authors refer to clinical practice guidelines to assert the legitimacy of their position. Csallner et al. (2013), the orthodox study, refers to the guidelines of the Infectious Disease Society of America (IDSA). By contrast, in the introduction of Johnson et al. (2011), the authors describe guidelines created by the rival, International Lyme and Associated Diseases Society (ILADS). In Johnson et al. (2011), the two societies are differentiated by how they describe the disease and their recommendations for treatment, but also in the qualifications of their membership. Both organisations have developed guidelines for doctors and patient advocacy groups have contested the guidelines produced by the IDSA in court (Auwaerter and Melia, 2012). The members of the IDSA are described by Johnson et al. (2011) as *'researchers, academicians or government employees'* whilst the associates of ILADs are *'primarily community health care providers [e.g. Lyme literate medical doctors] who are attempting to address significant and sometimes incapacitating illness in their patients'* ( pg. 65). Thus the authors establish a dichotomy; the orthodoxy is remote from daily practice but powerful and influential, whereas the heterodox practitioners are from the community and knowledgeable about the patient experience. These preliminary discussions establish the parameters for their study and justify their inclusion of respondents in their sample.

### Diagnostic Status of the Respondents

Next, we examined the nature of the sample, particularly whether respondents met orthodox medical standards or conformed to heterodox approaches to diagnosis. The four heterodox articles are unclear as to the diagnostic status of their sample. Ali and colleagues (2014) state that it is not a matter of concern for their paper since their focus is on the experience of the disease. Drew and Hewitt (2006) focus on CLD patients but are unclear as to how the diagnosis of their respondents was made or by whom, only stating that participants were on a home infusion company's database of patients. From this description, we concluded that

these patients were being treated by intravenous anti-biotics, usually recommended by heterodox authorities and so we decided that this article was written from a heterodox position. One survey (Johnson et al., 2011) accepts responses from people with diagnoses made by physicians outside the orthodoxy such as Lyme literate physicians. The other (Johnson et al., 2014) accepts responses from sufferers who had been diagnosed using tests that did not conform to medical criteria, recognised by the Centers for Disease Control (CDC).

In the clinical orthodox example, Csallner et al. (2013) conduct a series of clinical, psycho-behavioural and quality of life tests on patients awaiting a diagnosis for Lyme disease at a specialist clinic. The authors compare the test results of those with positive results to those with negative results. Therefore the orthodox diagnosis of Lyme disease becomes the central explanatory variable for their results.

Rebman et al. (2017) is categorised as taking an orthodox position concerning diagnostic status because their respondents had a clinical diagnosis of Lyme disease with a positive serological test result. They refute Csallner and colleagues' contention that the illness does not have a subjective element to claim that symptoms occur '*in the absence of observable physical exam or laboratory abnormalities*' (pg1.). Further, Rebman et al. (2017) cite the medical authority, IDSA, to support these claims in contradiction of the Johnson et al. (2011) article which argues that medical authorities do not recognise persistent symptoms: '*In IDSA's view, chronic infection with the Lyme spirochete is rare or non-existent*' (pg.64).

## Internal Relations

### Language used to describe chronic Lyme disease

The terminology used to denote CLD indicated positions in the argument. Drew and Hewitt (2006) are inconsistent in their use of the term, suggesting that its signification did not matter or the boundary between CLD and Lyme disease was porous. Ali et al. (2014) and Johnson et

al. (2014) used the term CLD to discuss the chronic nature of the disease. However, Johnson and colleagues (2011) refer only to ‘Lyme disease’ in their earlier article, revealing an inconsistency across their articles. Csallner et al. (2013) put the term in quotes, “chronic Lyme disease”, as if to underline its dubious nature, and prefer to use the more scientific term ‘borreliosis Lyme’ when discussing the condition. Rebman et al. (2017) are both consistent and inclusive, preferring to use the term PLDS/CLD (post Lyme disease syndrome/chronic Lyme disease) which combines the medically accepted label for persistent symptoms (PLDS) and a designation recognised by patients (CLD).

### Distinguishing between Acute and Chronic Populations

Johnson et al. (2011) make their case for an expanding the definition of Lyme disease beyond that recognised by IDSA, by pointing to the difficulty of those with a non-orthodox diagnosis to access care. In table 1 (pg.67), those diagnosed by the heterodox medical community are indicated by the items: (1) *‘How were you diagnosed? Clinically diagnosed with other supporting laboratory tests’*; and (2) *‘What type of physician(s) first officially diagnosed you with Lyme disease? Lyme literate medical doctor (LLMD)’*. They separate those diagnosed with CDC approved tests and those with tests developed by the heterodoxy, *‘other supporting laboratory tests’*, using the word *‘laboratory’* to underline the scientific legitimacy of the test. Likewise, the type of diagnosing physician indicates a heterodox position, since the designation *‘Lyme literate medical doctor’* is only recognised by ILADS. As in the test example, the use of descriptive term, *‘medical’* adds weight to their legitimacy claims.

In table 1, two samples emerge, those with an orthodox diagnosis and those with one from heterodox sources. In both items, the number of people in the heterodox categories far outnumber those in the orthodox categories. Those with a heterodox diagnosis saw a higher number of physicians before a diagnosis was obtained. Therefore, the authors conclude that these patients suffered from delays to diagnosis. However, they do not separate out the two

populations to show the correlations between those with a non-orthodox diagnosis path and access to health care as presented in table 2, (pg. 68). Through this elision, the authors give the impression that all those with a Lyme disease diagnosis are vulnerable to a denial of care, whether their diagnosis is by the orthodox route or not.

On the other hand, Csallner et al. (2013) maintain medical certainties.

*'In the case of organically unexplained conditions falsely attributed to Lyme borreliosis, this would be a thorough clinical examination and the exclusion of an active infection with Borrelia burgdorferi. [...] In addition to negative diagnostic findings, patients with "organically unexplained" symptoms falsely attributed to Lyme disease may also display certain positive features that are similar to those of somatizing patients. These criteria may facilitate a correct diagnosis and allow for a more specific management.'* (pg. 360)

In this extract, Csallner and colleagues use language to underline their orthodox position, with a repetition of the phrase, '*falsely attributed*' to signal their disapproval, and an endorsement of their own approach as '*facilitat[ing] a correct diagnosis.*' This binary argument of false / correct is the mirror image of the patient position where, rather than the certainty of experience, they promote the certainty of medical knowledge. Here the two types of patient, the genuine Lyme disease patients and those with a somatising illness are clearly delineated, essentially limiting the possibilities of a Lyme diagnosis to acute sufferers. So the articles shown to be advocating a particular position reduce the population of Lyme disease sufferers to one type, either acute (Csallner et al., 2013) or chronic (Johnson et al., 2011) and deny the existence of the other, either through psychosomatic explanation or by presenting their data in such a way as to conflate the two groups. Rebman and colleagues acknowledge both acute and chronic sufferers, but choose to discuss the experience of those with chronic symptoms.

## *The Sick Role*

Through his concept of the sick role, Parsons (1951) argued that sickness accorded the sufferer the right to give up normal social responsibilities and to call on support from others as long as they pursued recovery by seeking help from medically competent practitioners. CLD sufferers struggle to occupy the sick role since the lack of an accurate test to confirm a diagnosis questions their claims to a legitimate physical illness. The invisibility of their disease may lead to accusations of malingering, weak will and mental illness, all associated with character blemishes (Goffman, 1968). In turn, these accusations further discriminate against sufferers by frustrating their attempts to obtain medical help. Additionally, the chronic nature of their condition means that recovery is indefinitely postponed with the likelihood of dependency on others for the foreseeable future.

In considering the notion of the sick role in these articles, we focus on the normative concepts of recovery and help seeking identified by Parsons as the markers of a legitimate patient. Our examination of the internal relations focus on vocabulary connected to visibility.

## *External Relations*

### *Recovery*

The heterodox articles present their respondents as having conventional acute illness rather than chronic or MUS conditions, so they looked forward to recovery. For example, in Drew and Hewitt (2006), respondents held on to their healthy identity by talking about going back to work and recovering their former lives, after achieving the medical treatment they desired.

*'I fully intend to go back to work. I would love to be able to work and hopefully this year God willing . . . we'll finally emerge from this and we'll take antibiotics for a while . . . and hopefully we'll emerge and continue with our lives.'* (pg. 24)

However, patients in Ali et al. (2014) were less certain about their eventual recovery:

*"I've heard that you never fully recover—that it goes into remission,..."* (pg. 4)

This uncertainty contrasted with accounts of a clear difference between the patients' lives before the tick bite and life with the disease. Ali et al. (2014) describe the respondents as *'highly functional in their daily lives prior to CLD'* (pg. 4). In this telling, the patients delineate a clear boundary between their former healthy lives and their current condition. For Csallner et al. (2013), the solution is a correct diagnosis and recovery is implied: *'These criteria [for somatising illness] may facilitate a correct diagnosis and allow for a more specific management.'* (pg. 360).

In contrast, the patients in Rebman et al. (2017) expressed doubts about their future health and their ability to attribute symptoms to Lyme disease. Alongside doubts about recovery, participants also questioned their attributions of symptoms to the illness: *'Uncertainty also marked some participants' past illness narratives, specifically the extent to which health events occurring after their initial Lyme exposure were attributable to PLDS/CLD, to some other disease process, or would have happened regardless (e.g., "maybe I'm just getting older").'* (pg. 8)

Unlike the respondents in Drew and Hewitt (2006) who clung on to their healthy identity, the respondents in Rebman et al. (2017) grieved the losses inflicted by the illness and shifted their identity from prior health to illness so that they could accept this chronic condition:

*'For participants who described a "new normal," if only transiently while symptoms were at their peak, acceptance of limitations was also frequently described as a means to cope with a sense of loss or powerlessness. One man explained what had helped him: "Accepting things for the way they are. You aren't going to be who you thought you were going to be. You're just going to be different. Change the plan. Make a new plan."'* (pg. 6)

Rebman and colleagues suggest that these strategies are associated with diagnosed chronic illnesses, such as rheumatoid arthritis. The article shows the effort of changing

identity, but the conversations were more about acceptance than recovery:

### Help Seeking

The authors of the heterodox articles describe their respondents as seeking validation for their illness claims through diagnosis. The patients went to considerable lengths to gain a diagnosis:

*'It was just so maddening because here I finally after three and a half years got a diagnosis. It's just like unreal the stuff people have to go through, when they have Lyme, you know, just to get a diagnosis.'* (Drew & Hewitt 2006, pg. 23)

Johnson et al. (2011) document the efforts of patients to get a diagnosis and access care. Their article shows the problems and delays that patients faced in gaining a diagnosis and how those difficulties impacted on their access to care. The authors highlight the barrier of the IDSA guidelines which prevented insurance cover and admittance to hospital for those who did not meet the IDSA accredited diagnostic tests. Results from a further survey (Johnson et al., 2014) show that chronic Lyme disease patients used health services significantly more than those suffering from other chronic conditions.

In Johnson et al. (2014), the authors compare the experiences and symptoms of chronic Lyme disease sufferers with those suffering from legitimate illnesses such as heart disease, diabetes and cancer. These symptoms included depression, fatigue and '*poor mental health days*'. This comparison allows the authors to argue that the experiences of chronic Lyme disease patients justified their use of health services. On the other hand, Csallner et al. (2013), treat those who failed the orthodox diagnostic tests as suffering from a psychosomatic condition. In this article, patients' use of the health service is described as '*dysfunctional*' (pg. 364). Here, the patients' symptoms, similar to those reported in Johnson et al. (2014), are not treated as evidence of a bio-medical illness but rather a psychological one and, consequently, their use of medical services is further evidence of their psychopathology.

Csallner and colleagues use the legitimacy of the diagnostic tests to question the help seeking behaviour of the patients at their clinic.

A respondent in Rebman et al. (2017) also made a comparison between cancer and chronic Lyme disease, confessing that the isolation experienced as a result of the contested nature of the Lyme diagnosis added an extra burden, not experienced with the cancer diagnosis:

*'[Cancer] is obviously a very recognized disease. And at that point, all of a sudden I got the recognition and sympathy and support that was lacking because, you know, there was a chance I wasn't even going to make it. . . . Being a person of science, [my spouse] went okay now I know you really have something. And she couldn't have been better or more supportive to this day. But that was kind of a turning point in the psychological aspect because up until that point it was like oh yeah c'mon, tough it up, you're a guy, you can do this, blah blah blah. Because it gets that isolating where you just feel like your body's stopping to function and no one will listen. It's hard enough when you're declining and you get everybody's love and support. But to do it without anyone believing you is I think one of the most difficult things to deal with, as far as the psychology of the illness.'*

Rather than understanding the mental health repercussions are a result of physical illness and denial of care (Johnson et al., 2014), or that the mental health symptoms relate to mental rather than physical illness (Csallner et al., 2013), the respondent in Rebman et al. (2017) identified the psychological consequences of the stigma associated with a diagnosis considered socially illegitimate. The failure to achieve the sick role served to isolate the patient from his spouse who doubted his account, and only gave him support when he received the legitimate cancer diagnosis.

## Internal Relations

### Visibility

Respondents were aware of the importance of visible, tangible signs of illness to confirm their legitimacy. Respondents in Drew and Hewitt (2006) regarded the diagnosis as something ‘tangible’ (pg. 24). They talked about ‘having’ the disease and ‘holding’ it.

*‘He tested me for it and it came back positive. I was pleased. I can hold this now. I can deal with it. We’re gonna treat it. It’s not this invisible thing anymore.’ (pg. 24)*

The diagnosis as the legitimating test enabled this patient to gain access to care and become more visible or recognised by health authorities.

In Csallner et al. (2013), visibility is tied to notions of objectivity and subjectivity. *‘This observation implies that symptom severity rather than symptom type points towards a lack of organic explicability, and that additional consideration of psycho-behavioral characteristics, such as subjective illness consequences, is mandatory.’ (pg. 364)*

They open this sentence with the word ‘*observation*’ which conveys a sense of scientific detachment and implies a verifiable, general and visible claim. In contrast, they end the sentence with the phrase, ‘*subjective illness consequences*’ which attach to the individual, so not generalizable, and which, as ‘*subjective*’, may or may not arise because of the illness, and therefore not verifiable. So for these authors, CLD remains invisible because it is not scientifically observed.

In Rebman et al. (2017), comparisons are made with other illnesses to illustrate the isolation felt by patients, since sympathy was more easily extended to those patients who had more visible and accepted conditions. Here the respondent reflected on the implications of their illness remaining invisible.

*‘When you can see a bandage, you can see something hurt, you can see somebody getting treatment, you can see the effects; it’s there. But when you see somebody that looks normal,*

*do you know what I mean? It's a little different and I think sometimes, that can be the hard part.'* (pg. 6)

In this section, we have considered the social concept of the sick role and how it affects the respondents in these papers. In the heterodox articles, the concern is to achieve the sick role by assuming recovery in the normal arc of acute illness (Parsons, 1951), and to ascribe mental health symptoms to a physical illness and a denial of care because of late diagnosis. In the orthodox article, the authors deny the patients who failed the diagnostic tests the legitimacy of a bio-medical explanation for their symptoms, to suggest the less legitimate psychological causes. On the other hand, respondents in Rebman et al. (2017) grieved the loss of their former healthy selves and reflected on the psychological and social impacts of suffering from a contested condition.

#### *The Proto-professionalization of Patients*

Dent (2006) argues that the pervasiveness of New Public Management discourses in medicine prioritises managerial concerns about efficiency, effectiveness and accountability of health services, and brings new roles for patients to contribute to service improvement through the notion of patient choice.

In seeking the best doctor for their complaint, some patients have entered into a clientelistic relationship with doctors based on the reputation of the doctor and a simplified understanding of their illness (de Swaan, 1988). The double hermeneutic of partial and incomplete knowledge derived from the internet, the media and doctors themselves is at play in the help seeking strategies for patients with unexplained symptoms (de Swaan, 1988). In the context of Lyme disease, distrust of doctors may not be allayed by guidelines since patients can choose their doctors on the basis of alternative guidelines and other knowledge generated by experiences closer to their own.

Therefore, we consider the managerialist discourse of efficiency and accountability in

the articles, as well as the burdens placed on patients in choosing doctors and treatments. We discuss the use of the passive voice as a strategy for reducing and attributing responsibility for choices about treatment and care.

## External Relations

### Managerialism

One of the aims of Csallner et al. (2013) is to develop a checklist, a strategy that reduces the craft knowledge of doctors to discrete items, encouraging clinicians to behave more as administrators of care (Dent, 2006). With this checklist, doctors would be able to determine the psychosomatic indicators of patients with organically unexplained symptoms who claim to have Lyme disease. This instrument would channel patients towards more psychiatric disciplines and so categorise them correctly, bringing them closer to recovery.

*'Indeed, patients with OUS [organically unexplained symptoms] were considerably depressed and showed indicators of a dysfunctional health care use, with more change of providers, and more money spent outside of the broad German insurance coverage for health care costs. Therefore, active questioning for the whole range of a patient's symptoms must be an essential component of symptom work-ups.'* (pg. 364)

In this extract, the authors comment on the change of providers and the expenses of the patients, but clearly think that this was aberrant behaviour which could be prevented by improved technical processes carried out by doctors – *'symptom work-ups'*. The avoidance of *'dysfunctional health care use'* focusses on economic consequences arising from patients seeking alternative providers. This concern for inefficiencies is mirrored in Johnson et al. (2011; 2014) but the consequences in these articles accrue to the patients rather than the system, as sufferers paid for expenses not met by health insurers. However, there is a knock-on effect for society as individuals become unemployed, described as *'productivity losses'* (Johnson et al., 2014, pg. 11), because of the illness, and impoverished because of the health

costs of alternative providers (Johnson et al., 2011; 2014, Drew & Hewitt, 2006).

In their conclusion, Johnson et al. (2011) point out that the narrow definitions in the IDSA medical guidelines have economic as well as medical consequences for patients:

*'An influential medical society considers Lyme disease to be "rare" and has issued restrictive treatment guidelines. Our study raises concerns that these restrictions lead to delayed and inadequate treatment of patients with Lyme disease, resulting in concomitant reductions in health benefits and increases in economic costs. Our findings therefore indicate that there is substantial need for reform of the health care approach to Lyme disease in the United States.'* (pg. 70)

This text raises the issue of accountability since the restrictions placed on clinicians by these guidelines do not appear to meet the needs of all patients. So in their attempts to be accountable to their professional association, Johnson et al. (2011) argue that doctors fail in their greater accountability to society as a whole.

### Patient choice

As noted above, the authors of the orthodox article regard more frequent change of providers by patients with unexplained symptoms to be evidence of *'dysfunctional'* healthcare use as one outcome of greater patient choice.

In contrast, the heterodox articles record the difficulties that patients encountered in making and realising their choices. Respondents in Drew and Hewitt (2006) took on the responsibility of finding out about the illness from the internet, support groups and medical libraries and used this information to manage their interactions with the health care system:

*'The coordinator is the patient. I felt like I was my own general contractor, marshalling all my subs. A very difficult thing. I'll say it's disintegrated health care system. It's the patient that's got to make it all happen.'* (pg. 24)

This knowledge led to greater engagement in consultations with doctors, but also

conflict as patients sought to exercise greater control over their diagnosis and treatment:

*'...When I asked, 'Well what about Lyme?' - he never tested...never asked any questions. 'It can't be,' [he said]. ... It's like, 'Well who are we? We have no control over our lives? We're stupid? We don't know what's going on that you wouldn't even consider this?'' (Participant #4, Ali et al., 2014, pg. 5)*

The management of the illness extended to the choice of doctor. This often meant choosing doctors with a particular reputation for treating Lyme disease, so that the patients could get the diagnosis they wanted and access to treatment they believed they needed:

*'I was forced to leave the state and seek out these Lyme specialists in other states because they had treated three thousand, five thousand, six thousand Lyme patients and were familiar with the disease.'* (Drew & Hewitt, 2006, pg. 23)

In the two extracts from Drew and Hewitt 2006, the patients show both the control and agency of the active citizen and submission to the authority of alternative doctors, based on their reputation for treatment. This illustrates the bind of proto-professionalization where knowledge and information does not necessarily empower the patient (Dent, 2006).

In contrast, the authors in Rebman et al. (2017) document the burdens that the responsibility for making choices placed on the patients:

*'This sense of personal responsibility for future health also seemed to be fraught with feelings of both empowerment and self-doubt..... 'So you second-guess yourself, you think, well should I be insistent that I keep the PICC line? Gone another month? Would that have made that three-month hiatus from antibiotics not as devastating physically as it was? I don't know. I don't know. I don't have enough confidence in my own decision making about that because this is kind of an overwhelming disease.'* (pg.9)

In this quote the respondent equivocated about the choices available, unsure in their own knowledge about what would be best for them. They acknowledged their own frailties

due to the illness which they identified as affecting their judgement, so their illness impeded their judgement rather than being the basis for it.

## Internal Relations

### Use of the Passive Voice

In the earlier example of the patient who ‘*was forced*’ to seek care outside the state, the absent agent is the insurance companies. Johnson et al. (2011) discuss the financial burdens placed on patients due to the refusal of health insurers to cover their care in the passive voice. This gives the impression that patients were victims of an impersonal system.

*‘...39.9% were denied coverage because of their diagnosis. Among respondents with medical insurance, 12.8% were told by their insurance company to see an infectious disease specialist to cover their care. Furthermore, 30.5% of respondents applied for disability benefits, and 38.6% of these individuals were denied disability benefits based on failure to conform to the IDSA Lyme guidelines.’ (pg. 68)*

This strategy avoids blaming individual doctors but focusses disapproval on the bureaucratic procedures of ‘*conform[ing] to the IDSA guidelines*’. The authors have already identified in the introduction of this article that the IDSA guidelines are backed by a powerful elite, distant from community practitioners but exerting influence over careers and resources. Csallner et al.’s (2013) use of the passive voice enable them to protect doctors by avoiding discussing their role in referring the patients.

*‘Nevertheless, there is an increasing number of patients who claim to suffer from “Chronic Lyme Disease.” Despite nonspecific physical findings, negative laboratory testing, or adequate treatment, these patients attribute bodily symptoms to a persistent spirochetal infection, and often continue to take antibiotics for months or years. Due to this confusion, Lyme borreliosis tends to be over-diagnosed and over-treated; it is associated with “inappropriate use of health services, avoidable treatment-related illness, and substantial*

*disability and distress”.* (pg. 360).

Throughout the article the responsibility for the attribution of Lyme disease is squarely put on the shoulders of the patients. In this quote, doctors are obliquely referred to in the phrase ‘*over-diagnosed and over-treated*’, whereas in the previous sentence the patients play an active role in their own misattribution, contributing to the ‘*inappropriate*’ use of the system.

In this theme, the relationship between the individual and the system is developed by the authors. Both the heterodox and orthodox articles stress the economic consequences for the patients or the system. The patients suffered because they paid for private care and the system struggled to deal with the high costs associated with patients with organically unexplained symptoms.

## Discussion

In this article, we have demonstrated how CDA is useful in qualitative evidence syntheses on contested health issues for exposing the strategies used by authors to persuade readers of their position. This method enabled us to understand the orthodox and heterodox positions on chronic illness in the context of Lyme disease by discussing how the articles constructed the legitimacy of their position. In the theme, evidence based activism, the articles legitimised their positions by defining their populations as either chronic (Johnson et al., 2011; 2014; Ali et al., 2014), or acute (Csallner et al., 2013). Johnson and colleagues achieved this by conflating data from the experiences of patients diagnosed through heterodox processes and those with a diagnosis by orthodox routes. Csallner and colleagues used the medically orthodox diagnosis to classify those without bio-medically explained symptoms as suffering from a psychosomatic illness, thus denying the possibility of chronic Lyme disease. Rebman et al. (2017) were careful to describe both populations as officially recognised by the IDSA, and chose to focus on those with chronic illness.

The theme, the sick role, showed respondents in the heterodox articles conforming to normative beliefs about the legitimate patient, pursuing a cure for a recoverable condition (Ali et al., 2014; Drew & Hewitt, 2006). Similarly, Csallner et al. (2013) reinforced beliefs in somatic illness by describing the help-seeking activities of the chronic Lyme sufferers as ‘*inappropriate*’ or ‘*dysfunctional*’, since, for them, these patients are mentally rather than physically ill. However, respondents in Rebman et al. (2017) acknowledged the psychological costs of the stigma associated with a contested illness and how the added burden affected their physical symptoms.

Lastly, the authors of the heterodox and orthodox articles drew on economic discourses to emphasise the legitimacy of their position. The heterodox articles (Johnson et al., 2011; 2014) pointed to the economic consequences for patients arising from an apparent technical judgments contained in medical guidelines. These, they argued, mask an elitist perspective which denied patients access to care and led to unemployment and poverty. On the other hand, Csallner et al. (2013) identified the economic consequences for the health system if these guidelines are not followed. Rebman et al. (2017) drew attention to the complexities of decision making facing patients as they grappled with their particular symptoms which technical guidelines can only partially support.

The placement of the articles in particular journals reflected how the authors positioned their arguments and sought out sympathetic audiences. The heterodox articles targeted community practitioners and policy makers, tailoring their methods to their audiences. The orthodox article was written for mental health clinicians and policy makers, using validated tests to make their point. The neutral article, Rebman et al. (2017), was placed in a journal with a researcher audience, and as such may have been less concerned with persuasion and more with explanation.

The authors of heterodox articles reinforced the position of the orthodox article in their

bids to establish their credibility as legitimate patients, unintentionally rousing the suspicions of practitioners who are looking for accidental causes rather than rehearsed arguments (Greco 2017). Thus, the heterodox and orthodox articles refer implicitly to each other as two sides in the same argument and, as such, these articles represent a stalemate. In grappling with chronicity, Rebman et al. (2017) showed patients making links between the psychosocial and physical effects of their illness to reveal the inevitable feedback loops between these aspects. Through the reflections of their patients on their experience, Rebman and colleagues bring out the interactions between the aspects of the illness, physical and psychological, and societal constructions of illness and, relatedly, expectations of patients.

The need for an approach to expose and examine authors' strategies emerged during the course of our work. As we engaged with the articles in the systematic review process, it became apparent that the full complexity of the patient experience could not be examined without considering the underlying power relations of the dispute. Thus, our initial impetus to describe patient experience turned into an examination of how that experience is presented in academic literature. This has allowed a deeper examination of the phenomenon of chronic illness which connected the review texts to the literature concerning contested conditions, evidence based activism and patients as consumers. We argue that this synthesis of arguments surfaces the absences in the explanations offered by the authors as indications of the frames being used to channel the debate to particular conclusions, whether in the choice of populations examined or the ways the inter-relations between the psychological and physical aspects of illness are expressed.

### Strengths and Limitations

This was the first time we have tried CDA to understand a group of papers in a systematic review. A key strength of the approach was that the inter-textual analysis forced us to establish connections with a wider group of articles, enriching our analysis and enabling an

understanding of the broader phenomenon rather than limiting our conclusions to CLD. Further, this tactic brought the study into dialogue with other scholars in the area, and overcame the criticism that qualitative syntheses often fail to engage critically with their intellectual context (Thorne 2017, 2017a). The limitation of this approach for systematic reviewers is the small number of papers that can be handled in this way. The approach requires intensive critical engagement with articles and researchers may not have the time to devote to this. It may be a rare review where contestation is so explicit that a synthesis of arguments would be useful.

A major limitation of this particular study is the imbalance of evidence from each side of the debate. We found a lack of orthodox articles, setting out the position of the medical establishment, and, due to our extensive searching, it is unlikely that we have missed articles about the patient experience of Lyme disease.

## Conclusion

The application of CDA in this review enabled a new critical understanding of the debate around Lyme disease. We were able to identify the persuasive strategies of the heterodox and the orthodox positions as expressed in these research articles, with the help of the sociological critiques written to explain contested conditions. We suggest that this could be an especially productive strategy for reviews in cases where there is polemic intent in the primary research studies and thus where an analysis of the dispute would provide a fuller explanation of the phenomenon. Further work is needed to understand the extent to which the approach would be useful for qualitative syntheses on less contentious issues.

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