

AN INTERNET SURVEY OF LYME PATIENT'S EXPERIENCE OF ACCESS TO CARE

Keywords: Lyme disease; patients' experience; health services; tick-borne; patients; diagnosis

ABSTRACT

The aim of this study was to begin to explore patients lived experience of access to care of patients who had a Lyme disease diagnosis. A descriptive, retrospective internet based survey of 152 people who had been diagnosed professionally as having Lyme disease (LD) in the UK and Ireland was undertaken in 2011. Amongst this (self-selected) group of patients, there was a problematic experience of the NHS overall – the majority felt that they had been misdiagnosed and this was a cause of diagnostic delays. Over one third of patients (irrespective of NHS test results) felt that diagnostic delays were due to misdiagnosis. Time intervals between getting ill and being diagnosed with LD were often long. The data suggest there is room for improvement within the NHS, for a specific group of patients, at least. More work needs to be done to establish the biological, human and social/psychological factors (and dynamics) leading to this situation, and to understand how these sit within the policy and health services context. We also need to know if these types of problems are more widespread, and recognition of the potential causes in a patient-centred review, would be useful for policy-makers and other stakeholders.

1. INTRODUCTION

Lyme disease (also known as Lyme Borreliosis) is an illness caused by a tick-borne infection that has been considered endemic in certain areas of the UK and Ireland [1] and may also be found in some non-endemic areas of the UK such as parks, including in London [2]. It has been found in urban environments in ticks in some other European countries [3, 4]. It can potentially affect park workers and public users of leisure spaces, as well as those working in or using more traditional endemic areas such as wild country terrain, farms, etc. [5, 2, 6].

It has been described as the 'most common human tick-borne illness in the Northern Hemisphere' [7]. However, it is not clear how big an issue these illnesses are, for the UK or Ireland. There has been a fairly marked increase in cases reported for the UK and Ireland in recent years [8]. Between 2001 and 2010, the numbers of reported cases in *England and Wales*, and the rate per 100,000 population increased by at least threefold. Since 2007 the year-on-year rate of increase in numbers of reported cases varied between 2 - 7%. The overall incidence (number of new cases over a specific time period) is likely to be greater overall in Scotland and/or specific regions of England or Wales, and vary according to local area.

More recently, as the Health Protection Agency (HPA) [9] point out;

'In 2011, 959 cases of laboratory-confirmed Lyme borreliosis (LB) were identified in residents of England and Wales, an incidence rate of 1.73/100,000 total population. This compares with 905 cases and an incidence rate of 1.64/100,000 in 2010'.

However, confirming the exact number of incidents of LD is difficult. Clinically diagnosed cases (without corroborating NHS laboratory confirmation) are not included in existing official figures, and so the true incidence is not known. The HPA has suggested that the real number of cases could be three times the reported cases.

The HPA has reported the numbers of new cases, of Lyme disease, since 1997. However more recently;

'Since October 2010 ...every microbiology laboratory (including those in the private sector) in England is required to notify all laboratory diagnoses of borreliosis to the Health Protection Agency'...

Prior to 2010 (when another system that was voluntary was in place) requirements for inclusion of new cases were only for those in the armed forces, or occupational exposure, and in those in Scotland (the latter included 'clinically diagnosed' cases, without lab test confirmation).

In Ireland (Eire) the situation is even more confusing, since after early 2012 the figures reported were for neuroborreliosis only (a specific neurological condition). Blood samples have in the past been sent from there to one (English based) reference laboratory for testing. There is therefore no consistent timeline of data on new cases since the definition of cases, or method of collecting data, has changed within the UK and Ireland. Understanding trends through time is therefore difficult.

There is a lack of understanding of the long-term impact of this condition, on patients, given current practice in the UK and Ireland. To date, no detailed analysis has been done in the UK or Eire examining trends over time for different geographical regions in hospital admissions or GP/clinic attendance for Lyme disease. This would provide a better understanding of trends locally, than the regional level analysis that has been done for the last few years of cases [10]. Furthermore, no work has been done to examine the prevalence of undiagnosed cases, or the long-term morbidity from Lyme disease in the UK or Ireland, following treatment.

There are a small number of descriptive studies based on new cases examining some trends, including details of socio-demographic characteristics with some local or regional analysis [1]. Some work has also been done, specifically focusing on the south-west of England [11] and on cases referred to infectious diseases clinics [12, 1]. Several papers have described clinical characteristics in England, Scotland or Ireland, eg [13, 14, 15, 16].

Some of the morbidity related to the condition may be avoidable if early diagnosis and relevant treatment is achieved. The long term consequences from the condition, however, are not fully understood, and are being explored in European settings [17]. Little is known about how much of this morbidity can be attributed to late or delayed treatment. However, the range of potential symptoms can be considerable and can include fatigue, musculoskeletal pain, and neurocognitive difficulties [18, 19].] Some research identifies 'post-Lyme syndrome' as consisting of subjective symptoms [20, 21, 22] whilst others consider the possibility of on-going infection following standard treatment [23, 24, 25].

Many clinicians and researchers consider the process of assessing patients for Lyme disease difficult [26, 27] others believe it to be 'over-diagnosed' in patients [28].

The most well-known presenting sign of an acute Lyme disease infection from a tick bite is a distinctly circular bull's eye rash at the site of the bite. However, other rare symptoms can occur, such as Bell's palsy of the face, ocular or psychiatric or psychological manifestations [29]. However, it is known that many patients do not get a rash. Smith reviewed cases in England and Wales over ten years and found that only 41% had a known typical bull's eye rash [30].

2. MATERIALS AND METHODS

2.1 The relevance of research from the patient's perspective

Descriptive techniques have also been promoted as an important method of identifying new health or illness phenomena for further epidemiological investigation, or problems that required better planning around health care [31]. Approaches to the involvement of patients in research, and research about patients' experience of health-care, has been developing for some time [32]. This paper takes its focus from the social experience that patients undergo using descriptive approaches, capturing the 'social reality' of patients. However, there are some

potential disadvantages such as the lack of access to patients in more normal clinical referral pathways, and the use of methods that cannot be easily replicated.

2.2 Research group and ethical issues

Lyme Research UK is a community group whose main aim is to explore and engage with research that is related to policy and practice on tick-borne infections in the UK and Ireland on a voluntary basis. Eighteen hundred pounds was raised to support technical work on the project, from the community anonymously. These sponsors had no influence on the resultant research design or paper. Patients and patients' carers were involved in the research in terms of reviewing project proposals, the questionnaire, etc.

There were three distinct areas where ethical issues regarding this research arose: those related to patients' participation, the involvement of researchers as insiders and outsiders regarding Lyme disease networks/support groups. In general terms the project relied on ethical guidance from the Social Research Association and their ethics forum when needed. All participants provided informed consent via an online method.

2.3 Data collection and analysis

This preliminary work is exploratory. The main aim is to examine overall experiences of health care, irrespective of patients' specific clinical background, route to diagnosis or test results.

From mid October 2011, information was collected for eight weeks via a survey, which had an online and paper version. Patients were recruited to the study via Lyme support networks and various types of social and new media. A range of internet websites, some specific to tick-borne infections were utilised as access points. The project was advertised on charity websites, blogs, forums and support groups for Lyme and other chronic illnesses.

The specific criteria for inclusion was that they had been diagnosed initially with Lyme disease by a professional (medical or other health professional) and had either been infected abroad but lived in the UK and Eire, or diagnosed in the UK and now living abroad. Patients were asked about what types of professional provided them with their initial diagnosis, which included an option for self-diagnosis – without the involvement of a professional. These specific patients were not included in this paper. The numbers of patients from Eire (10) and living abroad (6) are small. The focus of this study was on those who indicated an initial diagnosis from a health professional. Of those people, 152 patients fulfilled basic eligibility criteria outlined above.

The group of people contributing to the survey are self-selected and likely to be receiving treatment of some kind, specific to their diagnosis. They are not fully representative of all those who become ill from a tick-borne infection in the population (including those who have not yet been diagnosed but are ill), or those who are diagnosed routinely in the context of NHS care based on standard (HPA) criteria for diagnosis and treatment.

The results therefore cannot be generalised to other groups. However, it is necessary to find cases where these issues are potentially most prominent. Other limitations to the approach taken include lack of knowledge about the accuracy of patients' memory and recollection, and lack of confirmed detail about tests and other events (i.e. missing information).

3. RESULTS

A wide range of questions were asked in the survey covering the context of the illness. Data related to routes and context to diagnosis and patients experiences, are presented here.

3.1 Main diagnostic indicators and route to diagnosis

3.1.1 Tick bites and associated rashes (N=152)

Only **48%** of this professionally diagnosed group 'remembered a tick bite that caused their illness'; the remainder (52%), 'did not remember', 'weren't sure' or considered 'another route of transmission' (such as 'congenital') Other routes of transmission (other than congenital) have not been reported in mainstream scientific literature.

The majority were not being 'regularly bitten' at the time they became ill (55%), but another 26% did not know if they were. **40%** had a distinctly circular (bull eye) rash near the time of being bitten, and another 17% had an 'atypical non-circular rash'. The remainder (43%) did not have a rash, or weren't sure. Of those with a rash (87), **67%** mentioned or showed the rash to a doctor (at some point).

31% were initially diagnosed by a GP, **19%** by an NHS consultant, and **49%** by a private consultant (including those who also had a practice in the NHS). 1% (two patients) were diagnosed by another kind of healthcare professional.

77% reported being tested on the NHS using standard tests, whilst 18% said that they were not, and **5%** were not sure. Of those tested with an NHS test, 44% reported they tested positive, whilst 56% that they tested negative.

3.1.2 Reported tick bites and rashes

It is known that many patients with Lyme disease fail to develop [33] or remember a rash, or possibly fail to present their rash to a doctor. In this survey, for those who had a rash, a considerable proportion had drawn their physician's attention to the rash 67%, however some did not. This could include patients who had had atypical (i.e. non bull's eye) rashes, which has been recognised as being linked to tick bites and subsequent *Borrelia* infection [34, 35].

Despite this, overall only 31% were initially diagnosed with Lyme disease by a GP. Almost half of the patients (49%) were initially diagnosed by private consultants. Surprisingly, a considerable proportion was never tested on the NHS (17%). This could include those who exhibited a clear bull's eye rash and were treated on clinical grounds, or people who did not get access to testing.

Patterns of, and routes to, diagnosis can be complex and varied. It is expected that **positive NHS test results** will lead to an NHS diagnosis. However, four patients (of 51 with **positive test results**) obtained a private diagnosis *initially*. They may have obtained the NHS test following a private consultation.

Amongst patients with **negative NHS tests** (66) some then went on to get an (initial) private diagnosis. 76% of those with **negative NHS test** results were 'diagnosed by a private doctor', and conversely only 24% with negative NHS results were 'diagnosed by the NHS'.

Nine patients with an NHS diagnosis and 18 who were privately diagnosed, were not tested on the NHS.

Diagnosis primarily on clinical grounds and/or based on private test results (without the diagnostic indicator of a bull's eye rash) seems to take place in both sectors of health care. There needs to be a better understanding of the different ways in which diagnosis takes place, and what factors lead to specific routes and pathways to this status.

3.2 Time to diagnosis

Amongst those who provided information on time between getting ill and being diagnosed (120), only 14% were diagnosed quickly, with another 15% diagnosed within 6 months (Table 1). Considerable numbers of patients in the sample experienced longer time intervals between becoming ill and diagnosis, with a notable proportion (15%) having '15 years or more' before being diagnosed.

Over 70% of patients took longer than 6 months to obtain a diagnosis. Clearly there are issues regarding how easily and quickly those at risk of Lyme disease, were able to get access to appropriate care in this group of patients. This problem = not just restricted to those who have less evidence in favour of Lyme disease. Problems of getting quick access to care appear to go beyond those who do not remember (or present) a tick bite or a rash of any kind, or have non-classic symptoms.

Table 1: Time between onset of symptoms and diagnosis of Lyme disease

	Number	%
Diagnosed when got ill =0	17	14.2
>0 yrs <= 0.5 yrs	18	15.0
>0.5 yrs <= 1.0 yrs	7	5.8
>1 yrs <= 2 yrs	9	7.5
>2 yrs <= 4 yrs	13	10.8
>4 yrs <= 6 yrs	11	9.2
6 to 10	16	13.3
10 to 15	11	9.2
15 to 20	9	7.5
>20 yrs	9	7.5
Total	120	100.0

Of those in the study (143) that provided this information, only 9% felt that they had '*not experienced a delay in diagnosis*', with 2.1% who were '*not sure*' if they did. In light of this, and in response to a question about the '*reasons for any delay in diagnosis*', **64%** indicated they felt that they had been '*misdiagnosed*'; **50%** said it was because they '*did not know about Lyme disease or its signs*'; and **41%** said delay was due to their '*symptoms being ignored*'.

Other reasons for the delay that were less common included – '*negative tests initially*' (**31%**); '*did not realise they had been bitten*' (**28%**); '*testing was not timely*' (**25%**); '*referred to wrong specialist*' (**26%**); '*symptoms took a long time to develop*' (**22%**); '*other tests and investigations took time*' (**20%**); '*symptoms not specific to Lyme*' (**20%**); '*did not visit doctor immediately*' (**18%**); '*exposure to ticks was routine and unremarkable*' (**9%**); '*complex non-classic symptoms*' (**9%**); or '*slow referral time*' (**4%**).

3.3 Patient experience and perception of diagnosis

There appeared to be specific issues for those with negative NHS test results (63 people). They were more likely to feel delay to diagnosis was due to being '*misdiagnosed*' (78%). (57%) of those with negative NHS test results felt that delays to diagnosis were because '*symptoms were ignored*' and (35%) because they '*did not receive timely testing*' and (37%) because they were '*referred to the wrong specialist*'.

However, these problems were also apparent for those with positive NHS test results (48 respondents). For example, one in five with positive test results reported delays to diagnosis were due to the fact that they '*did not*

receive timely testing' (21%), about one in four felt this was because 'symptoms were ignored' (23%), and more than one in six because they were 'referred the wrong specialist' (15%).

The data presented here begin to highlight the problems for some patients. We suggest that, for a number of patients at least, there is room for improvement regarding recognition of Lyme disease symptoms, and swift and early treatment.

As one patient commented in relation specifically to NHS testing and its impact;

"Hugely negative impact - utterly discrepant compared to previous experiences of NHS care. Has destroyed my faith in doctors. I believe I lost a year battling hopelessly with the NHS."

(Case no. 70: negative NHS test; private diagnosis initially; 6 months interval between becoming ill and diagnosis).

And another;

"I was tested early and it came back negative. They spent the next one and a half years trying to say I had MS, until a consultant suggested retesting for Lyme. That test was positive. Now if the doctors who saw me (and there were many) had any knowledge about Lyme they should have realized tests come back negative if tested early in the infection, because the body has not yet produced antibodies. So my treatment then was unnecessarily delayed. My opportunity for early treatment was missed and my disease became chronic."

(Case no. 92: positive NHS test, diagnosed initially by consultant, 16 months interval between becoming ill and diagnosis)

The testing process can have major consequences on the diagnostic process depending on the clinical and other circumstances and on who makes the diagnosis and how it is undertaken.

4. DISCUSSION

4.1 The social context – Lyme disease contested

Many of the core issues for protocols to deal with Lyme disease are disputed worldwide particularly by published researchers, clinicians, as well as patient groups. There are complex ideological, political, medical/clinical and policy debates about the issues related to the etiology of Lyme disease and its effective management [36, 37, 38, 39, 40, 41, 42]. In general terms, these debates have taken place primarily within the medical/research context, rather than from the perspective of social or political science, policy or sociology.

Lyme disease has reached a level of notoriety in terms of the social dynamics around prevention, testing, diagnosis and treatment. These debates engage issues such as whether Lyme disease is under- or over-diagnosed, under- or over-treated, chronic or acute, easily treated or not, a disseminated or localised infection, and so on. This background discussion can influence different stakeholder's experiences, or understanding of the condition and perceptions about the processes for, and outcomes from treatment.

4.2 The experience of patients with Lyme disease

Few studies have tackled issues around patients' experiences of the illness caused by Lyme disease, or the health care provided to them. Johnson (2011) [43] looked at access to care, and the overall burden of illness for people diagnosed with Lyme disease based on Centres for Disease Control prevention (CDC) criteria for diagnosis. They highlighted a number of issues in American healthcare systems, such as delays in diagnosis and treatment,

multiple referrals to physicians before diagnosis, etc. Drew [44] focussed on understanding the patients' diagnosis of Lyme disease, and compared concepts of trust with other chronic illnesses. Mechanic [45] examined concepts of trust comparing those with Lyme disease and two other conditions. Aronowitz [46] examined patients' concepts and models of illness in relation to their use of internet sources of health-related and other information. Mankoff [47] examined how patients with Lyme used new technology and were affected by different viewpoints. Marcu examined awareness of having been bitten, knowledge of ticks and Lyme disease, understanding of symptoms, suspicions of having Lyme disease and preferences for precautionary actions whilst in the countryside in the UK [48].

There is still no research in Europe on the knowledge base of doctors in relation to Lyme disease, and only a very small number of studies outside Europe in this area, for example [49]. Most of the studies focussed on patients experiences were undertaken in the context of the United States: little or no similar research in Europe currently exists. This study aims to begin to fill a gap in understanding of the experiences of a group of patients in the UK and Ireland.

Rapid or early diagnosis requires a number of different factors to be in place, including the ability of the patient to realise the need for medical advice. The skills of the initial doctor consulted, the clarity of the presenting symptoms and/or knowledge of the patient's exposure to ticks and infection, and the accuracy of the laboratory tests and other diagnostic or risk analysis techniques, are relevant. Ultimately diagnosis is a human process that involves both doctor and patient, relevant clinical information, knowledge levels, and the quality of government guidance and research evidence available. It may also rely on biological indicators such as laboratory test results.

Patient's knowledge of treatment options, contact with other patients, level of engagement with their health problems, and use of the internet and health support or advocacy groups is also relevant. Underlying these factors are biological/medical factors, such as the nature of their illness, clinical history and symptomatology. All of these influences may be relevant to the specific circumstances in which people diagnosed with Lyme disease find themselves.

5. CONCLUSIONS

The patients in this survey appear to have suffered various problems in obtaining (what they consider to be) timely diagnosis, or access to appropriate diagnostic support. Delays in diagnosis seem to result from and create difficulties of various kinds. A number of patients may perceive for example, that they obtained other (competing) diagnoses, which delayed their Lyme disease diagnosis, and consider this to be inappropriate. However, these social dynamics need to be understood in more detail for these patients and for the broader patient groups, including those who have remained undiagnosed.

Change towards ensuring a better patient experience for all people at risk of Lyme disease, is going to be difficult, since the types of services and processes involved in providing diagnostic care, are varied and complex. If the problems for patients are indeed systemic then so too, must be the solutions. Change might include, for example, developing new social and organisational structures or processes, or applying new or emerging knowledge within policy and practice, etc. Firstly, there needs to be recognition of the problems for some patients, before change can be possible. The background of political conflict and the scientific and medical uncertainty related to testing, diagnosis and treatment creates a contested arena for both clinicians and patients.

We need strategic thinking on the part of the medical professionals, their professional bodies, the government, the NHS, and the agencies that provide the policy context. Good outcomes from care will benefit all parties involved, and this would be achieved by accurate and rapid diagnosis and early treatment.

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