

A PATIENT SURVEY OF A COMMUNITY : LYME PATIENTS EXPERIENCES OF HEALTH CARE

Keywords: Lyme disease; Borrelia; patients' experience; internet; survey; health services; patients; satisfaction;

ABSTRACT

Background; Lyme disease is an illness caused by a tick-borne infection that is becoming more common and may cause chronic illness.

Aims: To explore patients experiences of care, including their satisfaction with services and care provided by different types of medical care provision (private and NHS).

Design: A descriptive, retrospective study using internet based survey software. Both quantitative and qualitative data were collected.

Participants: 152 people were recruited via patients networks and social media, who indicated they had been diagnosed professionally as having Lyme disease (LD).

Main variables studied: 'Patient centred' indicators of satisfaction were collected in the study, supplemented by information from other sources, from the public domain.

Main measures: General indicators of satisfaction and perceptions about care received were examined for both those with and without positive NHS test results.

Results: Amongst this (self-selected) group of patients, there was a problematic experience of the NHS overall. Most felt care had been inadequate. They may not be representative of the broader group patients who have had Lyme disease. Problems appeared in both those with positive and negative NHS test results, but this was more pronounced for the latter group.

Discussion and conclusions: Whilst there is a diversity of experience of healthcare within this group, there is room for improvement within the NHS. The results may be an indicator of problems with the healthcare systems that some patients encounter. It would be useful to know how widespread any problems are.

BACKGROUND

'Lyme Disease (LD) is a multisystem and multistage infection caused by three species of tick-borne spirochetes... LD has become the most common vector-borne disease in North America and EuropeLike other spirochetal infections, the signs and symptoms of LD occur in stages and involve a variety of tissues and organs, including the skin, joints, heart, and nervous system.' (Reed 2002) [1]

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 (Dillon et al 2010)[2] and may also be found in some non-endemic areas of the UK such as parks, including in London (Rees & Axford 1994)[3].

Many clinicians and researchers consider the process of assessing patients for Lyme disease difficult (Aucott & Seifter 2011; Fallon et al 1998)[4, 5] others believe it to be 'over-diagnosed' in patients to their detriment e.g. (Strle & Stanek 2009; O'Connell S 2010; Reid M C, et al 1998; Steere A C, et al 1993; Carrington Reid M 1998) [6, 7, 8, 9, 10]

The range of potential symptoms can be considerable (particularly at an advanced stage), and can include fatigue, musculoskeletal pain, and neurocognitive difficulties (Cairns & Godwin 2005) [11].

The most well-known presenting sign of an acute Lyme disease infection from a tick bite is a distinctly circular bull's eye rash, however, other common or rare symptoms can occur including psychological manifestations (Marzillier 2009). The knowledge base for protocols that cover the diagnosis, testing and treatment of Lyme disease, however, is disputed worldwide by published some researchers, clinicians, and patient groups. These disputes have reached into the realm of medico-legal issues and conflict, as explored by Ferguson (2012) [13].

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 et al (2011) [14] 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 (2006) [15] focussed on understanding the patients' diagnosis of Lyme disease, and compared concepts of trust with other chronic illnesses. Aronowitz (2007) [16] examined patients' concepts and models of illness in relation to their use of internet sources of health-related and other information.

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 (Marcu et al 2013) [17]. The focus of this research was on the knowledge and behaviour of patients who had had been diagnosed, and had positive NHS tests (only), at the interface with doctors and the NHS.

Most of the studies focussed on patients experiences and were undertaken in the context of the United States: little or no similar research in Europe currently exists and there is a distinct lack of research in this area. This study aims to begin to fill a gap in understanding of the experiences of a group of patients in the UK and Eire.

There is also very little research in Europe on the knowledge base of health professionals in relation to Lyme disease. Lieber M'bomeyo [18] only examines doctors in an endemic area of France (2003) and looks at their understanding of early stage Lyme and testing. There are only a small number of studies outside Europe e.g. (Capps et al 2013; Magri, J 2002) [19, 20].

The relevance of research from the patient's perspective

This survey will be of interest to a wide variety of professional groups and agencies, and organisations. It provides a retrospective and descriptive account of a self-selected group of patients', experiences. This is one of many potential ways of exploring the impact of policy and practice as experienced through interaction with health services, by groups of patients at risk of specific health problems.

Descriptive techniques have 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 (Grimes 2002) [21]. This could include for example, a first step towards describing a situation from a different perspective, reflecting on problems and issues that arise out of new or emerging conditions or circumstances, monitoring trends and planning to address needs accordingly.

Approaches to the involvement of patients in research and research about patients' experience of health-care, has been developing for some time. For some grant making bodies, involvement may be a requirement of funding (Neirse CJ et al 2011) [22]. However, providing patients with too much control over research processes has also

led to fears of lowering scientific standards, and concerns about professional expertise being downgraded (Stewart R & Liablo K 2012) [23].

However, there are different models and methods for this involvement, which may be linked to the way in which the problems or systems being explored are conceptualised (Boote 2002) [24].

For example, research by or with patients can be seen as part of an empowerment process, and enabling more critical approaches to be developed (Beresford & Evans 1999) [25] that;

‘Instead of endorsing the traditional 'scientific' research values of neutrality, objectivity and distance, which, 'evidence based' inquiry has re-emphasised, it has questioned both their desirability and feasibility. It values people's first-hand direct experience as a basis for knowledge’.

This research into patients diagnosed with Lyme disease, lies at the highest level of involvement since it was designed, delivered, and commissioned by patients/public. It takes its focus from the social experience that patients undergo. The ‘social reality’ of patients is captured, and discussion of potential social factors is enabled. This kind of approach may provide a very different picture, than that based on other approaches and methodologies, because of the patient’s perspective. However, there are potentially disadvantages of the approach taken, such as the lack of access to patients in other clinical referral pathways, the use of internet methods that cannot be easily replicated, and issues related to the unknown reliability and validity of data. However, there is still a need to describe a situation where there have been a number of concerns already expressed by patients, about access to service and appropriate care.

Surveys that aim to recruit from patient support groups, and/or via the internet such as this, are less common. This is possibly due to the variety of methodological issues around self-selection and representative-ness, etc. However, this type of approach has been used in the context of examining patients attitudes towards drugs and comparing different data collection methods (Hensler 2013) [26]; epidemiological and clinical features as well as therapeutic intervention in patients with Urticaria (Kalogeromitros 2011) [27]; causes of pain in cancer patients and analgesic therapy (Simone 2008) [28] and patients perceptions of diagnostic criteria related to psychological disorder (Kalapatopou 2010) [29] etc. The rationale in these studies included the need to explore issues in groups of patients and patient groups, which may be considered as relevant as those recruited via clinics, formal research panels or clinical trials, or by other means.

There are potential advantages of using the internet and recruiting from patients groups that mitigate (whilst not removing) methodological disadvantages. These include the opportunity to include a broader range of types of patients that would otherwise be included; allowing groups that behave as patient diasporas, to be investigated; enabling problems with accessing services to be revealed (recruiting those who are more likely to suffer problems); and allowing these different dimensions to be highlighted.

METHODS

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. Most of the work (ninety percent) was undertaken on a voluntary basis, and in collaboration with Tick Talk Ireland. However, in addition, fundraising provided eighteen hundred pounds to support operational costs. Patients and patients’ carers were involved in the research in terms of reviewing project proposals, the questionnaire, etc.

There were areas where ethical issues regarding this research arose. In general terms the project relied on ethical guidance from the Social Research Association and their ethics forum when needed. Patients were recruited using standard approaches to informed consent but using internet means of communication.

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. The survey included patients' views of both 'private' (including NHS clinicians practicing privately) and 'NHS care' (free at the point of delivery, via primary, hospital or clinic settings). In the current form of the NHS this (latter) kind of care does not include private clinicians paid for by the NHS, but 'private' care could include those who work for the NHS (ordinarily) but were providing private care at the time.

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 in this analysis 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. 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.

Study limitations

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 lack of representativeness of the patients relative to other communities of interest means that the results cannot be generalised to other groups. Other limitations to the approach taken include lack of knowledge about the accuracy of patients' recollection, and lack of confirmed detail about events or facts etc (i.e. missing information). There are also limitations associated with internet surveys, which are known to elicit different responses from other types of survey methods (Couper, M 2000) [30].

RESULTS

A wide range of questions were asked in the survey covering the context of the illness. Data related to the overall social experience of care, are presented here.

Main diagnostic indicators and route to diagnosis

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.

Reported tick bites and rashes

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.

Over 70% of patients took longer than 6 months to obtain a diagnosis. There may be issues regarding how quickly those at risk of Lyme disease, were able to get access to appropriate care in this group of patients.

Levels of satisfaction with services provided

Levels of satisfaction were explored in several ways, including various open-ended questions, comparisons of NHS and private care, and levels of complaints. Levels of complaints about private care were not included in the study, due to small (and identifiable) number of ID and other types of doctors in the UK in this position, creating an ethical issue. This creates a bias towards problems with NHS services being emphasized more than those that appear within a private context. However, this bias is limited since it only applies to the data on complaints.

Complaints about the NHS

21% of people in the study (141 responded to this question) had made 'a complaint about policy or their own case' at some point in the past, and **only 13%** indicated that a formal complaint was 'not relevant, happy with treatment'.

Of those who complained (28 people), 14 had done so to their Member of Parliament, Primary Care Trust (10), and/or local hospital (13). Other places that were contacted included the Health Protection Agency/Health and Safety Executive (6), a GP or local health clinic (5), Department of Health (4), and less often the ombudsman (2) or reference laboratory (3). Two patients indicated that they had taken a complaint about a doctor to the GMC.

More worryingly, those who *did not* complain cited a number of different reasons for this, suggesting that if patients were supported or confident, informed about the process, or well enough to complain, the proportion might be different.

Of the 84 patients who responded, when asked 'what was your reason for not making a complaint', 19 (23%) said this was because they 'didn't want to complaint/not relevant'.

The rest stated that they were '*too ill*' (50%); '*believe there is no point, system unchangeable*' (41%) and '*afraid of consequences*' (33%). Other reasons given included '*didn't have enough information or evidence*' (23%); '*complaints system too difficult/ complicated*' (21%); '*would rather just pay for treatment*' (24%); '*didn't know how to*' (21%); '*don't understand the policy or system sufficiently*' (20%); and least often '*told there was no point by lawyer or advisor*' (2%). These percentages would be higher if the '*didn't want to complaint/not relevant*' group had been excluded.

The problems for patients were again not simply polarised between those that had negative and those that had positive NHS test results. Of those 25 with positive test results, only one in three said that they '*didn't want to complain*' or '*it was not relevant*'. Nearly *one in three* with positive test results said they were '*too ill*' to complain (7), *one in ten* said that that they were '*afraid of the consequences*' of complaining (3), and nearly half said that there was '*no point, system unchangeable*' (12).

Dissatisfaction with current practice within the NHS was greater amongst those with negative test results, but similar issues were seen amongst those with positive test results.

Some illustrative comments from patients include:

"At the time I was very sick for many years and just wanted desperately to get better - I did not feel that complaining would be beneficial - I was also very exhausted".

"Because of the almost bullying attitude of healthcare officials, it wouldn't do my health any good to take them on because they would do everything to make sure they are right rather than deliver care".

It is particularly worrying that one in three of those people who did not think that '*they were happy with treatment*' felt that complaining was too '*risky*', and that they were possibly frightened of the consequences of doing so.

The Health Protection Agency believed in August 2011 that no complaints (FOI Ref: 11/06/2/ac/150) had been received to date about Lyme disease patients' issues. It appears that the level or types of problems that patients are experiencing on an on-going basis are not yet apparent to institutional processes of monitoring or improvement.

These complaints seem to disappear into the system and have not generated any review of the issues for patients. As a result, the NHS and its agencies may be missing the opportunity to understand how the general practices for those at risk of Lyme disease impacts on patients in the NHS.

Experience of NHS and private care

Other evidence of satisfaction in this group of people comes from the information about their experience of NHS care and private care for their Lyme disease. Response exposed some degree of variation. However, there was also some degree of polarisation in the response to NHS and private care overall, with the patients generally feeling they had better care from private sources.

Response to care was rated on a seven-point scale with a neutral central point. Overall, 30% of respondents rated their NHS (free) care as adequate (*sometimes, mostly and completely*) compared to 64% of those rating their private care. Conversely, 65% of patients rated the NHS care they had received as inadequate (*sometimes, mostly and completely*) compared to only 18% of patients rating their private care.

However, looking in more detail it appears that the largest proportion rated their private care as '*mostly adequate*' (31%) and the highest proportion of those rated NHS care as '*completely inadequate*' (36%).

Amongst those 47 people with positive NHS test results, 48% were more likely to say their care on the NHS was adequate (*sometimes, mostly and completely*) compared to only 12% of those 57 patients with negative NHS test results. However, more than half of those with positive NHS test results said their NHS care was inadequate (*sometimes, mostly and completely*) (51%). Those with positive and negative test results on the NHS share to some extent a poor experience of NHS care, as in both groups more than half say this care was '*inadequate*'.

A more complex picture emerges from information on reactions of patients to private care. Amongst those (19) that had access to private care, had positive NHS test results and who responded, 53% said private care was adequate (*sometimes, mostly and completely*) compared to 83% of those with negative test results (52). 37% of those with positive test results said private care was *inadequate* compared to 14% of those with negative results.

These patterns are difficult to interpret given the different types of private care that exist and the specific routes and ways in which individuals come to access that care. However, a different pattern is seen compared to the overall response to NHS care and the reasons for this must be explored and understood further.

Patients' experiences of main healthcare providers – GPs and NHS consultants

A considerable proportion of patients thought their GP lacked information or knowledge about these illnesses and/or the risk of tick-borne infections. **62%** of respondents did not feel that their GP was fully informed about infections from ticks when they became ill. **14%** felt their GP was fully informed, **20%** thought they were partially informed, and 4% didn't know.

Primary NHS consultants also fared badly in terms of the patients' assessments in the study. **63%** felt that their main NHS consultant was not equipped to deal with their health problems; only **8%** felt that they were 'fully equipped' and **14%** that they were 'partially equipped'. 14% answered 'don't know' or 'Not applicable/ didn't see a consultant'.

"It has been an awful ordeal, eight consultants, many differing diagnosis, many prescriptions with no success, lengthy waits, no care for me as an individual and no consideration for how all of this must be affecting my mental health."

(Case no. 51: positive NHS test, initially diagnosed by NHS consultant, 13 months between becoming ill and diagnosis)

DISCUSSION: Experience of NHS versus private care

The dynamics around private care are complex for many different reasons, including the fact that many choose private care because of past problems with the NHS, and many do not have access to private care at all. Private care may potentially be dealing with more difficult and complex cases, potentially including those where there had been longer delay before diagnosis.

Those who had successful NHS care may be less likely to seek private care. Whilst those who seek private care and those who do not (or cannot) access private care may in general, be different types of patients - it is the

similarities or overlap of experiences, which are revealing. General patterns show some degree of similarity between those with positive and negative NHS test results that provide a useful insight into the extent of problems amongst this group of patients.

One could expect that private care would inevitably be more satisfactory for patients unless the cost itself results in some dissatisfaction. In general, private care may make available more treatment options perceived to be tailored to individuals' complex history and specific needs. This may give hope to patients who had been untreated or whose treatment had failed. It is also possible that very different criteria are used by patients to judge the two sectors.

Expectations of the private sector may be different and may relate to the specific reasons why patients are consulting with them. The NHS may then be judged by patients with regard to options and standards set by private care, possibly offering a different range of treatment options.

One could also expect patients who have had problems with the NHS to be more likely to seek out and join a study of this kind. However, the most seriously ill might not even engage with social media or support groups, so may not be able to participate.

In reality, care is not neatly polarised between NHS or private care in a normal patient's clinical history and past. A mixture is often available through time to patients, and there are also distinctly different types of NHS consultant and private doctors available. There will also be changes in those experiences and opinions through time for individuals and groups - as time progresses, and further on into treatment dissatisfied patients will be more likely to seek private care (if they can).

There may be differences according to the ways in which patients are assessed and treated in different sectors, and the extent to which Lyme disease is attributed to symptoms or medical conditions by patients or their doctors. There can be differences of opinion amongst attending doctors, and medical opinions will change through time in the care of individuals, especially where new test results emerge from additional testing.

The information presented is only one 'slice' through a group of current patients, whose situations vary enormously as individuals, and whose history as a patient is likely to progress if they have unresolved illness.

Many patients will have multiple experiences of different types of care over a long period of time. They may dip in and out of private and NHS care, or experience both together. The responses to this survey will also be related to areas such as the quality of the patient-doctor relationship, the degree of severity of their condition, the extent to which their core concerns about health improvement are met, and their improvements or deterioration from treatment.

Despite the potential complexity of these factors, these survey results suggest an experience of health care within the NHS for these Lyme disease patients, which is not satisfactory in general terms.

The words of one patient highlight the difficulties for them in emotional terms and the kind of dynamics that exist for some patients;

"The NHS treats Lyme patients like hypochondriacs, I frequently came back from appointments humiliated and in tears."

Case no. 98: negative NHS test; privately diagnosed initially; 36 months between becoming ill and being diagnosed).

*"The whole experience of hospital ***was a nightmare: 'You cannot possibly have Lyme Disease'; almost to the point where it seemed that they might be deliberately not doing the testing properly in order to*

make sure there couldn't be a positive result. This attitude seems to have pervaded back to my GP and his comments above. What really staggers me is the wanton denial that there is a problem, and that it is possible to get infected abroad and bring the disease back to the UK."

(Case no. 49: negative NHS test, diagnosed initially by other alternative practitioner, 16 years between becoming ill and diagnosis)

Taking all these issues into account, the picture created of the experiences, is suggestive of problems with the systems within which some patients received care. These patients may be atypical, however, since they are a distinct group who appear to have experienced poor levels of satisfaction for NHS care.

The key question is whether these problems for patients, and this problematic experience of health care systems, are more widespread. Is this experience of the NHS indicative of a misunderstanding or lack of knowledge of Lyme disease within the NHS? GPs, for example, might find this a difficult disease to diagnose since there are many overlapping conditions, and so they may require better guidance, training and/or support in doing so.

Despite the issues concerning a self-selected sample of NHS diagnosed patients, these data raise important questions about patients' experiences and suggest a need to examine causes and solutions.

CONCLUSION: Patients' experiences

There are many varied ways in which diagnostic and treatment processes can succeed or fail, from a patient's perspective. Diagnostic processes are complex human interactions combined with health services systems and involve both the knowledge and behaviour, of patients, as well as doctors. In the middle of these social processes are the patients' and doctors perceptions about how their needs could (or should) be met.

Perceptions of patients will be influenced by a number of different factors, including their previous experiences. Underlying these factors are biological/medical factors, such as the nature of their illness, clinical history and symptomatology.

Patients may have very different ways of understanding their experience to doctors. In these kinds of circumstances, differences in perspectives are likely to develop between patients and doctors if there has been a delay before treatment. This can impact on the clinical relationships between patients and doctors, in various ways. This can also impact on the ways in which different sectors of healthcare are perceived, sought after, and experienced.

These are some of the possible underlying social dynamics that affect some Lyme patient's behaviour, opinions and attitudes. It is not yet clear which of these specific factors is most relevant to this group of patients, or to what degree, nor what the variation is, within this group.

The picture emerging from this research is that, in this group of patients, who have been diagnosed with Lyme disease, most do not have confidence in NHS services. They feel their doctors lack knowledge or information about tick-borne infections, and are largely dissatisfied with the services they have received.

Many would argue this is because it is a difficult illness to deal with in a chronic form, and those patients who suffer from 'post-Lyme syndrome' may have expectations that cannot be met in NHS care.

However, it is the social context that must be understood more fully. Attitudes and behaviour are both the consequence and cause of experience and levels of satisfaction with services. Expectations about how services could or should have operated, will also play a major part in social/psychological dynamics within patients and patient groups and their relationship with doctors. This will affect how experiences of services are understood and reviewed by patients, in terms of their overall satisfaction.

These beliefs will be shaped by their experiences of the illness, of care received and of knowledge they accumulate from a variety of sources, including other patients. People who get diagnosed with Lyme disease for example, maybe different in many ways, compared to those who remain undiagnosed in the community.

However, problems that arise in a self-selected group may highlight a need to consider issues that could affect other groups, such as those who have not yet obtained a diagnosis. Lessons can be learnt from an understanding of what could be the 'worst case scenario'. Improvements to services to groups of patient must be based on a realisation of where systems are not benefitting patients in terms of their experience, as well as clinical outcomes, since these two perspectives may not be distinct.

Declaration of interests:

The main author in this study has personal experience of Lyme disease, and set up the group Lymeresearchuk. She did not benefit financially as a result of the study. The second author received some re-numeration for some of her contribution. KB led design of the survey and collected the data, and VH helped with the interpretation of the findings, and writing of the article.

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