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When General Practitioners Say "I Don't Know": A Qualitative Study on the Construction of Lyme Borreliosis Diagnosis

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Abstract

Background: From the perspective of social science, diagnosis is not only a question of assigning a category, but also a process of producing knowledge.

Aim: The aim of this article is to explore the construction of Lyme borreliosis (LB) diagnosis as a process, in a population of French general practitioners.

Method: ReLyMeG was a French psychosocial and qualitative study conducted in 2021, which recruited 19 GPs as participants from different regions. Semi-directive interviews were conducted and then analyzed by conceptual categories analysis.

Results: Results from ReLyMeG made it possible to identify three processes in GPs' practice: The process of construction, of deconstruction, and of categorization. Different kinds of uncertainty were distinguished, as well as different psychosocial strategies that GPs used to manage uncertainty.

Conclusion: Exploring the multiple ways of managing uncertainty in the context of LB diagnosis made it possible to highlight some social identity issues concerning general practitioners, and to propose some possibilities for intervention with a view to improving their approach to uncertainty.

Keywords

Uncertainty, General practitioners, Lyme borreliosis, Social identity, Controversy

Introduction

In biomedical epistemology, diagnosing involves developing and applying categories [1] based on clear boundaries [2] with the aim of systematizing symptoms. In this sense, diagnosis makes it possible to classify illness and pain according to pre-existing and prototypical nosological labels. However, in this conception, the biomedical decision-making process is simplified and idealized [3]. In practice, diagnosis is not simply a matter of assigning a category, but also a process of producing knowledge [4-7]. Conceived as a process, diagnosis consists of all the practices of investigation, interpretation, negotiation, and decision-making surrounding

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patients and their health problems. In this process, the patient’s experience, the doctor’s experience, and the social (Rosenberg, 2002) and moral (Blaxter, 1983) framework interact. Individuals are not passive recipients of biomedical categories, but rather construct and modify those categories [8]. Considering diagnosis as a process makes it possible to emphasize its social dimension, as well as the socio-cultural and historical context in which it has been constructed. In this sense, diagnosis is not an objective, immutable, and neutral category, but the result of an ever-evolving co-construction in which the social and clinical dimensions are intertwined [9].

The case of Lyme borreliosis (LB) provides a good illustration of the social (and not only biomedical) dimension of the construction of diagnosis. In France, Northern Europe, and the US, LB is the most common tick-borne disease [10]. LB diagnosis is based on three elements: Known exposure to a tick bite, suggestive clinical signs, and positive serology in two stages for disseminated forms of the disease [11]. Furthermore, for this particular disease, the distinction between specific and non-specific symptoms is essential [12], with the latter sometimes being categorized as medically unexplained symptoms (MUS). LB is currently surrounded by a context of medical and social controversy [13]. Concerning diagnosis, some doctors consider the recommended serologies as unreliable and highlight the fact that a tick bite can go unobserved. In their opinion, LB diagnosis should be based on the examination of clinical signs (both specific and nonspecific ones) and on certain biomedical tests that have not been approved by official institutions.

The aim of this article is to explore the construction of LB diagnosis as a process, in a population of French general practitioners and in a context of controversy.

Material and Methods

ReLyMeG was a French psychosocial and qualitative study conducted in 2021, which recruited 19 GPs as participants from different regions. It aimed to capture the social representations and practices of healthcare providers whose representational system is made up of both expert and lay knowledge. Each semi-directive interview lasted approximately one hour and explored the following areas: the care relationship with patients who had been bitten by ticks; the care relationship with LB-(auto-)diagnosed patients (the management of uncertainty, the use of biomedical tools, decision-making and the announcement of the diagnosis, experiences of negotiation/conflict, the relationship with the patient’s family, etc.); LB in comparison with other diseases; and (potential) evolutions in medical practice as a result of controversies. ReLyMeG was authorized by the CEEI (Comité d’Evaluation Ethique de l’Inserm, IRB00003888, approval number 22-964).

Analysis

The Computer Assisted Qualitative Data Analysis Software (CAQDAS) package ATLAS.ti [14] was used to apply the iterative and comprehensive process required for the analysis of transcribed interview texts. We opted for an analysis by conceptualizing categories [15]. The work of thematization did not refer to syntheses of the content of the interviews (themes), but rather to processes and actions in progress [16]. The themes identified during the thematization can therefore be considered as “category starters,” sometimes requiring conceptual and processual reformulation. Unlike thematic analysis, analysis by conceptualizing categories is a method that enables phenomena to be identified directly. A conceptualizing category not only carries meaning, but also accounts for the evolutionary and processual dimension of phenomena. More specifically, we focused on the psychosocial processes involved in constructing and deconstructing the patients’ (auto-)diagnosis.

Results

The data analysis made it possible to identify three processes in GPs’ practice: The process of construction; the process of deconstruction; and the process of categorization (Table 1). The process of construction includes the construction of LB diagnosis, which is characterized by different kinds of uncertainty. The process of deconstruction includes the deconstruction of a patient’s auto-diagnosis of LB, the deconstruction of a diagnosis of chronic LB, and the deconstruction of social representations of chronic LB through discussion with patients regarding prevention strategies for tick-borne diseases. The process of categorization includes the categorization of LB as a social disease and the categorization of patients through stereotypes.

Nineteen GPs agreed to take part in the study. The GPs were recruited from several regions in France where LB is highly endemic (especially Bourgogne France-Comté and Grand Est), using different strategies. Some were identified because they were then consulting, or had previously consulted the Centre Hospitalier Régional Universitaire (CHRU) in Besançon or the

Table 1: Processes in GPs’ practice, from the results of the ReLyMeG study.

Type of process	Conceptual category
Construction	Constructing LB diagnosis
Deconstruction	Deconstructing LB autodiagnosis Deconstructing chronic LB diagnosis Deconstructing social representations of chronic LB through discussion of prevention strategies for tick-borne diseases
Categorization	Categorizing LB as a social disease Categorizing the profile of LB patients

Table 2: Socio-demographic characteristics of the ReLyMeG population (n = 19).

Mean age	42.8 years
Sex	
Men	9
Women	10
Mean length of professional experience as GP	14 years
Practice area	
Urban area	6
Semi-rural area	13

Nouvel Hôpital Civil (NHC) in Strasbourg, in particular to seek professional advice and/or to refer their patients to these hospitals. Others were taking part, or had previously taken part, in the CiTIQUE participatory program[a]. The only additional criterion was the fact of having worked as a GP for at least three years. Knowledge or interest in tick-borne diseases was not a recruitment criterion. In terms of socio-demographic characteristics (Table 2), the average age of the 19 participants was 42.8 years. There was an almost equal distribution of women (n = 10) and men (n = 9). Professional experience as a GP ranged from 4 to 28 years, with a mean of 14 years in practice.

All the participants agreed that, in cases where erythema migrans appeared after a tick bite, serology should not be used. All participants considered LB diagnosis to be a simple matter in such cases. In contrast, participants mentioned feelings of uncertainty when facing MUS and/or disseminated phases of LB. In these cases, diagnosing LB was conceived as a process of construction (i.e. the first kind of process in our results). In this article, we will essentially focus on this first process. In the first section, we will distinguish two levels of uncertainty: Individual uncertainty and structural uncertainty. In the second section, we will identify some psychosocial strategies that are implemented by GPs to manage their uncertainty: 1) The use of technological tools; 2) The valorization of clinic practice; 3) The definition of the role of GPs role through the delegation of diagnosis to specialists.

Levels of Uncertainty

The individual level

A minority of participants (n = 4) associated their uncertainty about LB diagnosis with a feeling of individual incompetence, especially when faced with cases that they considered "complicated, beyond [their] skills" (Adèle, 52-years-old). The possibility of "missing" an LB diagnosis due to a lack of experience was mentioned, but over-diagnosing was also perceived as possible. More precisely, participants evoked a feeling of incompetence and illegitimacy concerning the interpretation of symptoms and serological tests.

After the primary Lyme phase, I don't have a very good grasp of it, and it's rather vague, because it can cause a lot of different symptoms, and obviously when the symptoms can be very varied, it's really complicated. You should think about it often, but also not too often, so it's, it's very complicated (Marianne, 31-years-old).

Furthermore, GPs reported that they were often questioned by patients about controversial issues, such as the reliability of serological tests. In this context, some found it "impossible to make a decision" (Philippe, 56-years-old). For example, Marianne felt "discredited" because of a lack of knowledge of the context of the controversy. She insisted on the importance of "being honest" and of telling patients when she does not know something; however, this may result in not being able to "reassure patients" who are looking for an explanation for their health problems. In this respect, for a minority of GPs, the uncertainties linked to the controversy constitute the only problem associated with the management of LB, whereas the disease is not considered to be a complicated one from a purely medical point of view (n = 3).

The structural level

Structural causes were also put forward by GPs to justify their uncertainty. Some considered that medicine and science do not provide sufficiently reliable tools for diagnosing LB in its disseminated stages, "except for certain cases of facial paralysis" (Emma, 35-years-old).

I'm always quite cautious, because I tell myself that we don't know everything, and that in a few years' time, well, what we think isn't a case of Lyme disease, may turn out to be, so I'm always quite cautious and tell them "well, as things stand today, it's unlikely," but I'll never say "oh no, it's 100% certain." So, you see, I'm always quite cautious and I tell myself that I have to stay very humble. There are some things we know now, but they'll evolve, that can change, so I try to trust the recommendations we have, the guide to good practice, while remaining open to the possibility that there may be something else. And that also means that patients can re-consult if there are new symptoms, because sometimes we get off to a bad start, a pathology might start by producing one type of symptom, and then over time other symptoms appear, and that feeds into our diagnosis or others, so... There you have it, I'm quite cautious and quite... open, because there's a lot of vagueness in Lyme disease (Charlotte, 40-years-old).

In this interview extract, Charlotte highlights the "humble" stance she tries to adopt with patients: Remaining open to various hypotheses, following official recommendations, while acknowledging the limits of medicine in the context of LB. More precisely, diagnosing LB in its disseminated phases can be perceived as "difficult, because the symptoms can look like anything and everything" (Anne, 35-years-old).

Statistically, people who have Lyme disease, well, who have a real, attested Lyme disease, don't remember or don't necessarily know that they've been bitten. So it's not easy, because it can be any symptom, well not absolutely any symptom, but many neurological or articular symptoms can suggest Lyme disease. In fact, there's no specific

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[a] CiTIQUE is a participatory French research program that allows citizens to participate in every stage of research on TBDs, through workshops and a mobile app.

symptomatology for Lyme disease, the only specific thing is the association of tick bite and symptoms. But, as we often don't have the datum of the tick bite, well, it's not that simple (Anne, 35-years-old).

According to Xavier (37-years-old), communicating with his patients about the "limits of medicine" in the context of LB is an "honest" approach. Given that making a mistake is one of the possible risks in the context of this disease, the participants to the ReLyMeG study are often led to admit their uncertainty to patients, or to "not assert with certainty" in cases where the diagnosis is "just a hypothesis" (Emma, 35-years-old). According to Emma and Marianne, knowing how to say "I don't know" strengthens the relationship of trust with their patients.

I don't know how to make [LB] diagnoses and I wouldn't necessarily know when to suggest them, and if I do suggest them, how do I eliminate them? Or how do I confirm them? I don't know how. […] I don't go looking for it because I don't know what to do afterwards. So, clearly, I don't know how to manage this type of patient. I don't know how to diagnose them, I don't know how to refer them, I don't know how to manage them, so, as I don't know, I don't see it, I don't do it. That's it, we only treat what we know. We only look into what we've raised as a possibility (Xavier, 37-years-old).

In this case, the hypothesis of LB is ruled out for reasons that relate to the GP's skills, and not on the basis of medical and biomedical criteria. Nevertheless, Xavier insisted on the "universality" of this uncertainty: It is not a question of individual incompetence, but of structural and scientific limitations that make it difficult to make an "objective diagnosis of Lyme disease" (Paul, 56-years-old). Discussing the limitations of LB diagnosis sometimes led participants to mention the difficulties related to the interpretation of MUS.

It's people who complain of fatigue, or pain, whether general or localized, who try to find a cause and we don't necessarily find it. It's a kind of failure of our science (Stéphanie, 57-years-old).

It is the failure of medicine that creates the impossibility of "putting a name" to these health problems (Paul, 56-years-old), and leads to GPs "not being able to find an explanation" (n = 3) for them: For Louis, it is a matter that "medicine is unable to contain." When they found themselves unable to make a clear diagnosis, GPs focused their communication with patients on the "current state of science," which is "not advanced enough" (Anne, 35-years-old) to understand the causes of MUS. According to this GP, in the case of LB, the high prevalence of self-diagnosis among certain patients is a result of the limitations of science in this domain.

Whether for individual or structural reasons, the feeling of uncertainty regarding the disseminated phases of LB was often associated with a perception that medical training was poor with regard to this disease (n = 6).

I find that there's a real lack of training, even as doctors, I mean… I'm not saying that there isn't any available, but during our studies, especially in our regions, I find that we don't focus enough on what to do when we have a positive serology test in our hands and the steps to follow, etc. It's true that it's a complicated issue, and that we all deal with it according to our own feelings, knowledge and beliefs. It's very unpredictable and we even vary what we do depending on the day, if we want to take the time to have a long discussion with the patient or if we want to cut the consultation short, we won't necessarily follow the same approach. Personally, I recognize that (Alice, 37-years-old).

In this interview extract, "feelings, knowledge, and beliefs" were mentioned as elements that contribute to the diagnosis of LB, as complements to uncertain biomedical knowledge. Furthermore, some GPs do not feel able to talk with patients about the context of controversy since the latter is not the subject of university training.

So when it comes to Lyme disease, the pathophysiology of treatment, etc., I'm pretty sure that's what I was taught, and that all I'd have to do is re-open a book to find the information, that's for sure, and on that I think the training is good. The thing I don't remember hearing about when I was at university is all these, these legends about Lyme disease and these, these problems with tests and these… yeah, this sort of mistrust people have of the quality of tests, of their reliability. I don't remember hearing about it at university and so, of course, when you're confronted with it, it's never very easy to deal with it… so maybe there's something more to be done or to warn future doctors that it's not that simple to deal with, you know? I have the impression that it's not like just any other infectious disease, you open a book, you find the answer, you find the treatment and then that's it. For Lyme, I think even if I reread my chapter on Lyme disease in depth, I'd still find myself in situations that aren't easy to manage, with questions about the tests that are ultimately beyond what's taught (Marianne, 31-years-old).

Marianne, the youngest and least experienced GPs in our study especially reported difficulties in dealing with controversial subjects associated with LB. Practice in the field, informal exchanges with other GPs and specialist colleagues, and access to specific training on LB seem to enable the most experienced GPs to tackle controversial subjects more easily and to put in place appropriate communication strategies. For this reason, Pierre (48-years-old) suggested that GPs could benefit from attending a dedicated university training about how to deal with "patients who think they have LB, to answer their questions."

Uncertainty as the intrinsic condition of medicine

The data analysis highlighted the experiences of uncertainty related to the professional representations expressed by GPs. More precisely, uncertainty was described as an intrinsic condition of their job. "Wandering" (Louis, 40-years-old) and "navigating in the unknown" (Xavier, 37-years-old) were defined as essential parts of a GP's work. From this perspective, the case of LB can be viewed in the context of a science that is "never certain" (n = 4): Like other diseases, LB is "simple to learn from books and complicated when it comes to the real thing" (Marianne, 31-years-old). Uncertainty is the "daily lot" of a GP's job (Charlotte, 40-years-old), since "knowledge is fluid" (Emma, 35-years-old).

I often say to people "listen, on this day, this is the information I've got" and then I give them the date, like "Wednesday December 15 at 10 p.m., right now, I'm telling you this, but maybe in a year and a half, I won't be saying that anymore" (Emma, 35-years-old).

According to Emma, during the Covid-19 health crisis, people increasingly took on board the idea that knowledge changes over time, since this situation led to developments in medical knowledge being called into question in the short-term. In this sense, doubt can be viewed as a fundamental element of scientific and diagnostic reasoning: "Questioning, checking, rechecking, trying to be rational" (Auguste, 54-years-old), without having certainties.

The psychosocial strategies used for managing uncertainty

The data analysis showed that GPs used various psychosocial (and not only biomedical) strategies to manage uncertainty in the context of LB.

First, GPs introduced antibiotic treatments as diagnostic tools: if the antibiotic prescription proves effective, the diagnosis of LB is probably confirmed. Some GPs chose this strategy when the results of serology were doubtful (n = 2), while others adopted it regardless of serology (n = 4). A minority implemented this strategy on their own, without seeking the advice of infectious disease specialists (n = 2). The others did not consider this strategy because, in their view, it does not fall within the remit of a GP. From a psychosocial point of view, the aim of implementing this strategy was to reassure patients (n = 3). This therapeutic choice was aligned with a principle of "guiding people towards treating symptoms" (Anne, 35-years-old), rather than focusing on their cause.

The other psychosocial strategies concerned were: 1) The valorization of the clinical approach and of the role associated with GPs' practice; 2) The valorization of biomedical diagnostic tools; 3) The definition of GPs' role through the delegation of diagnosis to specialists.

The valorization of the clinic approach and of the role of GPs

Most participants conceived of the serological and clinical approaches as being complementary, and applied the two-thirds-testing approach [17].

Well, it's a mixture of the two [the clinical and serological approaches], actually. And the two are not disconnected. With a clinical examination, you're looking for a certain number of elements, but there won't be any that are 100% sure to be Lyme. That's why the two are always intertwined for me (Philippe, 56-years-old).

More specifically, there is a hierarchy between the two approaches. The clinical analysis justifies the use of serologies. The clinical factors are conceived as "contextual" elements (n = 3) that make it possible to relate the "patient's history through traceable clues" (Emma, 35-years-old) (exposure to ticks, symptoms and signs, a belief that there have been neglected tick bites in the past, etc.). Consequently, serology is not carried out systematically: "we do not treat blood tests, but patients" (Emma, 35-years-old). Using only serological tests would be like "fishing for information" (Louis) in a decontextualized way.

It's a bit like, if I were to draw a parallel, tumor markers, for example, when we ask for a certain number of tumor markers, they're difficult to interpret. PSA, the prostate marker, is sometimes difficult to interpret out of context. So what do you do if the PSA is high, but there are no other symptoms? That's the limitation, sometimes it's the beginning of hyper-medicalization. We're going to go in and do loads of tests, when there was actually nothing there in the beginning (Benoît, 35-years-old).

The GP's understanding of the symptoms is conceived as "the starting point for knowing how to raise the possibility of Lyme" (Anne). Most participants stressed the primacy of the clinical approach. Given that "the disease is above all a clinical expression" (Pierre), "the priority approach is clinical" (Pauline, 38-years-old). Serological tests are possibly prescribed following a "correct scientific approach" (Stephanie, 57-years-old), which focuses first and foremost on the symptoms. The clinical approach "guides the use of serology" (Benoît, 35-years-old). That means that the GP's role in the diagnostic process is enhanced, because the GP "gathers the clinical evidence" (Louis, 40-years-old) and "accumulates the bundles of evidence" (Emma, 35-years-old). In the same way, the GP decides when to exclude certain diagnostic hypotheses, sometimes pursuing the possibility of an LB diagnosis even despite negative serology results. Given a random list of symptoms, the GP has to "sort it out" (n = 3), guided by his or her knowledge and experience, but also by the relationship and communication with the patient. Biomedical results are considered as being insufficient when viewed as isolated elements, but they do have meaning if they are integrated into a more global reasoning, which is undertaken by the GP.

The valorization of biomedical diagnostic tools

In the participants' practice, serology was used more to rule out than to confirm the hypothesis of LB. For this reason, several GPs defined LB diagnosis as a diagnosis of elimination: Serology is prescribed with the aim of ruling out the hypothesis of LB from the GP's "decision tree" (Pierre, 48-years-old), and consequently allowing the GP to search for another diagnosis. In general practice, this happens over the long term, which allows the GP to "take a step back" (n = 3) from the clinical investigation. Taking a step back means being able to rank diagnostic hypotheses "between what is probable, less probable, and very probable, because certainty does not exist" (Charlotte, 40-years-old), and being able to carry out this ranking over time. During this process, LB is rarely mentioned by GPs as being very probable.

Say I'm doing a work-up for neuropathy of the lower limbs, I'm more inclined to start by considering poorly balanced diabetes, alcohol consumption or things like that, I'm not going to start by saying "oh well, it could be Lyme," honestly. […] I think it's partly because, well, at least in my practice, it's really a diagnosis of elimination… I'm not going to do an examination and say "yeah, that really fits in with Lyme," I think it's too… with Lyme there are too many other possibilities to… well, for us to go straight to that. If it's not a straightforward case, then… In any case, if it's really secondary or tertiary Lyme, [I'll raise it] at the end of the consultation, but I'm not going to start with that (Ariane, 42-years-old).

Even though many GPs defined LB as a diagnosis of elimination, our analysis showed that there are different meanings attributed to the term "elimination." For some GPs, a diagnosis of elimination using serology is undertaken when, once the symptoms have been analyzed, the GP has no "diagnostic lead in mind" (Baptiste, 39-years-old) and/or the symptoms may be partially suggestive of LB: this does not mean that the GP "believes" in this lead, but rather the GP checks it in order to be able to rule it out. For some other GPs, undertaking a diagnosis of elimination means sticking to a procedural approach: LB may be one diagnosis among others to be eliminated during the biological work-up, before prescribing specialist consultations, according to a professional standard shared within medical practice.

I'll do [Lyme serology] but not because I believe that's what it is. It's a diagnosis of elimination, which means I'll do it just like I'd certainly do a protein electrophoresis, just in case, but without believing that's what it is. But I say to myself: afterwards, if I don't find anything, I can't send for an opinion if I haven't done that. You know what I mean? I'm not going to refer it to a specialist, because I need to have eliminated all the things that could do that (Ariane, 42-years-old).

Finally, for some GPs, a diagnosis of elimination means that LB diagnosis is ultimately retained because all other diagnostic hypotheses have been ruled out. Given that serology may be doubtful, if the other hypotheses are ruled out, LB may be identified as the only possible explanation for the patient's symptoms: Serology is thus used as a decision aid. However, in this case too, selecting the LB hypothesis from among others does not mean that the GP systematically believes that it is the "correct diagnosis" (Philippe, 56-years-old).

It's still a diagnosis of elimination, because we haven't found anything else… because it's still a diagnosis of elimination among many other things. Before you have a neuro-Lyme, you have to check that it's not, well, I don't know, that it's not Guillain-Barré syndrome, that it's not some other thing that you may or may not think of, you see (Emma, 35-years-old).

GPs reported that, when they explained the diagnosis of elimination to their patients, their aim was to reassure them. For example, Charlotte (40-years-old) explained to her patients that "finding nothing through an examination," such as the serology, may be "the aim of the procedure." Emma prescribed specialist examinations and consultations "without putting the prescription in an envelope," so that patients are aware of the reasoning behind these prescriptions. More precisely, she reported that she shared with them the degree of probability she assigned to each hypothesis. In her opinion, it reassures patients when she includes them in her strategy, making them aware of her uncertainties and hypotheses. Sharing the diagnostic pathway was viewed as a way of building a relationship of trust with patients, because "patients are involved in the decisions" (Emma, 35-years-old). In this context, the communication strategies adopted by GPs with their patients may include the use of metaphors.

I'll explain to the patient that, in fact, when they arrive at the doctor's, it's a bit like I've got a library with lots of open drawers, which allows me to do my investigation, and if I know they can walk and talk -I close certain drawers- if they've got pain here or there -I can close other drawers- and then little by little, by closing drawers, we'll make progress, and we'll make more and more progress toward a diagnosis that will be the right diagnosis for them. […] Sometimes people come to me and I tell them, "at some point, with this disease, the dermatologist will have to do an HIV serology test, even if it's something that's going to be negative, but as long as we haven't done it, we won't be able to close that drawer." It's something can they understand well (Benoît, 35-years-old).

Diagnosing means "closing drawers" (Benoît, 35-years-old), addressing possibilities even when they are unlikely.

The definition of GPs' role through the delegation of diagnosis to specialists

The third strategy used by GPs for managing uncertainty was that of seeking advice from specialists. In the context of LB, the most frequently consulted were infectious diseases specialists, neurologists, rheumatologists, dermatologists, and internists.

From a biomedical point of view, specialists may be called in for various reasons. First scenario: The GP considers the possibility of LB in its disseminated phases, due to persistent neurological and/or joint symptoms whose cause has not been identified by further examinations. Second scenario: GPs are inclined to prescribe a serology test and/or antibiotics following a suspicion of LB, but prefer to first receive the opinion of a specialist. Third scenario: The patient asks for a serology prescription, but this is refused by the GP, who delegates the management of this question to specialists.

From a psychosocial point of view, analyzing the referral of patients to specialists provides access to GPs' perceptions of their own role.

First of all, for some GPs, "knowing how to hand over the reins" (n = 2) is a skill to be developed as part of their profession. "Relying on a third party" means being aware of one's "place" (Charlotte, 40-years-old) and, more generally, of the "limits of one's skills" (n = 5). For example, some GPs said they preferred to refer to specialists for practices considered as being "outside the remit" (Emma, 35-years-old) of what a GP can control.

When it comes to the complicated phases [of LB] […] we just speak briefly about it, we don't go into it deeply, but because it's not really my job, clearly, I feel that I've had the elements I needed to do my job and, afterwards, to hand over the reins, but I think you have to know how to hand over the reins (Jeanne, 36-years-old).

If there are clinical signs, I prescribe when it's something I'm sure of, but when someone says "ah, but could it be neuro-Lyme, Lyme arthritis?" or whatever it is, I say to myself: Ok, in any case, if it's come to that, it's a matter for referral, it's not something for which I, as a general practitioner, can arrive at a diagnosis, so I pass it on to someone else, I hand over the reins. I think that, as a GP, there comes a time when you have to know when to hand over the reins, in other words, if I don't know, if I'm not sure, well, I'm a primary care doctor and my job is also to refer patients to the right people at the right time (Emma, 35-years-old).

Furthermore, some GPs felt that the specialists' point of view is more respected by patients than the advice they can give to them. The specialists' advice was considered by some GPs as "clearer and more complex" (Ariane, 42-years-old), and specialists' opinions also constituted a point of reference. Giving specialists a say helps to "avoid situations of conflict" (Philippe, 56-years-old), and to "settle questions" (Paul) between GPs and patients, which helps to reassure the latter. For this reason, specialists are sometimes called in when patients insist on a serology prescription: the GP feels that his or her opinion will not be "credible" (Charlotte, 40-years-old) or "sufficient" (Jeanne, 36-years-old). In this case, it is not so much a question of mobilizing biomedical knowledge, but rather of mobilizing a form of authority, sometimes in the role of "judge of the peace" (Philippe, 56-years-old).

General practitioners don't carry much weight… in people's perceptions, compared with certain specialists, so yes, ultimately we prefer to direct them there (Auguste, 54-years-old).

GPs also reported a "form of relief" (Charlotte, 40-years-old) in sharing patient's concerns and not having to deal with the situation on their own. Calling in specialists could make it possible to "get the message across in other words" (Charlotte, 40-years-old). Furthermore, the GPs acquired their knowledge of LB during in-service training run by specialists and/or through more informal exchanges with them. Against this background, the GPs evoked a relationship of trust: The called-in specialists were defined as competent and reliable (n = 6).

We were fortunate to meet people who were often very, very, very competent and who shared their knowledge with us, which was great. They were people we worked with and with whom, each time, we could adjust our knowledge and when we had concerns about changes in, well, that's how we made progress. (Paul, 56-years-old).

The limitations of specialist care were sometimes highlighted, particularly regarding cases where a diagnosis remains unidentified (n = 7). However, these limitations were not associated with the individual skills of specialists, but rather with the shortcomings of medicine, which, in its current state, cannot explain certain symptoms.

Discussion

The present study aimed to explore the construction of LB diagnosis as a process, in a population of French general practitioners mainly practicing in regions where LB is endemic. All the participants in this study considered LB diagnosis in its early stages to be straightforward: in such cases, information from the field and medical knowledge are in line with one another. In contrast, the disseminated phases of LB were perceived as a source of difficulty and uncertainty for almost all the participants. In the day-to-day practice of the study participants, there were actually few cases of disseminated LB being diagnosed, and most of the participants had never made this diagnosis. As a result, the participants reported experiences of uncertainty when faced with patients with MUS and/or suspicions of disseminated LB. According to Baszanger [8], one of the difficulties for doctors lies in understanding whether their uncertainty stems from the limits of their personal skills (level 1) or from the limits of medical knowledge (level 2). Our results showed that the boundaries between these levels of uncertainty can be blurred in GPs' representations. For most of them, structural causes were more likely to be evoked than causes linked to their individual abilities. More specifically, some GPs stressed the mismatch between the biomedical categories learned at university and the reality of practice [8]. Similarly, Sarradon-Eck [18] (2020, p. 10) describes the "epistemological incongruence between, on the one hand, the ideal models of illness taught and the medical ideals of healing, and, on the other hand, the reality of these patients' persistent suffering." Furthermore, in the fraught context of LB, knowing about the controversy seems to be a key factor in understanding the disease and managing the relationship with patients. Finally, at level 3, uncertainty is related to the intrinsic condition of medicine and science, which are founded on doubt. According to Fox [19], the epistemology of general medicine is based on uncertainty and on the imperfect mastery of scientific knowledge. Similarly, Motte and colleagues [20] assert that uncertainty is a fundamental feature of general practice. In this respect, some of the participants in this study emphasized uncertainty and doubt as the basis of medical knowledge and, more broadly, of scientific knowledge.

As well as viewing uncertainty in terms of levels, as above, it is also possible to distinguish some ideal-types of uncertainty [21]. We applied two of the four ideal-types presented by Bloy, in order to identify some of the psychosocial strategies put in place by the participants, as well identifying representational and identity issues that were mobilized as a way of facing uncertainty. These ideal-types do not correspond to clear-cut profiles of the participants in this study: the practices of a given GP may lie at the intersection between different ideal-types. First, by relying on "the dominant scientific standards" [21] (Bloy, 2008, p. 80), GPs tried to control uncertainty by promoting scientific and biomedical technical tools that are designed to detect the organic nature of diseases (mechanical objectivity, Porter, [22]). According to Sarradon-Eck [18] (2020, p. 14), these GPs applied "the clinical approach without straying from the marked-out path of evidence-based medicine (EBM) and protocolized practice." These GPs viewed individual clinical practice as a resource to be mobilized in a complementary way, and especially focused on the use of serology to make a diagnosis or -in most cases- to invalidate it. LB was often conceived as a differential diagnosis, of the sort used when several diagnoses are possible in light of a given set of information collected from patients [9,21]. Serology was then prescribed so as to "avoid missing out" on a pathology [18] (Sarradon-Eck, 2020, p. 14). In this sense, Sarradon-Eck [18] (2020, p. 17) defines cases of MUS as diagnoses of elimination: "They are not defined by what they are, but rather by what they are not." Besides the prescription of serological tests, the second technical and biomedical strategy analyzed is the use of test treatments, which aim to diagnose LB indirectly. In this case, a drug is used to construct the diagnosis [23] and becomes the source of knowledge consulted by GPs [24]. Nevertheless, when GPs opt for a technical choice (Ring et al., 2005), this approach does not guarantee a way out of uncertainty, since technology itself is not immune to uncertainty (Nettleton, 2006). The enhancement of the "technical and organic dimensions of care" [18] (Sarradon-Eck, 2020, p. 14), and at the same time the consequent reduction in the complexity of patients' experiences, may itself be a source of uncertainty [18].

The second ideal-type of uncertainty is associated with the GPs' discourse about their central role in the process of diagnostic reasoning. In other words, they conceived themselves as the main agents of diagnosis thanks to their clinical approach, which allows them to contextualize the biomedical results. When the degree of uncertainty became too great, they delegated this form of power to specialists. However, most of them, and especially the youngest, mentioned the way they shared the construction of diagnosis with their patients. More precisely, they highlighted the importance of telling their patients when they did not know something. Faced with the "omnipractice" [21] of general practice, these GPs tell their patients about the limits of their knowledge and of medicine in general: according to Bloy [21] (2008, p. 73), this involves "the ability to discern, to admit to oneself, and to admit to the patient the limits of one's skills" [21] (Bloy, 2008, p. 73). When GPs recognize that their own uncertainty is also a characteristic of science in general, they are acknowledging not only patients' suffering, but also the instability of scientific knowledge.

From an interventional perspective, it is necessary not only to encourage clear and honest communication with patients, but also to integrate the management of uncertainty into training for general medicine [24]. In other words, it is not (only) a question of providing GPs with detailed biomedical knowledge about LB: since general practice is by definition "global," it is not possible to provide exhaustive knowledge relating to all diseases [20]. It is a question of managing uncertainty: For Bakken [24], presenting comparisons of LB cases and "non-LB" cases could prove useful in preventing GPs from approaching symptomatology and diagnosis in an abstract and isolated way. More broadly, it is important to encourage the use of cross-disciplinary methods that affect LB but also, at the same time, other diseases, and particularly those that present various non-specific symptoms.

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Declaration of Interest Statement

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this article.

Data Availability Statement

The datasets generated and/or analysed during the current study are not publicly available due to ethical reasons but are available from the corresponding author on reasonable request.

Ethical Approval

ReLyMeG study was authorized by the CEEI (Comité d'Evaluation Ethique de l'Inserm, IRB00003888, approval number 22-964).

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