

## Confidence of recurrent cellulitis self-diagnosis among people with lymphoedema:

a qualitative interview study

### Abstract

#### Background

Cellulitis can sometimes be challenging for healthcare professionals to diagnose, with no validated diagnostic criteria available. Supporting healthcare professionals to make a more accurate diagnosis of cellulitis in different groups, such as those with lymphoedema, is a cellulitis research priority. However, to the authors knowledge, no previous studies have looked at the involvement of non-healthcare professionals in the diagnostic process.

#### Aim

To explore the experience of people with lymphoedema and recurrent cellulitis in the diagnosis of lower-limb cellulitis.

#### Design and setting

Single, semi-structured, qualitative interviews carried out between 29 October and 19 December 2018.

#### Method

Adults with a suspected episode of cellulitis who had been diagnosed in the last 12 months or had a history of recurrent cellulitis were interviewed.

#### Results

Three key themes emerged: the recurrent nature of cellulitis symptoms, participants' experience of getting a cellulitis diagnosis, and participants' suggestions of how cellulitis diagnosis might be improved. Generally, people with lymphoedema experienced similar clinical features during each of their own recurrent cellulitis episodes and were confident that they could make a self-diagnosis of cellulitis. This is also reflected in the participants' perceived trust from the healthcare professional in being able to make a self-diagnosis. A diagnostic checklist and educational resources were suggested as methods to improve diagnosis.

#### Conclusion

Selected people with lymphoedema who have recurrent cellulitis are confident in self-diagnosing their own recurrent cellulitis episodes. There may be a role for greater involvement of people with lymphoedema in their cellulitis diagnosis.

#### Keywords

cellulitis; confidence; diagnosis; lower limb; lymphoedema; qualitative research; self-diagnosis.

### INTRODUCTION

Cellulitis is a common presentation in primary care, with 60% of cases affecting the lower limbs.<sup>1</sup> Approximately one-third of people with cellulitis have recurrent episodes,<sup>2</sup> with lymphoedema shown to be the strongest risk factor for recurrent cellulitis.<sup>3</sup>

However, the diagnosis of cellulitis can be difficult, with approximately one-third of presentations of suspected lower-limb cellulitis subsequently found to be other diagnoses such as venous stasis dermatitis.<sup>4</sup> Currently, there are no agreed diagnostic criteria for cellulitis; a systematic review showed no robustly developed and validated diagnostic criteria or tools for lower-limb cellulitis.<sup>5</sup>

A UK cellulitis research priority setting partnership ranked questions on identifying early signs and symptoms in different groups of people with cellulitis, such as those with lymphoedema, as important for future cellulitis research.<sup>6</sup> A 2019 mixed-methods study found that people with cellulitis had a low awareness of cellulitis before their first episode,<sup>7</sup> but the views of people with recurrent cellulitis are not known. Also, despite lymphoedema being strongly associated with cellulitis, no previous studies have looked at the experience of cellulitis diagnosis in this group.

The aim of this interview study was to explore the experience of receiving a diagnosis

of lower-limb cellulitis among people with lymphoedema and recurrent cellulitis.

### METHOD

The study protocol was registered on the Centre of Evidence Based Dermatology website (<https://www.nottingham.ac.uk/research/groups/cebd/documents/researchdocs/protocol-cellulitis-interview-study-with-patients.pdf>) on 5 November 2018. For each participant, the interviewer obtained verbal consent before the start of the interview and written consent from each participant either before or after the interview.

The primary objective of the study was to explore the experience of people with lymphoedema and recurrent cellulitis in the diagnosis of lower-limb cellulitis.

Secondary objectives were to explore the key features of cellulitis that prompt participants to seek medical advice; to describe experiences where a diagnosis of cellulitis was correct, incorrect, or delayed; and to describe experiences of getting a diagnosis of cellulitis with different healthcare professionals.

### Eligibility criteria

Inclusion criteria were age >18 years; all ethnicities; people with a suspected episode of lower-limb cellulitis in the last 12 months (or two or more episodes within the last

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## How this fits in

Diagnosing recurrent lower-limb cellulitis in people with lymphoedema can be challenging for healthcare professionals. People with lymphoedema and healthcare professionals want better support to make a more accurate diagnosis of cellulitis. Selected people with lymphoedema are confident about making a self-diagnosis when they experience an episode of recurrent cellulitis and can potentially be more involved in the early diagnosis of cellulitis. Healthcare professionals often trust these expert people in making the diagnosis of cellulitis.

2 years); ability to give informed consent; and ability to speak English.

Patients with non-lower-limb cellulitis were excluded from the study.

### Participant selection

Participants were pragmatically recruited from a pre-existing cellulitis research database held at the Centre of Evidence Based Dermatology, including participants in previous cellulitis trials,<sup>8,9</sup> and James Lind Alliance cellulitis priority setting partnership,<sup>6</sup> and from the Lymphoedema Support Network (<https://www.lymphoedema.org/>).

### Sampling strategy

Purposive sampling was used to ensure that participants included individuals >50 years as cellulitis prevalence increases with age and those managed by different types of healthcare professionals, so that different pathways to diagnosis might be captured. This was achieved by sending a short questionnaire to eligible participants to determine this information.

Data collection and analysis were undertaken concurrently, and sampling ceased when thematic saturation had been achieved, that is, new interviews generated no new insight.

### Researcher characteristics

One researcher conducted the interviews, and two researchers coded and analysed the interviews (both GP trainees). The broader research group included experienced clinical academics, a patient representative, and research methodologists.

### Interview setting

Each participant took part in a single, semi-structured, qualitative interview, with a mean duration of 30 minutes. These were either face to face or via telephone, according to

participant preference. All participants received a 20 GBP reimbursement voucher.

### Data collection

In anticipation of the interview, participants were invited to reflect on their experience of cellulitis diagnosis.

A topic guide, informed by a previous review,<sup>10</sup> was used to structure the interview (Box 1). Throughout the interview, participants were encouraged to introduce and/or develop topics that they felt were most pertinent to their experience of diagnosis.

### Data processing and analysis

Interviews were audiorecorded and transcribed verbatim by two professional transcribers, who were independent of the study. Transcripts were checked and data handled using NVivo software (version 12).

Data analysis was inductive, finding themes in the data rather than predetermining concepts of interest. A structured, systematic, multistage approach to thematic analysis was followed.<sup>11</sup>

One researcher coded the data, and another researcher independently coded the first six transcripts. Disputes and uncertainties in coding and thematic organisation were resolved in consultation with the other authors. The final codebook was agreed by all authors and participants (Box 2).

## RESULTS

Eighteen people with recurrent cellulitis were interviewed (Table 1); all except one had a history of lymphoedema. Interviews were conducted between 29 October and 19 December 2018. A summary of how the codes mapped to the overarching themes is presented in Box 3.

Three key themes were identified in the data: the recurrent nature of cellulitis symptoms; participants' experience of getting a cellulitis diagnosis; and participants' suggestions of how cellulitis diagnosis might be improved.

### The recurrent nature of cellulitis symptoms

Participants described a red, warm, painful limb as being the core symptoms:

*'I get a real bad bruise pain ... It's the pain, bit like when you break a leg ... Generally speaking, if I get that pain, I check my leg out to see where it's red, or raised or hot.'* (Participant [P]2, 56-year-old female)

However, these features are also seen in other diseases and pose a diagnostic challenge. According to the interviewees,

## Box 1. Topic guide used to structure the interview

### Can you tell me about when you were last told you may have cellulitis?

Prompts:

- What did you notice?
- What made you go and seek medical advice?
- How long did you wait to seek help?
- Who did you see?
- Why did you see this person?
- What happened then?
- Were any tests done?
- What do you think went well?
- Was there anything that might have been more helpful?
- How was this similar to previous cases of cellulitis you have had?

### Can you tell me about any occasion when diagnosing your cellulitis was a problem?

Prompts:

- What did you have on this occasion?
- At what point did you seek medical advice?
- What was diagnosed?
- Do you know why this was diagnosed?
- Did anything change from how you were?
- What did you do next?
- How long did you wait to seek advice again?
- What was done differently this time?
- Do you know what the final diagnosis was?

### We are interested in how different people diagnose cellulitis

Prompts:

- Who normally makes the diagnosis of your cellulitis?
- Are you confident that they will make the correct diagnosis?
- Would you see them again regarding cellulitis?
- Has your cellulitis ever been diagnosed by anybody else?
- If so, was there a difference in the approach that was used?
- What did they ask?
- What tests did they use?
- Has this changed who you would see in future?

examples of incorrect initial diagnoses included fungal infection (P1, 58-year-old female) and deep vein thrombosis (P4, 74-year-old male). In some cases, further investigations in secondary care including bloods tests and imaging with ultrasound were required:

*'I woke up with my leg ... so swollen that the skin was tight, very red, very hot, and the doctor said he thought it might be a clot.'* (P5, 69-year-old female)

Swelling was also described as a common symptom by some participants, although it was recognised that diagnosis

rests in swelling being accompanied by other features such as erythema and pain:

*'There is the heat in the leg, swelling in my leg and that swelling is of course, could be confused with the lymphoedema side of things. But it's the heat and the swelling, not just a swelling.'* (P4)

Other symptoms including an 'itch in the skin', 'champagne bubbles popping underneath the skin' (P1), a 'burning oil [sensation]' (P2), and a smell 'like a bad piece of meat' (P3, 71-year-old female) were described.

Having a history of lymphoedema made identifying the features of cellulitis more difficult in the early stages, but, with recurrent episodes, participants felt more confident in identifying cellulitis themselves:

*'There is a clear difference between every day if there's a swelling with cellulitis.'* (P7, 47-year-old female)

Many participants described experiencing constitutional symptoms as marking the onset of cellulitis; these included feeling 'sort of flu-ey' (P14, 63-year-old female), generally 'feeling tired' (P4), and 'detached' (P18, 52-year-old female). This type of symptom prompted some participants 'to monitor my legs even [more] closely' (P5).

However, vague 'flu-like' symptoms would not always prompt a healthcare professional to make a diagnosis of cellulitis. They would require more typical features present on the leg to do this:

*'Until the symptoms show themselves totally... they [doctors] are reluctant to make that [diagnosis], that it is cellulitis, but they are quite happy the day after when it's more apparent that this is it.'* (P4)

One patient sympathised with the healthcare practitioner:

*'From your point of view as a doctor, it is quite difficult and then to start ramming antibiotics to a high level down someone's throat.'* (P4)

Most interviewees felt that the clinical features of cellulitis during recurrent episodes were similar and that this helped them to recognise the diagnosis:

*'Because this was my second episode ... symptoms I felt were very similar to the first time around but obviously I recognised them this time around.'* (P9, 71-year-old male)

## Box 2. Standardised codebook used by two independent coders

### Codes used

- Symptoms and signs
- Recurrent episodes
- Tests
- Underlying cause
- Seeking medical advice
- Relative's involvement
- Approach by the healthcare professional
- Challenges for the healthcare professional
- Participants' confidence
- Participants' preferred healthcare professional to see
- Seeing different healthcare professional
- Pathways in different countries
- Participants' expert knowledge
- Healthcare professional's trust in the patient
- Participants not agreeing with the healthcare professional
- Solutions to help
- Participants' concern about a diagnosis
- Wanting an early diagnosis
- Delayed or incorrect diagnosis
- Lymphoedema as a challenge
- Other comorbidities as a challenge

**Table 1. Characteristics of the participants (n = 18)**

Characteristic	Participants, n (%)
<b>Sex</b>	
Male	4 (22)
Female	14 (78)
<b>Age, years</b>	
18–24	0 (0)
25–34	1 (6)
35–44	1 (6)
45–54	2 (11)
55–64	8 (44)
65–74	6 (33)
≥75	0
<b>Ethnicity</b>	
White	18 (100)
<b>Total number of cellulitis episodes in their lifetime</b>	
1–5	6 (33)
6–10	2 (11)
>10	10 (56)
<b>History of lymphoedema</b>	
Yes	17 (94)
No	1 (6)

This made participants more confident in seeking a medical review or starting emergency antibiotics that had been provided to them in advance by the GP.

The recurrent pattern of the clinical presentation of cellulitis also allowed family members to identify features to look out for:

*'At that point that I think I might get cellulitis and then they watch for signals as well.'* (P1)

Sometimes family members would also notice other changes that the participants were not aware of:

*'My husband says I don't look well ... I go much paler, glassy eyed, there we go, these are things I don't know 'cos I don't look at myself.'* (P15, 62-year-old female)

### The experience of the participant getting a cellulitis diagnosis

Learning from recurrent episodes of cellulitis allowed participants with lymphoedema to become more 'expert' in making a self-diagnosis before seeing a healthcare practitioner:

*'As I've had it so many times, my [self] diagnosis has got better. Simply because I know more about it myself.'* (P1)

Some were aware of looking to see any breaks in the skin where cellulitis could develop after undertaking activities such as gardening or walking barefoot (which might increase the risk).

Some participants felt positive that healthcare professionals in primary care and in the emergency department trusted their self-diagnosis:

*'There are a lot of GPs who appreciate that I have had it so often and they know what is happening and they will go with my instinct.'* (P1)

## Box 3. Summary of how the codes map to the overarching themes

Theme	Code
The recurrent nature of cellulitis symptoms	Symptoms and signs
	Delayed or incorrect diagnosis
	Lymphoedema as a challenge
	Recurrent episodes
	Relative's involvement
Participants' experience of getting a cellulitis diagnosis	Challenges for the HCP
	Participants' expert knowledge
	Seeking medical advice
	HCP's trust in the patient
	Wanting an early diagnosis
	Seeing different HCP
Participants' suggestions of how cellulitis diagnosis might be improved	Approach by the HCP
	Participants' confidence in the HCP
	Participants' preferred HCP to see
	Participants not agreeing with the HCP
	Solutions to help
	Tests

HCP = healthcare professional.

Continuity in care was important for participants; some discussed how they had developed a strong relationship with healthcare professionals over a period of time, which built awareness of their recurrent history:

*'I have a bond with my GP ... that I have known for a long time ... who know me well enough.'* (P1)

Previous recorded episodes of cellulitis can also influence diagnosis in the out-of-hours setting and the emergency department:

*'He looked at my records [in urgent care] and he noticed that I had a record of cellulitis and he said "It certainly looks like it and I'm not going to take any chances".'* (P9)

Many participants wanted a diagnosis quickly and sought medical advice as soon as the first symptom appeared:

*'Straight away [to be seen], immediately when I notice it [symptoms].'* (P7)

This was not always easy, especially in primary care, leading some to rely on out-of-hours and the emergency department:

*'The reason I do that is because if I go to my local surgery, the least I'm going to have to wait is next day and that's too long.'* (P9)

Others were content to wait for changes in the limb before seeking help:

*'I draw around it to see how quickly it is going.'* (P11, 63-year-old female)

However, others started treatment at home first before seeking medical advice:

*'I have antibiotics that I keep at home so that if this happens, I can start taking them but I started taking them and it hadn't gone away so I made an emergency appointment to see my GP.'* (P8, 36-year-old female)

Participants consult a range of different healthcare professionals: GPs, emergency physicians, dermatologists, lymphoedema nurses, nurses in primary care, and pharmacists. Despite this variation, assessing for possible cellulitis was described as being similar across all professional groups:

*'I don't actually think that they [emergency department] asked anything particularly different [to the GP].'* (P8)

Later presentation, with development of clinical features in the emergency department, might provide a more straightforward diagnosis:

*'I suppose by that point [in the emergency department], basically everyone had already thought the day before that it was probably cellulitis ... I actually went there with the diagnosis whereas because I was sort of a bit further down the line.'* (P8)

Participants were generally confident that all healthcare professionals, irrespective of setting, would make the correct diagnosis of cellulitis:

*'Well, yeah, I think so because I mean everyone seems to recognise it.'* (P9)

Others pointed to confident self-diagnosis as a factor in this:

*'[A correct diagnosis?] I think so because of the fact that I tell them, I give them the background history.'* (P2)

One participant thought that the lymphoedema nurse and community nursing team were good at making a cellulitis diagnosis, as they are more familiar with its features:

*'Funnily enough, the best person I have found for picking it up has been one of my district nurses. She's had previous experience of cellulitis ... I think that they see it more.'* (P5)

As participants felt confident in making a self-diagnosis of cellulitis, they would become more determined for a healthcare professional to accept their judgement. If a professional did not concur, some would seek a second opinion:

*'If I was sure it was cellulitis, and someone was saying "definitely not", then I would say "look, I know it is cellulitis, we need to get someone else to look at it because I know now what I am looking at".'* (P11)

Some participants would push for a diagnosis even when a healthcare professional is unsure:

*'I think I am a bit pushy maybe [getting a diagnosis] and I push for it.'* (P2)

This often stemmed from the impact that cellulitis had on them and their urgency to get a quick diagnosis and treatment. Delays might impact on their role in the workplace, social activities, or as a carer; delays in

diagnosis might also lead to needing hospital admission for treatment.

### **Participants' suggestions of how cellulitis diagnosis can be improved**

When asked about resources that may help a healthcare professional to make an accurate diagnosis more quickly, further education, with prompts and pictures, were suggested:

*'Education — because I'm sure it's not something they come across every day so they'll just think, they need to be shown examples, pictures, anything, or even have somebody speak to them who suffers with it.'* (P7)

However, among participants with lymphoedema, educating professionals on how cellulitis can present in lymphoedema was a specific area where more education might be beneficial. Other resources mentioned to assist diagnosis included a specific blood test:

*'A specific blood test or antigen that they could test for and they can find out if that is what the problem was.'* (P2)

When asked about being seen in a cellulitis clinic, participants thought this would be ideal:

*'A dedicated clinic for me would be amazing. Because then you are dealing with people who know what cellulitis is on regular basis and familiar with it and everything.'* (P1)

Some participants thought a symptom checklist could help, both for themselves and professionals:

*'If I had a checklist that once I had completed it said yes, it is definitely cellulitis, this is how you treat it ... I would certainly do it myself.'* (P13, 55-year-old female)

However, regarding self-diagnosis, any self-diagnostic guide should have clear instructions about when to seek medical advice from the healthcare professional:

*'I think you have to be very clear about if it reaches this stage, you need to get a health professional involved.'* (P18)

## **DISCUSSION**

### **Summary**

This qualitative study found that people with lymphoedema experience similar clinical features during each of their own recurrent cellulitis episodes and generally

feel confident in making their own clinical diagnosis. Participants often experience constitutional 'flu-like' symptoms and fatigue, typically before they noticed the inflammatory features of pain, warmth, and erythema. Relatives close to the patient could also detect some changes in the patient when cellulitis occurred.

However, swelling associated with cellulitis, particularly among people with lymphoedema, can be difficult to differentiate from pre-existing swelling. In addition, the typical features of cellulitis can also present in many differential diagnoses, making the diagnosis challenging.

Participants believed that the clinical diagnostic approach of various healthcare professionals that they consulted were comparable, with speed of being seen and being able to see a known healthcare professional as determining factors about who to consult. Participants were generally confident that a healthcare professional would make the correct diagnosis in recurrent episodes of cellulitis because of their previous history.

Participants consider themselves to have a great amount of knowledge in diagnosing their own cellulitis episodes and many perceive they have the trust of their healthcare professional in making a diagnosis and starting treatment. More education and a diagnostic checklist that both healthcare professionals and people with cellulitis could use were suggested as ways to improve diagnosis.

### **Strengths and limitations**

The key strength of the qualitative approach used is that it allowed experiences to be gained in detail. Two independent coders used a standardised codebook to improve inter-coder reliability. Participants, as well as the authors, provided feedback on the final themes. Participants included are those at higher risk of experiencing recurrent cellulitis.<sup>3</sup>

The limitations stem from the pragmatic design and feasibility of the study. The authors initially wanted to explore the experiences in people with a single acute episode or recurrent episodes of cellulitis, and those with and without lymphoedema. However, all the people who contacted the study team had recurrent cellulitis and all except one had lymphoedema. Also, more females participated, which may reflect a higher incidence of lymphoedema in this group or that females are more likely to participate in research. Greater ethnic diversity in the present sample would also have enhanced the generalisability of findings.

In future, screening primary and secondary care health records with the appropriate ethical approval could improve the sample strategy.

People who are confident in making a self-diagnosis, more knowledgeable about their condition by being under the care of specialist lymphoedema services, and perhaps more willing to take responsibility of their health, are more likely to take part in this study. These participants, through their previous experiences, especially negative ones, are perhaps more likely to push for a diagnosis. Therefore, their views may not be generalisable. However, the wealth of experience that participants with recurrent cellulitis have gained over the years about their symptoms and when to seek treatment are invaluable. Also, this select group provided insight into distinguishing the early diagnosis of cellulitis in lymphoedema, a common diagnostic dilemma.

All participants were aware the interviewer was a doctor and this could influence their responses. Finally, the participants' overall confidence in self-diagnosis cellulitis limits the discussion of diagnostic uncertainty.

#### Comparison with existing literature

It is participants' knowledge and confidence in self-diagnosis that marks this study out from comparable research that has considered patients' understanding of cellulitis. Studies by Teasdale *et al*<sup>7,13</sup> and by Carter<sup>14</sup> show that many individuals demonstrate a degree of uncertainty about the cause and management of cellulitis, and that some feel ill-informed about the recurrent nature of cellulitis and are unprepared to manage such.<sup>7</sup> In contrast, interview data generated here, with patients who have both lymphoedema and recurrent cellulitis, presents a more confident and active patient population who are knowledgeable about how to manage their cellulitis. This is a population who know how to manage their cellulitis and who are confident in negotiating healthcare systems (and with healthcare professionals). Previous research has suggested that healthcare professionals' response to cellulitis can vary, and can be less than satisfactory for patients.<sup>13</sup>

This research shows that patients with both lymphoedema and recurrent cellulitis are (unsurprisingly) more knowledgeable than those experiencing their first incident of cellulitis. However, in line with previous

research,<sup>7,13,14</sup> it suggests the importance of information, awareness, and education for people with cellulitis and the healthcare professionals who support them.

#### Implications for research and practice

The study findings can be applied to people with recurrent cellulitis and lymphoedema, a condition that predisposes to recurrent cellulitis. The key clinical features described, as well as the diagnostic overlap of these features with other pathologies, is well known in clinical practice and this study confirms this. The similarity of clinical features in recurrent cases is likely to be something healthcare professionals take into account when making a diagnosis, given that they seem to be more willing to diagnose cellulitis in a person with multiple previous episodes.

Constitutional features could be an indication of viral illness that does not require antibiotics, or an early feature of infection where the source of infection is not yet apparent. This poses great challenges to professionals in diagnosing cellulitis: it is a fine balance not to overdiagnose and to maintain antibiotic stewardship while not delaying cellulitis diagnosis.

With increasing pressures on health care in the UK and a growing cohort of 'expert groups', empowering individuals to self-diagnose and self-manage may become more common. However, this must be done cautiously by professionals who know the person with cellulitis well, with clear safety nets put in place. A shared validated diagnostic tool or set of criteria that both professionals and people with recurrent cellulitis can use may allow this to be done safely, similar to those available in asthma and chronic obstructive pulmonary disease. With reference to the interview findings that some participants find it difficult to access their primary care provider quickly during an acute episode, having a self-management plan becomes even more relevant. Other methods proposed to aid diagnosis include educational resources such as clinical images of cellulitis presentations made available to the healthcare professional or specialist cellulitis clinics, which have been shown to improve accurate diagnosis.<sup>12</sup>

Further research is also required to find a specific and validated biomarker for cellulitis, with no current single test available.

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#### Ethical approval

Ethical approval was granted by the Faculty of Medicine and Health Sciences Ethics Committee, University of Nottingham (5 October 2018) (Ref: 105-1809).

#### Provenance

Freely submitted; externally peer reviewed.

#### Competing interests

The authors have declared no competing interests.

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