**Title: Confidence of recurrent cellulitis self-diagnosis amongst people with lymphoedema. An interview study.**

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**Study registration:** Centre of Evidence Based Dermatology website (https://www.nottingham.ac.uk/research/groups/cebd/documents/researchdocs/protocol-cellulitis-interview-study-with-patients.pdf)

## How this fits in

**What is already known about this topic?**

- Diagnosing recurrent lower limb cellulitis in people with lymphoedema can be challenging for health care professionals.
- People with lymphoedema and health care professionals want better support to make a more accurate diagnosis of cellulitis.

**What does this study add and clinical implications?**

- Selected people with lymphoedema are confident in making a self-diagnosis when they experience an episode of recurrent cellulitis and can potentially be more involved in the early diagnosis of cellulitis.
- Health care professionals often trust these expert people in making the diagnosis of cellulitis.

## Abstract

**Background:** Cellulitis can sometimes be a challenging diagnosis to make for health care professionals (HCP), with no validated diagnostic criteria available. Supporting HCPs to make a more accurate diagnosis of cellulitis in different groups, such as those with lymphoedema, is a cellulitis research priority. However, no previous studies have looked at the involvement of non-HCPs in the diagnostic process.

**Aim:** We sought 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 interview.

**Methods:** We interviewed adults with a suspected episode of cellulitis who had been diagnosed in the last 12 months or had a history of recurrent cellulitis.

**Results:** Three key themes emerged 1) the recurrent nature of cellulitis symptoms, 2) participants' experience of getting a cellulitis diagnosis, 3) 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 HCP in being able to make a self-diagnosis. A diagnostic checklist and educational resources have been 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: lower limb, cellulitis, recurrent, lymphoedema, self-diagnosis, confidence**

1 ## Introduction

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

5 However, the diagnosis of cellulitis can be difficult, with approximately a third of presentations
6 of suspected lower limb cellulitis, subsequently found to be other diagnoses such as venous
7 stasis dermatitis [4]. Currently, there are no agreed diagnostic criteria for cellulitis; our
8 systematic review showed no robustly developed and validated diagnostic criteria or tools for
9 lower limb cellulitis [5].

10 A UK cellulitis research priority setting partnership ranked questions on identifying early signs
11 and symptoms in different groups of people with cellulitis, such as those with lymphoedema,
12 as important for future cellulitis research [6]. A recent mixed methods study found that people
13 with cellulitis had a low awareness of cellulitis before their first episode [7], but what are the
14 views of people with recurrent cellulitis? Also, despite lymphoedema being strongly associated
15 with cellulitis, no previous studies have looked at the experience of cellulitis diagnosis in this
16 group.

17 The aim of this interview study was to explore the experience of getting a diagnosis of lower
18 limb cellulitis amongst people with lymphoedema and recurrent cellulitis.

19

20 ## Methods

21 ### Protocol registration and Ethics

22 The protocol was registered on the Centre of Evidence Based Dermatology (CEBD) website
23 (5 November 2018). Ethical approval was granted by the Faculty of Medicine and Health
24 Sciences Ethics committee, University of Nottingham (5 October 2018). For each participant,

the interviewer (MP) obtained verbal consent before the start of the interview and written consent from each participant either before or after the interview.

### Objectives

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

The secondary objectives were to: explore the key features of cellulitis that prompts participants to seek medical advice; describe experiences where a diagnosis of cellulitis was correct, incorrect or delayed; and describe experiences of getting a diagnosis of cellulitis with different health care professionals (HCP).

### Eligibility criteria

### Inclusion criteria

Age >18 years; all ethnicities; people with a suspected episode of lower limb cellulitis in the last twelve months (or two or more episodes within the last two years); able to give informed consent; speak English language.

### Exclusion criteria

Non lower limb cellulitis

### Selection of participants

Participants were pragmatically recruited from a pre-existing cellulitis research database held at the CEBD (including participants in previous cellulitis trials [8,9] and James Lind Alliance cellulitis priority setting partnership [6]) and from the lymphoedema support network (LSN) [10].

### Sampling strategy

Purposive sampling was employed to ensure that participants included: individuals over fifty years of age (cellulitis prevalence increases with age) and those managed by different types

1 of HCP (so that different pathways to diagnosis might be captured). This was achieved by
2 sending a short questionnaire to eligible participants to determine this information.
3 Data collection and analysis were undertaken concurrently and sampling ceased when
4 thematic saturation had been achieved (i.e. new interviews generated no new insight).

5 **Researcher characteristics**

6 Interviews were conducted by MP, and coded and analysed by MP and SIL (both general
7 practitioner (GP) trainees). The broader research group includes experienced clinical-
8 academics (JK and NL), a patient representative (PS), and research methodologists (KT and
9 PL).

10 **Interview setting**

11 Each participant took part in a single, semi-structured, qualitative interview, with a mean
12 duration of 30 minutes. These were either face-to-face or via telephone, according to
13 participant preference. All participants received a £20 reimbursement voucher.

14 **Data collection**

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

17 A topic guide, informed by a prior review [11], was used to structure the interview (Figure 1).
18 Throughout participants were encouraged to introduce and/or develop topics which they felt
19 were most pertinent to their experience of diagnosis.

20 **Data processing**

21 Interviews were audio-recorded and transcribed verbatim by two professional transcribers,
22 who were independent to the study. Transcripts were checked (by MP) and data handled using
23 QSR NVivo 12 software.

24

1 **Data analysis**

2 Analysis was inductive, finding themes in the data rather than pre-determining concepts of
3 interest. A structured, systematic, multi-stage approach to thematic analysis was followed [12].

4 Data was coded by MP, with SIL independently coding the first six transcripts. Disputes and
5 uncertainties in coding and thematic organisation were resolved in consultation with the other
6 authors. The final codebook was agreed by all authors and participants and is presented in
7 Figure 2.

8

9 ## Results

10 Eighteen people with recurrent cellulitis were interviewed (Table 1); all except one had a
11 history of lymphoedema. Interviews were conducted between 29 October and 19 December
12 2018. How the codes mapped to the overarching themes are presented in Table 2.

13 **Main findings**

14 Three key themes were identified in the data: 1) the recurrent nature of cellulitis symptoms, 2)
15 participants' experience of getting a cellulitis diagnosis, and 3) participants' suggestions of
16 how cellulitis diagnosis might be improved.

17 **The recurrent nature of cellulitis symptoms**

18 Participants described red, warm, painful limb as being the core symptoms.

19 > 'I get a real bad bruise pain ... It's the pain, bit like when you break a leg….Generally
20 > speaking if I get that pain, I check my leg out to see where its red, or raised or hot'

21 > (Participant (P)2, 56 year old female)

22 However these features are also seen in other diseases and poses a diagnostic challenge.
23 According to the interviewees, examples of incorrect initial diagnoses included fungal infection

(P1) and deep vein thrombosis (P4). 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, 74 year old male)

Other symptoms including an ‘itch in the skin’, ‘champagne bubbles popping underneath the skin’ (P 1, 58 year old female),‘burning oil [sensation]’ (P2) and ‘smelt 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 ‘felt sort of flu-ey’ (P14, 63 year old female), generally ‘feeling tired’ (P4) and ‘detached’ (P18, 52 year old female). This type of symptom prompts some participants ‘to monitor my legs even [more] closely’ (P5).

However, vague ‘flu like’ symptoms would not always prompt a HCP 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 its more apparent that this is it’

(P4)

One patient sympathised with the HCP, ‘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).

The majority of 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)

This made participants more confident in seeking a medical review or starting emergency antibiotics that were 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 lymphoedema participants to become more ‘expert’ in making a self-diagnosis before seeing a HCP.

> '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 bare foot (which might increase the risk).

Some participants felt positive that HCPs (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)

Continuity in care was important for participants, some discussed how they had developed a strong relationship with HCPs 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 appears '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 upon 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).

1 Others were content to wait for changes in the limb before seeking help 'I draw around it to
2 see how quickly it is going' (P11, 63 year old female), whilst others started treatment at home
3 first before seeking medical advice.

4 'I have antibiotics that I keep at home so that if this happens, I can start taking them
5 but I started taking them and it hadn't gone away so I made an emergency appointment
6 to see my GP'

7 (P8, 36 year old female)

8 Participants consult a range of different HCPs: GPs, emergency physicians, dermatologists,
9 lymphoedema nurses, nurses in primary care and pharmacists. Despite this variation
10 assessing for possible cellulitis was described as being similar across all professional groups:
11 'I don't actually think that they [emergency department] asked anything particularly
12 different [to the GP]'
13 (P8)
14 Later presentation, with development of clinical features in the emergency department, might
15 provide a more straightforward diagnosis.
16 'I suppose by that point [in the emergency department], basically everyone had already
17 thought the day before that it was probably cellulitis….I actually went there with the
18 diagnosis whereas because I was sort of a bit further down the line'
19 (P8)
20 Participants were generally confident that all HCPs (irrespective of setting) would make the
21 correct diagnosis of cellulitis, 'Well yeah I think so because I mean everyone seems to
22 recognise it' (P9).

23 Others pointed to confident self-diagnosis as a factor in this, '[*a correct diagnosis?*] I think so
24 because of the fact that I tell them, I give them the background history' (P2).

25 One participant felt that the lymphoedema nurse and community nursing team were good at
26 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 HCP 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 HCP 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 upon roles 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, amongst 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 a being seen in a cellulitis clinic, participants thought this was 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 HCP.

'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. Constitutional 'flu like' symptoms and fatigue are often experienced by participants, typically before the inflammatory features of pain, warmth and erythema were noticed. Relatives close to the patient could also detect some changes in the patient when cellulitis occurred.

However, swelling associated with cellulitis, particularly amongst 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 felt that the clinical diagnostic approach of various HCPs that they consulted were comparable, with speed of being seen and being able to see a known HCP as determining factors of who to consult. Participants were generally confident that a HCP would make the correct diagnosis in recurrent episodes of cellulitis due to 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 HCP in making a diagnosis and starting treatment. More education and a diagnostic checklist that both HCPs 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 [3].

The limitations of this study stems from the pragmatic design and feasibility of the study. We 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 women participated, which may reflect a higher incidence of lymphoedema in this group or that they are more likely to participate in research.

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

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

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

13 **Implications for research and practice**

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

20 Constitutional features could be an indication of viral illness that does not require antibiotics,
21 or an early feature of infection but the source of infection is not apparent yet. This poses great
22 challenges to professionals in diagnosing cellulitis: not to over diagnose and maintaining
23 antibiotic stewardship versus not delaying cellulitis diagnosis is a fine balance to tread.

24 With increasing pressures on health care in the UK and a growing cohort of ‘expert groups’,
25 empowering individuals to self-diagnose and self-manage may become more common.
26 However this must be done cautiously by professionals who knows the person with cellulitis

well and clear safety nets put in place. A shared validated diagnostic tool or set of criteria that both the 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 HCP or specialist cellulitis clinics, which have been shown to improve accurate diagnosis [13] . Further research is also required to find both a specific and validated biomarker for cellulitis, with no current single test available.

## Conclusion

This interview study has shown that selected adult individuals with lymphoedema and recurrent cellulitis have an awareness of when they have an acute episode of cellulitis and could be involved in the diagnostic decision making. However, it is important to emphasise that many of the common features of cellulitis are also seen in other diseases which may present in a similar way. Cellulitis remains a diagnostic challenge for HCPs and for those affected.

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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).

**Conflicts of Interest**

None declared

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1 **Table 1: Characteristics of the 18 participants**

| Participant characteristics | Number of participants, n (%) |
|---|---|
| Gender | |
| Male | 4 (22) |
| Female | 14 (78) |
| Age | |
| 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 |
| Ethnicity | |
| White | 18 (100) |
| Total number of cellulitis episodes in their lifetime | |
| 1-5 | 6 (33) |
| 6-10 | 2 (11) |
| 10+ | 10 (56) |
| History of lymphoedema | |
| Yes | 17 (94) |
| No | 1 (6) |

2

3

4

1 **Figure 1:** Topic guide used to structure the interview

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

3 Prompts:

4
- What did you notice?
5
- What made you go and seek medical advice?
6
- How long did you wait to seek help?
7
- Who did you see?
8
- Why did you see this person?
9
- What happened then?
10
- Were any tests done?
11
- What do you think went well?
12
- Was there anything that might have been more helpful?
13
- How was this similar to previous cases of cellulitis you have had?

14

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

16 Prompts:

17
- What did you have on this occasion?
18
- At what point did you seek medical advice?
19
- What was diagnosed?
20
- Do you know why this was diagnosed?
21
- Did anything change from how you were?
22
- What did you do next?
23
- How long did you wait to seek advice again?
24
- What was done differently this time?
25
- Do you know what the final diagnosis was?

26

27 **We are interested in how different people diagnose cellulitis.**

28 Prompts:

29
- Who normally makes the diagnosis of your cellulitis?
30
- Are you confident that they will make the correct diagnosis?
31
- Would you see them again regarding cellulitis?
32
- Has your cellulitis ever been diagnosed by anybody else?
33
- If so, was there a difference in the approach that was used?
34
- What did they ask?
35
- What tests did they use?
36
- Has this changed who you would see in future?

37

38

39

**Figure 2:** Standardised codebook used by two independent coders

Codes used

- Symptoms and signs
- Recurrent episodes
- Tests
- Underlying cause
- Seeking medical advice
- Relatives involvement
- Approach by the HCP
- Challenges for the HCP
- Participants' confidence
- Participants' preferred HCP to see
- Seeing different HCP
- Pathways in different countries
- Participants' expert knowledge
- HCP's trust in the patient
- Participants' not agreeing with the HCP
- 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