

Patients' experiences of lupus related foot problems: a qualitative investigation

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Keywords

Systemic lupus erythematosus; foot; podiatry; interviews; qualitative; experiences

Abstract

Background: Systemic lupus erythematosus (SLE) can present with a variety of symptoms. Previous research has shown there is a high prevalence of lower limb and foot problems in patients with SLE associated with the musculoskeletal, vascular and neurological changes. Furthermore, there is a high prevalence of infections affecting the feet and a range of common skin and nail problems. However, it is not known how these foot problems impact upon people's lives. Therefore, we aimed to explore this using a qualitative approach.

Method: Following ethical approval, 12 participants were recruited who had a diagnosis of SLE, current and/or past experience of foot problems and were over 18 years in age. Following consent, interviews were carried out with an interpretivist phenomenological approach to both data collection and analysis.

Results: Seven themes provide insight into: foot problems and symptoms; the impact of these foot problems and symptoms on activities; disclosure and diagnosis of foot problems; treatment of foot problems and symptoms; perceived barriers to professional foot care; unanswered questions about feet and foot care; and identification of the need for professional foot care and foot care advice.

Conclusion: These participants tend to "self-treat" rather than disclose that they may need professional foot care. A lack of focus upon foot health within a medical consultation is attributed to the participant's belief that it is not within the doctor's role, even though it is noted to contribute to reduced daily activity. There is a need for feet to be included as a part of patient monitoring and for foot health management to be made accessible for people with SLE.

Background

Systemic lupus erythematosus (SLE) affects multiple systems [1]. Along with skin manifestations, there can be a variety of musculoskeletal [2, 3] and vascular problems [4, 5] which can affect the feet [6], [7, 8]. Additionally, resistance to infections is reduced [9] and hence viral (verrucae), bacterial and fungal infections proliferate in the feet together with a range of common foot problems such as corns, callus and ingrown toenails [8]. As SLE can negatively impact on health related quality of life [10], it is possible that foot problems contribute to the burden of living with a chronic disease. However, the details of how foot problems impact on the lives of people with SLE, their experiences of foot care or what their foot care needs are not known. Therefore, this study aimed to explore in depth the impact of foot problems on those with SLE and their experiences of foot care.

Method

Ethical approval was granted by the University of Salford (HSCR14/25) and NRES (14/SC/1009). The participant inclusion criteria were: Fulfilment of the ACR criteria for diagnosis of SLE [1, 11], able and willing to be interviewed about their experiences of foot/ lower limb problems and aged 18 years or over. Patients were excluded if they did not meet these criteria and also if they were involved in another research study. Patients were approached by their consultant or specialist nurse at one hospital in the South of England and provided with a participant information leaflet [12]. Twelve consecutive patients were recruited. Written, informed consent was obtained prior to data collection. The conversational-style interviews were carried out by one researcher (AB) who was a podiatrist who had prior experience of the underpinning interpretivist phenomenological approach (IPA) to both the data collection (digitally recorded) and data analysis

[13]. The philosophy of an IPA approach is to obtain in-depth personal accounts of an experience and this dialogue is interpreted by the researcher with transparency about their own experience[13]. An opening question was used for all participants: "Tell me about your experiences of having foot problems?" If necessary, further trigger questions were used in order to maintain the conversation and the focus on foot problems such as, "...how does this/these problems affect you in your daily activities?" and "...what do you think may help with these problems?"

These questions were identified as being important by an advisory group of people with lupus and health professionals. When all interviews were completed, data was transcribed verbatim, verified by the participants and analysed using a thematic framework approach [14].

Results

All participants were female, white Caucasian with an age range of 42-72 years (SD=9.26). The range of years from diagnosis was 11-35 (SD= 8.07) with varied organ involvement, disease status and treatment (Table 1). Seven themes emerged and are outlined in Table 2.

THEME 1 - FOOT PROBLEMS AND SYMPTOMS

The participants contextualised severe foot symptoms within their whole experience of living with SLE, being resigned that they are yet another problem to live with. However, there is clearly concern about feet with some reporting signs and symptoms that could be associated with circulation:

003 "...I used to get into a bath and my feet would go purple.... Cold purple feet – not mentioned to consultant ...it's the least of my, sort of, worries really..."

With others being more focussed on the musculoskeletal signs and symptoms,

009 *"the pain. It's like, you wake up in the morning and it's like here we go I've got to get out of bed, you know, and they're hurting before you even put your feet on the floor, you know, you're thinking "oh God....my arches have dropped so that's another thing".*

Some reported a disordered or loss of sensation in the feet and nearly all described having infections such as verruca. One participant reported a severe infection (cellulitis) following a fungal infection,

007 *" ...get repeated fungal infections ...have had cellulitis which they say started from the fungal infection... they thought I was going to lose my toe...it went (black)...it was frightening how quick it went...the next morning it was very mucky...I knew it was a major problem ...".*

Some reported blisters,

009 *"...like little red blisters appearing on my toes and I just...I don't know... over the space of 3 to 4 days they turned into lots of things that looked like blisters but in desperation I tried popping one and it wasn't a blister. My feet were burning. They were hot. They were sore".*

Whilst many reported dry skin on the feet and nail changes,

005 *"...dry skin.... Um and it feels like walking on pebbles when I'm walking...The corns and hard skin. They're tiny little things but they are so painful", also,*

002 *"They go quite ridged... the nail beds lifted ...They hurt...if they get too long they start hurting badly."*

Additionally, the emotions of hate and shame are reported about feet,

004 *"...I hate feet so the less amount I can spend on them the better really...my feet are ugly", and*

010 *"It's a vanity issue- I feel self-conscious....old before time".*

It is clear that foot problems impact on these participants in relation to severity of symptoms and how they feel about them.

THEME 2 -THE IMPACT OF FOOT PROBLEMS and SYMPTOMS ON ACTIVITIES

Most carry on with activities either because they need to or desire to maintain a sense of normality,

008 *"...as if I was walking on hot glass and that was in the sole of my foot and it's been really quite difficult for me to walk.... I suppose with, sort of, the pressure of ordinary living...normal everyday life you just have to keep going ...".*

Though some do stop activities,

007*"The poor dog...more often than not I have to rely on people to walk her because I can't even walk down to the field. The pain (foot pain) is that bad".*

One revealed dire consequences for her overall wellbeing and mental health,

009 *"...very depressed, very... I'm very paranoid about my feet ... I used to do Pilates and things but, of course, when you have a white build-up of skin and... you look down at other people's feet and they look normal and you look at yours and think "God"... the fact that I can't often even walk to the end of the road...I am actually getting to the stage now where I don't like leaving the house and that's actually quite bad.*

People have noticed that I am quite good at cancelling these days. I try to make the effort to go out...initially it was the feet, but you kind of lose self-esteem, confidence. It sort of...it stemmed from my feet..."

The majority modify their footwear use,

004 "...I try to wear heeled shoes but I give up very quicklySo I go back to trainers, um...fit flops", and

010 "...I went to a wedding reception and I wore my heels, but there weren't any seats there... put my shoes in the car and just walked around bare foot for the whole evening".

Overall, there is a strong sense of loss and fear for the future with foot problems creating frustration and anger because of having to modify or give up activities.

THEME 3 – DISCLOSURE AND DIAGNOSIS OF FOOT PROBLEMS

Foot problems are generally perceived to be last on the list of things to discuss with their consultant and therefore, they do not disclose them as a priority,

005 "I mentioned it (foot pain) ...but he didn't know if it was lupus ...too busy talking about the blood results and I had other things of greater priority. "

Participants generally did not mention foot problems until the symptoms got unbearable,

012 "...I knew something wasn't right because it didn't go away. I thought it was probably a light sensitivity rash that I get. But it didn't go with the steroid cream... it was purply ...just seemed to be getting worse, so painful...had to do something."

Professional diagnosis of foot problems tends to be incidental and not by the rheumatology team,

007 "...I've just been to the doctors (GP) for something else and she saw my feet and was more interested in that and they split and they can bleed because they get so dry".

Many try to diagnose foot problems themselves by sourcing information from the internet, leaflets or talks via support groups,

001 "...no recall of feet being mentioned in clinic...I love google... It answers all my questions", also,

However, self-diagnosis can create anxiety,

002 "...it is interesting to kind of look things up um...and with the internet there it's so easy to look things ...You've just got to be careful not to think 'I'm going to lose my leg because my toe's gone purple' or something".

Very few participants had been to a podiatrist for a diagnosis of foot problems although some attend 'chiropractors' privately. Interestingly the expectations were that a 'chiropractor' carries out simple foot care such as nail cutting and removal of hard skin and that podiatrists are more specialised,

010 "...I used to go to a Chiropractor for nail care but I wouldn't even know how to start going to a Podiatrist for specialist assessment and insoles".

Crucially, podiatrists are viewed as having advanced diagnostic skills,

006 *"... there was a mole which he referred to and I just thought it was a mole with a bit of a lump on it and um... yes, so I didn't have to wait for an extra appointment ...got referred on quickly...thankfully".*

The patients focus during the consultation is on their medical management of the SLE on the whole and hence the opportunity for diagnosis of foot problems and referral to podiatry services is missed.

THEME 4 - TREATMENT OF FOOT PROBLEMS AND SYMPTOMS

These participants revealed how they try to help themselves rather than seeking professional help, using a variety of treatments, such as the use of hot water bottles, massagers, emollients, 'tiger balm' and self 'treatments' for fungal infection and verrucae. In relation to footwear, some look for specific features, although many reported wearing flip flops even in the winter,

010 *"...I don't tend to cover my feet up much either now. I just find it sets everything off more...wear flip flops in summer and winter".*

There is a high level of self-treatment with an ethos of 'trial and error',

010 *"...the only thing I found that even helped slightly (blisters) was antihistamine cream. I worked my way through my drug cabinet and medicine drawer and, you know... I thought I would just chuck that on". Also,*

Most revealed that they knew about their medication and immune system putting them at risk of infections but their management of infections are variable and inappropriate,

006 *"My husband usually does...we just use white spirit on... (fungal infection). Just puts it between each of the toes and that tends to dry it out quickly."*

Also, some reported that they carried out self-treatment of hard skin, which can reduce the skins resistance to infection,

007 *"...I've got an electronic Pedi-thing...pedicure I do use that but not too much - I do use a mandolin...like a cheese grater but I found that actually made them sore."*

Many of the self-treatment strategies could be deemed inappropriate and even dangerous. There is a clear need for professional foot care and guided self-care with information on when and how to seek professional foot care.

THEME 5 - PERCIEVED BARRIERS TO PROFESSIONAL FOOTCARE

Despite what is revealed through Theme 4 they found it impossible to know when and from whom they should seek professional foot care. They report that this is so because they do not perceive it to be a rheumatology problem,

002 *"... you know, I probably haven't (mentioned foot problems) ...um...and I should. There's probably a lot of things on my list of symptoms that I haven't actually mentioned about just because I...it's just an everyday thing", also,*

008 *" I haven't been offered anything specific around my feet...because I think other things have been more important to look at.... the swelling of the joints and the lack of movement in the joints and that sort of thing and that's what I've laid the emphasis on because that's what's been the most prescriptive and the feet have come up in that discussion but it was more on the pills".*

It is not clear which patients can be accepted for NHS podiatry foot care and as a result, some pay for private foot care which, in some cases is beyond what they can afford.

007 "...I have been to see a chiropodist a few years back ...the skin was quite bad. Then it was a case of having to keep going and when you're working full time...of course I had to pay anyway... from what I gather, a referral on the NHS it's a no go...I didn't fit the criteria".

A further obstacle is that the problems are not always evident when the patient consults a health practitioner, with one participant resorting to drastic measures so that the problem was present when she saw her GP,

010" I'd been to the GP... when my feet first flared up ... to be honest I had a hot bath because I knew it would keep them, and it sounded awful, but I wanted him to see them as they are, ...I was desperate."

These participants are unsure about who and when to reveal their foot problems to until they have to take desperate measures.

THEME 6 - UNANSWERED QUESTIONS ABOUT FEET AND FOOTCARE

There was evidence of many unanswered questions relating to the symptoms, diagnosis and management of foot problems,

002 "...I do quite a bit of walking and I do find that every now and again I do get quite severe pain across the bottom of my feet and I've been to the doctors before and they can't explain it... nobody knows why and I wonder what it is...quite worrying".

The unknown prognosis of foot problems induces anxiety,

010 "... I worry a lot about the circulation aspect. The acrocyanosis and the fact that I'm not on Nifedipine to open up... what happens? They go so cold ...my feet are really, really sort of purple ...So it's are they going to get worse, what will happen?"

And finding the right person to answer the questions,

009 "...I go to different people all the time, um, in the hope that someone will be able to tell me something. You can't go to see your GP about nail conditions and things like that, there's no one really who you can speak to, its' all a bit... trivial."

Throughout, there is evidence of anxiety about foot problems because questions remain answered. These questions could be answered through explanation, advice and signposting to appropriate patient education by all health professionals involved in the care of people with SLE.

THEME 7 - NEED FOR PROFESSIONAL FOOT CARE AND FOOTCARE ADVICE

There was clearly some knowledge about what podiatrists could offer,

004 "... gait analysis to look at how the feet affect the whole body" and

005 "...I suppose I could badger my doctor more about where I should see a podiatrist or something I just want a cure for these fungal nails".

They also identified the need to have their foot problems managed by someone with specialist knowledge rather than a generalist,

009 "...there are chances you are going to go to somebody who has only got the basic knowledge and hasn't read up on anything for like 30 years, um... I went to one chap

and he said 'no you haven't got nail fungus, you haven't got athletes foot'... turns out I did".

There is a need for this patient group to be included in the NHS podiatry service referral criteria and referral pathways,

007 "If the pathways are there you would fit the criteria but you won't fit the criteria, as far as I understand on Lupus, from what gather...the criteria, um, from what I knew locally you won't get a referral."

In order for feet to be a focus of the consultation a suggestion was made for a screening questionnaire to be available for patients prior to their appointment so that they could communicate their foot symptoms and concerns to their consultant.

010 "...you should be screened for other things first, before you go in to see the Consultant.... you know, 15 minutes or something prior to your appointment you are seen by somebody else who has a list you can go through."

Most articulated the need for appropriate guidance on self-care underpinned with why foot problems occur,

009. "I am quite happy to do things for myself but I really would appreciate someone listening to what I am saying and actually saying, 'ok let's just see what we actually can do and this is how to do it'."

Discussion

This study has provided unique insight into the experiences of people with SLE who live with foot problems. We now understand what specific problems impact on the lives of these individuals, and the challenges experienced in relation to diagnosis. We found that these participants had many unanswered questions about foot health, inappropriate self-care strategies and identified obstacles to accessing professional specialist foot care. The need for professional foot care and advice to support appropriate self-care was recognised by participants.

The participants in this study have revealed much about their experiences from which we can learn, make sensible assumptions and transfer this learning to the benefit of others with SLE. That foot problems are overlooked by both patients and healthcare providers within the clinical context aligns with what we know from people with rheumatoid arthritis[15]. This indicates that there is the need for a mechanism to prevent non- disclosure by patients so that foot problems are not ignored until the point in time that they become critical.

Despite reporting foot pain, negative emotions and activity restrictions related to their foot symptoms, these people with SLE tend to 'get on with it' and self-treat rather than seek professional foot care. Part of the problem is the lack of focus on feet in the medical consultation partly due to the participants' belief that feet are not part of the consultant's role and thus they do not reveal their problems. Similarly, this lack of disclosure has been identified previously in people with rheumatoid arthritis [16]. Hence, there is a need for simple foot assessments to be included in the medical consultation with appropriate referral pathways and specialist foot care provided as recommended by ARMA[17]. In relation to their needs being met, the participants suggested that they should be included in the referral criteria for NHS podiatry care.

However, one of the main obstacles to accessing specialist foot care for SLE patients has been the focus on developing specialist podiatry roles for people with diabetes rather than for those with

rheumatic diseases [18]. Also, despite guidelines for foot health in rheumatic disease [19], generalist podiatrists may not have the specialist skills and knowledge required to manage this patient group [20, 21]. As a result, podiatry service provision for patients with rheumatic disease has been a long standing problem [22]. One solution may be the training of health professionals within the rheumatology team in foot health screening, for example, vascular and musculoskeletal assessment. However, advanced skills are needed in order to achieve diagnoses [23] and hence there is still the need for specialist podiatrists . As a minimum, increased knowledge of foot problems in SLE by health care professionals is essential in order to signpost patients to podiatry services and foot health information from patient organisations. This study has revealed the need for educational material to be available and accurate to support safe self-management and signpost to professional foot care. This need is in alignment with the findings of a national survey of people with rheumatoid arthritis [24] and needs addressing within the wider rheumatology community.

Despite the valuable results and ensuing recommendations we acknowledge that this study may be perceived as lacking generalisability due to the small number of participants. However, this may not be an issue as Rheumatology services adhere to guidelines [25]. Furthermore, there are similar foot practices across the UK [22] and a survey has revealed the scale and types of foot problems[8]. Our intention was to obtain an in-depth insight into the impact of foot problems on some individuals.

Clearly there is room for future research studies to evaluate foot health interventions, the screening of foot problems and the referral processes for people with SLE-related foot problems. The first step would be to develop a foot health needs screening tool. This would not only provide patients with a 'voice' about their foot health, but also provide health professionals with

information on what advice to give or where to refer these patients to. This ultimately has the potential to improve foot health and the lives of people with SLE related foot problems.

Authors' contributions

AW conceived of the study, led the design of the study, the coordination of the study and led the drafting of the manuscript. LC contributed to the design of the study, AB carried out the interviews and primary data analysis. LST contributed to the inception of the study. LST, CE, NH, BAP and EV participated in the protocol development. All authors contributed to the manuscript and then read and approved the final manuscript.

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Declaration of Conflicting Interests

The authors declare no conflicts of interest relating to this work.

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	Organ involvement	Auto-antibodies	ESR at study time	Current treatment
1	MSK	anti-Ro, anti-cardiolipin	Normal	Hydroxychloroquine
2	MSK, renal, haematological, skin, lung	ANA, Anti-dsDNA	Normal	Mycophenolate mofetil, prednisolone hydroxychloroquine,
3	MSK, Heart, Lung	ANA, anti-dsDNA	Normal	Hydroxychloroquine
4	MSK, renal, eye	ANA	Mild increase	Hydroxychloroquine
5	MSK, skin	ANA, anti-dsDNA, anti-cardiolipin	Normal	Methotrexate, hydroxychloroquine
6	MSK, skin	ANA, anti-RNP	Mild increase	None
7	MSK, Brain, thrombocytopenia	ANA, anti-cardiolipin	Normal	Hydroxychloroquine
8	MSK, Brain, thrombocytopenia	ANA	Normal	None
9	MSK	anti-Ro, anti-cardiolipin	Normal	Hydroxychloroquine
10	MSK, skin	ANA, anti-Ro, anti-La	Mild increase	Hydroxychloroquine
11	MSK, skin	ANA, anti-dsDNA	Mild increase	Hydroxychloroquine, prednisolone
12	MSK, skin, renal	ANA, anti-dsDNA, anti-Ro, anti-cardiolipin	Mild increase	Mycophenolate mofetil, prednisolone hydroxychloroquine

Table 1 Participants' organ involvement, disease status and current treatment

1. Foot problems and symptoms
2. The impact of foot problems and symptoms on activities
3. Disclosure and diagnosis of foot problems
4. Treatment of foot problems and symptoms
5. Perceived barriers to professional foot care
6. Unanswered questions about feet and foot care
7. Need for professional foot care and foot care advice

Table 2 Themes derived from the data