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The prevalence of self-reported lower limb and foot health problems experienced by participants with systemic lupus erythematosus: Results of a UK national survey

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Key words: Systemic Lupus Erythematosus, foot, pain, mobility, infection, survey

Abstract

Objective: The main aim of this survey was to determine the frequency of self-reported lower limb or foot and ankle complications experienced by participants with SLE. A secondary aim was to determine the frequency of treatments that have been received or that participants with SLE may like to receive if offered.

Method: A quantitative, cross-sectional, self-reported survey design was utilised. The developed survey was checked for face and content validity prior to patient partner cognitive debriefing in order to ensure usability, understanding of the process of completion and of the questions posed. The full protocol for survey development has been published previously.

Results: This is the first comprehensive national UK survey of lower limb and foot health problems reported by participants with SLE. A high prevalence of vascular, dermatological and musculoskeletal complications was reported by survey respondents. Additionally, whilst the relative prevalence of sensory loss was low, a quarter of people reported having had a fall related to changes in foot sensation demonstrating a previously unknown rate and cause of falls.

Conclusion: Complications related to vascular, dermatological and musculoskeletal health are identified as particularly prevalent in participants with SLE. Further, there is a suggestion that the provision of interventions to maintain lower limb health is highly varied and lacks national standardisation, despite there being a strong indication of participant reported need. The findings of this work can be used to inform care guideline development in addition to identifying areas for future research.

Background

Systemic lupus erythematosus (SLE) is a complex, chronic, multi-system autoimmune disease which varies in prevalence and incidence depending upon ethnicity and is diagnosed about nine times more frequently in women than men [1, 2]. In the UK approximately 25,000 people have a diagnosis of SLE [3]. The disease is highly heterogeneous in that it varies in clinical and serological manifestations and severity between individuals. Disfigurement caused by the involvement of skin and joints [3] can affect the patient's perception of body image and sexuality and can have an impact on emotional health [4] and overall quality of life [5].

Involvement of the musculoskeletal system is common during the clinical course of SLE, occurring in up to 95% of patients, with joint pain being the first presenting symptom in up to 50% of cases [6]. The extra-articular manifestations of SLE include soft tissue pathology such as capsular swelling, synovial hypertrophy (thickening of joint lining) and tenosynovitis [7] which can lead to tendon rupture [8] or tendon contracture [9]. Tendons are the force transmitting units of the musculoskeletal system, but due to their low metabolic rate and slow healing, injury can result in considerable morbidity and prolonged disability [10, 11]. In relation to the symptoms associated with muscle involvement, these can range in severity from mild aches in up to 80% of cases to painful inflammatory myositis in up to 11% of cases [7].

In addition to the musculoskeletal involvement in cases of SLE, people may also present with vasculopathy. Vascular involvement can be either a direct complication of SLE or develop as co-morbidity and represents one of the most frequent causes of death [12]. Mathieu et al [13] identified that abnormal vascular reactivity and coagulopathy both contribute to an increased risk of atheroma and therefore recommend careful monitoring for any vascular change with the aim of preventing tissue necrosis and ultimately amputation or death.

Focussing on the foot, a narrative review of the literature [14] identified that SLE affects foot and lower limb morbidity and that these have the potential to impact upon health related quality of life. However, the scale of these problems is unclear and little research in this area has been completed to date. It could be speculated that the altered musculoskeletal, peripheral neurovascular and tissue health experienced by people with SLE renders their feet particularly susceptible to deformity, poor function, ulceration and/or infection and pain. However the effects and extent of SLE upon body systems within the periphery are unclear; e.g. with consideration to neurological function, the extent of patient reported motor neuropathy (e.g. muscle weakness), sensory neuropathy (e.g. lost pressure detection) or autonomic neuropathy (e.g. poor temperature regulation) is unclear. Further, the attention given to patients' feet during the clinical consultation may be limited as has been evidenced

for people with rheumatoid arthritis [16]. Thus, the opportunity to provide timely advice clinical intervention is missed. As such, there is a need to determine the prevalence of lower limb or foot and ankle complications experienced by people with SLE. Thus, the main aim of this survey was to determine the frequency of self-reported lower limb or foot and ankle complications experienced by people with SLE. A secondary aim was to determine the frequency of treatments that have been received or that people with SLE may like to receive if offered.

Methods

Ethics, consent and permissions

Ethical approval for the study was granted by the University of Salford (HSCR14/25) and NRES (14/SC/1009). All research was completed in accordance with the declaration of Helsinki guidelines for research practice. Information about the purpose and intended use of the study was included in a covering letter as part of the survey data sheet. Consent to take part in the survey was considered implicit following the completion and return of the form.

Study and survey design

A quantitative, cross-sectional, self-reported survey design was utilised. To aid survey design a patient and practitioner advisory group was formed. The group was comprised of members of the research team, rheumatologists, podiatrists and participants with SLE. An initial group meeting, held following review of existing literature related to problems associated with SLE, generated an item pool from which the survey could be developed. From this preliminary work the survey was developed based on the agreed themes, categories, question format and overall structure [17]. The survey was checked for face and content validity prior to cognitive debriefing in order to ensure usability, understanding of the process of completion and of the questions posed. The choice of language within the survey was considered and advice sought during the survey development process from the patient partners. Where it was felt that the use of technical terminology was appropriate, clarifying text was also included; e.g. 'Have you had any breaks in the skin that have been slow to heal (known as ulceration)?'. The full protocol for survey development has been published previously [17].

The final survey consisted of 5 sections: 1. Lower limb circulatory health, 2. Lower limb nerve function, 3. Foot and Ankle skin health, 4. Lower limb musculoskeletal health and 5. Received or 'needed' foot and ankle treatments.

Survey distribution

The survey was distributed consecutively to all eligible participants with SLE attending 6 UK NHS Rheumatology departments, with whom the research team are associated (Blackburn, Christchurch, Leeds, Manchester, Salford and Southampton) and distributed to all members of the Lupus UK membership register. Using this approach, it was not possible to determine how many people declined to participate in the survey.

Analysis

All analysis was completed using SPSS version 18.0 (Chicago, USA). Prior to analysis, data was checked for inconsistencies, outliers or missing information. Descriptive statistics (count and percentage data) were used throughout.

Results

Survey data

A total of 182 completed surveys were returned to the research team. The reported age range of participants was normally distributed, with the majority of participants being with the ranges of 40-49 years and 50-59 years. The mean reported disease duration was 14.6 (± 9.9) years. 19 participants were active smokers. The reported ethnicity of participants was as follows: white n=125, black Caribbean n=3, black African n=3, black other n=3, Indian n=7, Pakistani n=7, Bangladeshi n=1, Chinese n=6, other n=4, non-disclosed n=23.

Lower limb circulatory health

Overall, 85% (n=156) reported having experienced some form of lower limb circulatory impairment. As shown in table 1, the most frequently reported symptom of impaired circulation was night cramps (74%; n=135) and the least frequent was chilblains (21%; n=38).

The receipt of treatment for lower limb circulatory complications was reported by 18% (n=32). Reported treatments included prescribed medication use 66% (n=21), surgical intervention 19% (n=6), or compression hosiery 6% (n=2). The nature of treatment was unspecified by 3 people. The reported prescribed medications included Nifedipine, Clopidogrel, Sildenafil, Cyclophosphamide, Iloprost or Epoprostenol Sodium.

Lower limb nerve function

Overall, 16% (n=29) reported having experienced symptoms consistent with sensory neuropathy (described as a 'loss of feeling' for the purposes of this survey), whilst 25% (n=46) reported having had

a fall because of altered sensation in their feet. Whilst specific questions relating to painful neuropathy were not included in the survey, 10 patients reported experiencing symptoms consistent with neuropathic pain within the free text comments section of the survey.

The receipt of treatment for lower limb nerve complications was reported by 8% (n=14). Reported treatments included Amitriptyline or Pregabalin, steroid injection, Extra-Corporeal Shockwave Therapy, Low Level Laser Therapy or Acupuncture.

Foot and ankle skin health

Overall, 86% (n=157) reported having experienced some form of foot or ankle skin health complaint. As shown in table 1, the most frequently reported complication was callus or corn formation (71%; n=129) and the least frequent was ulceration (24%; n=44).

'Having ever' experienced viral skin infection (Verrucae Pedis) was reported by 42% (n=77), fungal skin infection by 42% (n=76) and fungal nail infection (onychomycosis) by 36% (n=66). Comparatively, reported previous or current bacterial infection, for which antibiotic treatment was issued, was lowest at 15% (n=27) and 2% (n=3) respectively.

Lower limb musculoskeletal health

Overall, 158 (87%) reported having experienced some form of lower limb musculoskeletal complication. As shown in table 1, the most frequently reported complication was joint pain (80%; n=145) and the least frequent was a change in foot shape (36%; n=65). A previous or current episode of loss of function, such that it was difficult or impossible to walk, was reported by 37% (n=67) and 12% (n=22) respectively.

Received or wanted foot and ankle treatments

Overall, 33% (n=60) reported having ever discussed their foot health with a doctor (rheumatologist or general practitioner) and 23% (n=41) reported having ever been diagnosed with a specific foot or ankle problem.

A summary of the frequency of the common treatments reportedly received is shown in table 2. The number of participants who reported that they thought they would benefit from these treatments is also shown. A further 27% (n=50) of participants additionally reported that they thought they would benefit from general foot health and care advice.

Discussion

To our knowledge, this is the first comprehensive national UK survey of lower limb and foot health problems reported by people with SLE. This novel survey has captured the reported high prevalence of vascular, dermatological and musculoskeletal complications experienced by this group of participants. Additionally, whilst the relative prevalence of sensory loss was low, a quarter of participants reported having had a fall related to changes in foot sensation. This demonstrates a previously unknown potential cause of falls amongst people with SLE. Awareness of potential falls risk factors creates opportunity to target prevention strategies. Importantly this patient population are already at increased fracture risk due to comorbid health needs and /or treatments and therefore there is a potentially large detrimental consequence of falling.

Interestingly, the findings of this UK survey are similar to those reported by Otter et al [18] in cross-sectional study completed in New Zealand. The comparative reported prevalence of vascular, musculoskeletal and neurological complications are similar between studies suggesting that despite differences in methodological approach the findings may on average accurately reflect the foot health status of this group of participants. However to date, to our knowledge, there is currently no comparative research available against which it is possible to compare the prevalence of infection (approximately half of participants) or callus/corns (approximately three quarters of participants) identified in this survey.

There was a high prevalence of vascular complications and symptoms, with varied drug or surgical intervention, reported. Of note 85% of participants reported having experienced some form of vascular complication whilst only 18% of participants reported having received treatment for peripheral vascular health. The results of this survey therefore suggest a current mis-match between participant reported vascular symptoms and treatment. Additionally, a range in treatment approaches were reported. Overall, the authors suggest that the findings of this survey show a potential area for improved clinician and patient awareness and standardisation of clinical practice (e.g. identifying when prophylactic pharmacology, such as Sildanfil, is indicated). It is hypothesised by the research team that this could be achieved nationally through guidance documentation or locally through advice and screening at each consultation in order to detect and treat early changes and reduce the risk of serious progressive consequences such as ulceration and necrosis [19]. Although not evidenced by the findings of this study, arguably, there is potential for non-drug treatment approaches to also improve lower limb vascular health (e.g. exercise for the reduction of intermittent claudication symptoms) although further research is required to determine the mobility impact of SLE and to evaluate the potential efficacy of exercise/mobility prescription in participants with SLE [20].

Participants did note experiencing loss of feeling, with symptoms of 'numbness' and/or neuropathic pain also referenced in the free text comments received. Additionally, a number of participants reported falls as a consequence of altered sensation in their feet. However, there is insufficient detail in the context of this survey to further clarify the exact nature of the altered sensation experienced and how this led to a fall; or indeed whether the fall related to specifically to factors directly related SLE. Further qualitative research that clarifies the nature and impact of such problems experienced by this group is warranted. It is also proposed that mobility and falls may represent an important and potentially under-appreciated area of concern that requires further investigation.

Over a third of participants reported having ever experienced an episode of musculoskeletal complication that resulted in an inability to walk. This has a high potential for reduced mobility and subsequently may have far reaching impact on comorbid health complications (e.g. further compromise of vascular status or compound tissue deconditioning) which does not appear to be addressed by current health care practice for this population. There is a need to further explore the impact of compromised mobility experienced by this patient group on health, work, socialisation or quality of life.

Foot problems that are prevalent in the general population such as corns, callus and nail thickening were also evident in this group. However, it is theoretically possible that the consequences of these problems can be progressive and multifactorial, leading quickly to tissue breakdown, ulceration with potential for resistant bacterial infection or necrosis and delayed wound healing. In addition, fungal and viral infections may become more widespread due to the autoimmune nature of SLE and the immunosuppressive medication that can be used for its management. It is recommended that further research is required to fully appreciate the nature of infection prevalence, identification and risk management/treatment in this patient group. The impact and burden of self-treatment for repeated fungal infections is reported in free text responses and a need for professional diagnosis and advice about the most effective treatments suggested.

Despite the seemingly high prevalence of lower limb complications reported, only a third of respondents reported ever having been asked about their foot health by a doctor and even fewer reported having been given any specific diagnosis. However, it is possible that the patients do not report these problems to a doctor, as talking about feet may not be seen as a medical role; This lack

of disclosure is reported by Blake et al [21] in their study of patients with rheumatoid arthritis. It is currently unclear whether this is also the case for people with SLE.

The most frequent intervention for foot problems reported in this survey was the provision of foot orthoses. However, despite being the most frequent intervention this was only reported by 27% of participants and a clear request for further assistance was evidenced, especially for general foot health education or nail and skin care. However, further research is needed to evaluate the effectiveness of the range of potential foot health interventions for this patient group. It is perhaps of note, the number of participants reporting that they would like to receive treatment is greater than those who has had treatment of any kind. This represents a potentially unmet foot health care burden and further research to better understand the specific nature of any unmet need is required.

There may be unknown responder bias evidenced within the findings of this survey and this represents a limitation of this work; it may be that those participants who have previously experienced complications are more likely to complete and return the survey. The results of the survey may also be subject to recall bias; e.g. participants may over or under-report phenomena depending upon their ability to accurately recall their past experiences. Further the survey was limited to a UK population although data was collected from varied geographical locations nationally. Globally, SLE is demographically variable and there is the need to replicate this survey in other global contexts to fully appreciate the ranging prevalence and burden of poor foot health for people with SLE. Due to the self-reported nature of the survey, it was not possible to ascertain the participants current SLE disease activity. The findings of this initial survey could therefore be enhanced with the completion of disease activity and damage indices through additional clinical study.

Despite the limitations, this is the first UK survey to obtain data about the prevalence and management of self-reported foot problems experienced by participants with SLE. The findings indicate that foot health should be part of a health care consultation. A particular focus on vascular, dermatological and musculoskeletal complications is indicated although neurological health and falls risk should also be considered.

Conclusion

This novel national survey demonstrates a high prevalence of previously unreported lower limb and foot health complications experienced by participants with SLE and therefore achieves the primary research aim. Complications related to vascular, dermatological and musculoskeletal health are

identified as particularly prevalent in participants with SLE. The frequency of treatments reported was relatively low compared to the reported prevalence of complication or reported perceived need. The type of treatments currently offered are variable and appear to lack national standardisation. Overall, there is a high prevalence of lower limb complications reported by participants with SLE for which treatment is currently reported as nationally variable or not offered, although is perceived as needed by the majority.

Author's contributions

LC & AW led the design of the study, the coordination of the study and LC led the preparation of data, completion of analysis and drafting of the manuscript. CE, NH, BAP, AB and EV participated in the protocol development and LST contributed to the inception of the study. All authors contributed to, read and have 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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Tables

Table 1: Reported prevalence of self-reported lower limb complications experienced by people with SLE

	Ever n (%)	Currently n (%)
Circulation		
Raynaud's	93 (51)	34 (19)
Chilblains	38 (21)	14 (8)
Intermittent Claudication	99 (54)	30 (16)
Night cramps	135 (74)	33 (18)
Neurological		
Sensory loss	29 (16)	12 (7)
Sensory loss related fall	46 (25)	-
Skin health		
Ulceration	44 (24)	15 (8)
Callus or Corns	129 (71)	75 (41)
Onychocryptosis	68 (37)	23 (13)
Rashes or Blistering	62 (34)	11 (6)
Skin infection		
Tinea Pedis	76 (42)	20 (11)
Onychomycosis	65 (36)	35 (19)
Verrucae Pedis	76 (42)	16 (9)
Musculoskeletal health		
Joint pain	145 (80)	60 (33)
Joint stiffness	134 (74)	50 (27)
Joint swelling	93 (51)	29 (16)
Change in foot shape	65 (36)	-
Functional impairment	67 (37)	22 (12)

Table 2: Treatment received and "would like to receive" to aid foot health people with SLE

Treatment	Received (NHS) n (%)	Received (Private) n (%)	Would like to receive n (%)
Orthoses	49 (27)	10 (5)	51 (28)
Specialist footwear	12 (7)	4 (2)	19 (10)
Footwear advice	35 (19)	8 (4)	49 (27)
Removal of callus or corns	20 (11)	21 (12)	49 (27)
Nail care	18 (10)	13 (7)	54 (30)
Nail surgery	12 (7)	3 (2)	9 (5)
Surgery	28 (15)	0	22 (12)