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Patients' unmet needs and treatment preferences concerning digital ulcers in systemic sclerosis

Giulia Bandini [1], Alessia Alunno [2], Begonya Alcacer-Pitarch [3], Barbara Ruaro[4], Ilaria Galetti[5], Khadija El-Aoufy[6], Filipe Pinheiro [7], Giulia Campanaro[1], Judith Jade[8], Stefano Di Donato[3], Lindsay Muir[9], Alberto Moggi Pignone[1], Silvia Bellando Randone[10], Francesco Del Galdo [3], Zsuzsanna H. McMahan[11], Marco Matucci-Cerinic[12], Michael Hughes[13,14,]*

[1]Department of Experimental and Clinical Medicine, Division of Internal Medicine, University of Florence, Florence, Italy
[2]University of L'Aquila, Department of Clinical Medicine, Life Health and Environmental Sciences, Internal Medicine and Nephrology Division, ASL1 Avezzano-Sulmona-L'Aquila, L'Aquila, Italy
[3]Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds, Leeds, UK
[4]Pulmonology Unit, University of Trieste, Department of Medical Surgical and Health Sciences, Hospital of Cattinara, Trieste, Italy
[5]FESCA (Federation of European Scleroderma Associations) Belgium, & GILS (Gruppo Italiano, Lotta alla Sclerodermia), Italy
[6]Department of Experimental and Clinical Medicine, University of Florence, Florence, Italy
[7]Department of Rheumatology, Centro Hospitalar Universitário de São João, Porto, Portugal
[8]Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK
[9]Department of Hand Surgery, Salford Royal, Salford, UK
[10]Department of Experimental and Clinical Medicine, Division of Rheumatology, University of Florence, Florence, Italy
[11]Department of Medicine, Division of Rheumatology, University of Texas Health Science Center at Houston, Houston, USA
[12]Unit of Immunology, Rheumatology, Allergy and Rare diseases (UnIRAR), IRCCS San Raffaele Hospital, Milan, Italy
[13]Department of Rheumatology, Northern Care Alliance NHS Foundation Trust, Salford Care Organisation, Salford, UK
[14]Division of Musculoskeletal and Dermatological Sciences, The University of Manchester, Manchester Academic Health Science Centre, Manchester, UK

*Correspondence to: Michael Hughes, Department of Rheumatology, Salford Royal Hospital, Northern Care Alliance NHS Foundation Trust, Stott Lane, Salford M6 8HD, UK; Division of Musculoskeletal and Dermatological Sciences, The University of Manchester, Manchester Academic Health Science Centre, Manchester, UK. E-mail: Michael.hughes-6@postgrad.manchester.ac.uk

Abstract

Objective: Digital ulcers (DUs) significantly impact on quality of life and function in patients with systemic sclerosis (SSc). The aim of our survey was to explore patients' perspectives and their unmet needs concerning SSc-DUs.

Methods: SSc patients were invited through international patient associations and social media to participate in an online survey.

Results: A total of 358 responses were obtained from 34 countries: US (65.6%), UK (11.5%) and Canada (4.5%). Recurrent DUs were found to be common: >10 DUs (46.1%), 5–10 DUs (21.5%), 1–5 DUs (28.5%), 1 DU (3.9%). Fingertip DUs were most frequent (84.9%), followed by those overlying the IP joints (50.8%). The impact of DUs on patients is considerable, from broad-ranging emotional impacts to impact on activities of daily living, and on personal relationships. Around half of the respondents (51.7%) reported that they received wound/ulcer care, most often provided by non-specialist wound care clinics (63.8%). There was significant variation in local (wound) DU care, in particular regarding the use of debridement and pain management. DU-related education was only provided to one-third of patients. One-quarter of the patients (24.6%) were 'very satisfied' or 'satisfied' that the provided DU treatment(s) relieved their DU symptoms. Pain, limited hand function, and ulcer duration/chronicity were the main reasons for patients to consider changing DU treatment.

Conclusion: Our data show that there is a large variation in DU treatment between countries. Patient access to specialist wound-care services is limited, and only a small proportion of patients had their DU needs met. Moreover, patient education is often neglected. Evidence-based treatment pathways are urgently needed for DU management.

Keywords: systemic sclerosis, digital ulcers, quality of life, unmet needs, management, treatment.

Rheumatology key messages

- There is a large variation in DU treatment between countries.
- Patient access to specialist wound-care services is limited.
- Only a small proportion of patients report having their DU treatment needs met.

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Introduction

Approximately 40–50% of patients with SSc develop digital ulcers (DUs) during their disease course [1–3]. DUs typically develop on the fingertips and overlying the bony prominences of the inter-phalangeal (IP) joints of the hands, often in relation to contractures [4, 5], although DUs can also appear on other areas of the fingers where pitting scars or s.c. calcinosis may be present [6, 7]. The main aetiology of DUs is ischaemic, due to the underlying vasculopathy, which is the hallmark of the disease. Thus, the aetiopathogenic mechanisms should be considered when treating DU, as they will have pivotal implications for treatment [8, 9].

It is well known that DUs have wide-ranging impacts on patients' quality of life and function (e.g. occupation), and are associated with significant personal, economic and societal burden (e.g. inability to work and increased costs from health-care utilization) [2, 10–15]. Important improvements in the management (i.e. prevention and healing) of DUs have been obtained, and today we have at our disposal a broad therapeutic armamentarium [16–20]. However, in practice DUs are often slow to heal [5] and are frequently refractory [10], despite local debridement, and systemic and combined therapy [10].

However, the major challenge is to demonstrate the treatment efficacy of new approaches to SSc-DUs [21]. Furthermore, significant heterogeneity remains concerning the clinical systemic and local management of DUs [22]. To date, no studies have specifically investigated patient perceptions of available DU treatments, their access to specialist wound care services, and their satisfaction with DU treatment in meeting their needs. Nonetheless, the SSc patient community, represented by I.G., is confused by the heterogeneity of care and management of DUs. Lowering pain and thus improving the quality of life and emotional well-being are considered of paramount importance.

The aim of our multinational survey was to better understand the DU multifaceted lived experiences of SSc patients, identifying their perspectives and perceived unmet needs that are relevant to updating clinical practice, including the development of co-patient–centered services, and the design of clinical trials.

Materials and methods

A steering board of health-care professionals with an interest in SSc (G.B., B.R., B.A.P., F.P., G.C., J.J., S.D.D., L.M., A.M. P., S.B.R., F.D.G., Z.H.M., M.M.C., and M.H.), a nurse representative (K.E.A.), patient representation (I.G.), and a methodologist (A.A.), developed a custom-built survey for exploring the experience and unmet needs of SSc patients concerning SSc-DUs. All participants gave their informed consent for using their anonymous responses before starting the survey. The study was conducted in accordance with the Declaration of Helsinki, and it was impossible at any time to link responses to individuals.

Survey questions

The survey consisted of 22 questions (see Supplementary Data, available at *Rheumatology* online), which included questions about patient- and disease-related characteristics and specific questions concerning their DU history (location, number and complications). A series of questions were dedicated to treatment, including local ulcer/wound care, pharmacological therapies, and surgical intervention. We also explored the impact of DUs on patients' activities of daily living, including (but not limited to) occupation, interpersonal relationships incorporating social activities, and future planning. Perceived DU unmet needs were examined, as were patients' perspectives on current treatment strategies.

Survey distribution and responses

Eligible participants were SSc patients who experienced at least one DU during their disease course and were at least 18 years old. The survey was available only in English and it was launched on 31 January 2023 and kept open for 4 weeks. The link to the survey was widely distributed to a large number of SSc patients through social media (e.g. Twitter®) and SSc patient-led organizations. Ethical approval was not required, because no personal information was collected at any point, participation was voluntary, and respondents could terminate their participation at any point. By the action of completing the survey, the patients gave their agreement to the use of their anonymous answers for the objectives of the study.

Statistical analysis

Only completed questionnaires were analysed. Descriptive statistics were utilized to summarize the data. Absolute and relative frequencies were calculated and depicted in tabular form. For all variables, we report the data based on the numbers of responses to each question. All analyses were conducted using SPSS® software.

Results

Survey responses

A total of 358 evaluable responses were collected from patients in 34 countries. The majority of respondents were from the USA ($N=235$; 65.6%), UK ($N=41$; 11.5%) and Canada ($N=16$; 4.5%); however, there was international uptake of the survey in other countries (see Supplementary Materials, available at *Rheumatology* online).

Respondent demographics

The respondents' demographics are presented in Table 1. The majority ($N=333$; 93%) of respondents were female and were aged between 30 and 70 years. More than half were white ($N=237$; 66.2%), and other ethnic groups were also represented (Table 1). Concerning SSc classification, the majority had either dcSSc or lcSSc ($N=129$; 36% and $N=127$; 35.5%, respectively) or overlap-SSc ($N=70$; 19.6%), and fewer had SSc sine scleroderma ($N=18$; 5%) or the very early diagnosis of SSc (VEDOSS) ($N=14$; 3.9%). Over half ($N=206$; 57.5%) had received a university-level education, and one-fifth ($N=68$; 19%) had high-school-level educational attainment. Over half of the respondents (57.8%) were treated for their SSc disease in Public/National Health Services ($N=141$; 39.4% General Rheumatology Service, $N=66$; 18.4% Rheumatology Service specializing in scleroderma), whereas one-quarter ($N=92$; 25.7%) were managed by a private general rheumatologist, and around one-tenth ($N=45$; 12.6%) by a SSc specialized private service.

Table 1. Survey respondent characteristics

	n (%)
Age (years)	
18–30	24 (6.7)
30–50	127 (35.5)
50–70	165 (46.1)
>70	42 (11.7)
Sex	
Female	333 (93)
Male	23 (6.4)
Other	1 (0.3)
Prefer not to specify	1 (0.3)
Ethnicity	
Asian	30 (8.4)
Black or African American	23 (6.4)
Hispanic or Latino	38 (10.6)
White	237 (66.2)
Other	20 (5.6)
Prefer not to specify	10 (2.8)
Education	
Primary school	2 (0.6)
High school	68 (19)
University	206 (57.5)
Other	82 (22.9)
Type of SSc	
lcSSc	127 (35.5)
dcSSc	129 (36)
SSc sine scleroderma	18 (5)
VEDOSS	14 (3.9)

VEDOSS: very early diagnosis of SSc.

History of digital ischaemia

Almost half of the patients (*N* = 165; 46.1%) reported >10 DUs, and around a quarter either 5–10 (*N* = 77; 21.5%) or 1–5 (*N* = 102; 28.5%) DUs. A few patients had only experienced a single DU (*N* = 14; 3.9%). The fingertips (*N* = 304; 84.9%) were the most frequently reported ulcer location, followed by overlying the IP joints (*N* = 182; 50.8%). Less frequent DU sites were either under (*N* = 131; 36.6%) or at the base (*N* = 112; 31.3%) of the nail. Over one-quarter of the patients (*N* = 98; 27.4%) reported previous gangrene affecting the fingers. Among 98 respondents, 10.6% (*N* = 38) had previously had a finger or part of a finger amputated due to gangrene.

Impact of DUs

Respondents were asked about perceived limitations from the presence of DUs (‘strongly disagree’, ‘disagree’, ‘neutral’, ‘agree’ or ‘strongly agree)’. Most respondents either ‘strongly agreed’ or ‘agreed’ that impacts were related to limitation of the activities of normal daily living (*N* = 281; 78.5%, neutral *N* = 27; 7.5%) and work activities (*N* = 260; 72.6%, neutral *N* = 36; 12.8%), and over half indicated impact on their interpersonal relationships and/or social activities (*N* = 212; 59.2%, neutral *N* = 74; 20.7%) or future planning (*N* = 229; 64%, neutral *N* = 66; 18.4%).

Emotional impact of DUs

The perceived emotional impact of DUs is presented in Table 2. Respondents were asked about their feelings during the previous week concerning DUs (assessed as ‘never’, ‘rarely’, ‘often’, ‘very often’, ‘always’): the most frequent feelings were ‘worried’ (*N* = 97; 27.1% ‘often’, *N* = 121; 33.7% ‘very often/always’), ‘uncertain about the future’ (*N* = 72; 20.1% ‘often’, *N* = 124; 34.6% ‘very often/always’) and ‘helpless that ulcers are unavoidable’ (*N* = 92; 25.7% ‘often’, *N* = 151; 42.2% ‘very often/always’).

Current DU treatment satisfaction

Only around one-quarter of respondents were either ‘very satisfied’ (*N* = 26; 7.3%) or ‘satisfied’ (*N* = 62; 17.3%) that their current medication(s) relieved their DU symptoms, e.g. pain, whereas the majority were ‘neither satisfied nor dissatisfied’ (*N* = 106; 29.6%), ‘dissatisfied’ (*N* = 91; 25.4%) or ‘very dissatisfied’ (*N* = 54; 15.1%).

DU wound care

Only around a half of the respondents (*N* = 185; 51.7%) reported that they received wound/ulcer care, most often (*N* = 118; 63.8%) provided by a non-rheumatology specialist wound care clinic; only a third (*N* = 58, 31.4%) received would/ulcer care through a dedicated rheumatological/wound care clinic. The health-care practitioners involved in DU management and the most frequent treatments received are summarized in Table 3.

Among the patients (*N* = 49) who received DU debridement, 37 (74%) reported that this procedure was painful. The most frequent type of pain management used during DU debridement was topical or local anaesthesia (*N* = 33; 66%), whereas general anesthesia (*N* = 5; 10%) was less frequently used. Furthermore, 10% (*N* = 5) of respondents declared they did not receive any measure to manage pain while having debridement. Around half of the respondents considered the method used for reducing pain during ulcer debridement was either ‘definitely effective’ (*N* = 7; 14.0%) or ‘slightly effective’ (*N* = 17; 34.7%), while 10.2% (*N* = 5) were ‘neutral’ about it, and the others considered it ‘slightly effective’ (*N* = 11; 22%) or ‘not effective at all’ (*N* = 9; 18%).

DU education

Among the patients receiving wound care (*N* = 185), only 28.1% (*N* = 52) received education concerning the causes of DUs and their treatment (*N* = 63; 34.1%), or information on how complications may develop (e.g. pain and redness) (*N* = 57; 30.8%), and on what to do if complications arise (*N* = 48; 25.9%).

Factors affecting DU healing

The perceived factors that may delay DU healing are presented in Fig. 1. Respondents reported a broad range of factors that they considered to slow/delay DU healing. The most significant factors were cold temperature (*N* = 294; 82.1%), poor blood circulation (*N* = 262; 73.2%), trauma (*N* = 151; 42.2%), underlying calcinosis (*N* = 149; 41.6%), skin problems (i.e. fibrosis/tightening, pitting scars, dry skin) (*N* = 212; 59.2%), and infections (*N* = 125; 34.9%). Diet (*N* = 20; 5.6%) and lifestyle factors (including smoking) were considered as important by only a minority of respondents (*N* = 17; 4.7%).

Reasons for seeking health-care input

The main reason for seeking advice from health-care professionals for DUs are presented in Fig. 2. Pain was the main reason for seeking advice from health-care professionals (*N* = 283; 79.1%), followed by inability to use the hands due to ulcers (*N* = 205; 67.3%), presence of infection (*N* = 209; 58.4%), time/ulcer persistence for weeks/months *N* = 197;

Table 2. Frequency of feelings caused by digital ulcers during the previous week

	Never (*n*, %)	Rarely (*n*, %)	Often (*n*, %)	Very often (*n*, %)	Always (*n*, %)
Sad	46 (12.8)	92 (25.7)	94 (26.3)	58 (16.2)	36 (10.1)
Embarrassed	73 (20.4)	98 (27.4)	66 (18.4)	53 (14.8)	36 (10.1)
Anxious	57 (15.9)	78 (21.8)	95 (26.5)	61 (17.0)	35 (9.8)
Depressed	69 (19.3)	115 (32.1)	71 (19.8)	41 (11.5)	30 (8.4)
Worried	41 (11.5)	67 (18.7)	97 (27.1)	75 (20.9)	46 (12.8)
Afraid	77 (21.5)	91 (25.4)	85 (23.7)	42 (11.7)	31 (8.7)
Angry	72 (20.1)	103 (28.8)	76 (21.2)	46 (12.8)	29 (8.1)
Uncertain about the future	49 (13.7)	81 (22.6)	72 (20.1)	68 (19.0)	56 (15.6)
Helpless and that ulcers are unavoidable	29 (8.1)	54 (15.1)	92 (25.7)	77 (21.5)	74 (20.7)

Table 3. Practitioners involved in DU management and most frequent treatment received

	(*n*, %)
Health-care practitioner	
Nurses	65 (35.1)
Rheumatology consultants	54 (29.2)
Hand surgeons	39 (21.1)
Plastic surgeons	20 (10.8)
Podiatrists	12 (6.5)
Treatment received	
Ulcer dressing	117 (63.2)
Wound cleaning	109 (58.9)
Debridement	50 (27)
Surgery	31 (16.8)
Sympathectomy	19 (10.3)
Botulinum injection	15 (8.1)
Fat injection	3 (1.6)

(55%), sleep disturbance (*N* = 134; 37.4%), discharge (*N* = 118; 33%), redness (*N* = 209; 31.3%), emotional impact (*N* = 92; 25.7%), tingling or numbness (*N* = 86; 24.0%), and smell (*N* = 38; 10.6%).

Reasons for considering changing DU treatment

In Fig. 3, the reasons for changing DU treatment are reported. Pain was the principal reason for considering change in treatment (*N* = 277; 77.4%), followed by inability to use the hands due to DUs (*N* = 251; 70.1%), time/ulcer persistence for weeks/months (*N* = 181; 50.6%), sleep disturbance (*N* = 148; 41.3%), emotional impact (*N* = 126; 35.2%), discharge (e.g. pus) (*N* = 99; 27.7%), tingling or numbness (*N* = 95; 26.5%), discharge (*N* = 99; 27.7%), redness (*N* = 75; 20.9%), and smell (e.g. offensive smell) (*N* = 70; 19.6%).

Treatment preferences for the management of DUs

Local treatments (e.g. wound care, dressings and outpatient debridement) were preferred (*N* = 255; 71.3% likely/very likely). Generally, oral drug treatment (e.g. nifedipine or sildenafil) (*N* = 245; 68.4% likely/very likely) was preferred over i.v. treatment (e.g. iloprost or epoprostenol) (*N* = 157; 43.8% likely/very likely), whereas the surgical intervention was least preferred (*N* = 109; 30.4% likely/very likely).

Discussion

Our survey benchmarks the multifaceted lived experiences of DUs among SSc patients, identifying their specific perspectives and perceived unmet needs. In SSc, DUs are frequent, and physical and emotional impacts and complications are not uncommon (e.g. infection and gangrene), which may necessitate digital amputation. A key finding of our study is that only one-quarter of respondents reported that their current medication(s) relieved their DU symptoms (e.g. pain).

In SSc, wound care is an essential component in the management of DUs, akin to other diseases (e.g. diabetic, pressure, venous, etc.) that are characterized by cutaneous ulceration [23, 24]. However, only half of the respondents received wound/ulcer care, and this was most often provided by a non-rheumatology specialist wound care clinic. The most frequent DU treatments received were wound cleaning, ulcer dressing, and debridement. It is important to focus on the fact that tissue (ulcer) debridement is a fundamental procedure of wound care, involving the removal of overlying devitalized/necrotic material and the remnants of previous dressings [23, 24]. Ulcer debridement can be performed using a variety of methods, most commonly using either a 'sharp' (e.g. a scalpel or curette) or 'autolytic' debridement, or a combination [23, 24]. For pain management during local wound bed cleaning, an adequate peri-procedural analgesia is required [23, 24], particularly when sharp debridement is performed [25, 26]. In our survey, topical or local anaesthesia (66%) were the most commonly used form of pain management during ulcer debridement. An exceedingly high number of respondents reported that debridement was painful, and that there was a significant variability in the perceived effectiveness of the method used for pain management during debridement. Indeed, only around half of the respondents deemed the method used to be slightly or definitely effective, while 10% of respondents did not receive any pain management during DU debridement. According to the patient representative, local anaesthesia should be recommended, to reduce pain and to retain patients through their treatment.

Our survey highlights the fact that patient education is largely neglected, as only the minority of respondents (around one-third) were educated regarding the cause(s) and treatment of DUs, and how to recognize/manage ulcer complications. Taken together, these data highlight the critical need for high-quality information for patients with SSc, including information about DUs, throughout the course of their disease [27]. Education, as well as health literacy, empower patients to be proactive in their care, potentially minimizing the risk of some complications (e.g. through hand hygiene and avoidance of some chemical products) and motivating them to seek medical attention in a timely manner.

In conclusion, our data confirm that patients can provide novel insights into the precipitating factors for DUs, which supports our previously reported findings [4]. Furthermore, some of these factors are potentially able to be reduced or

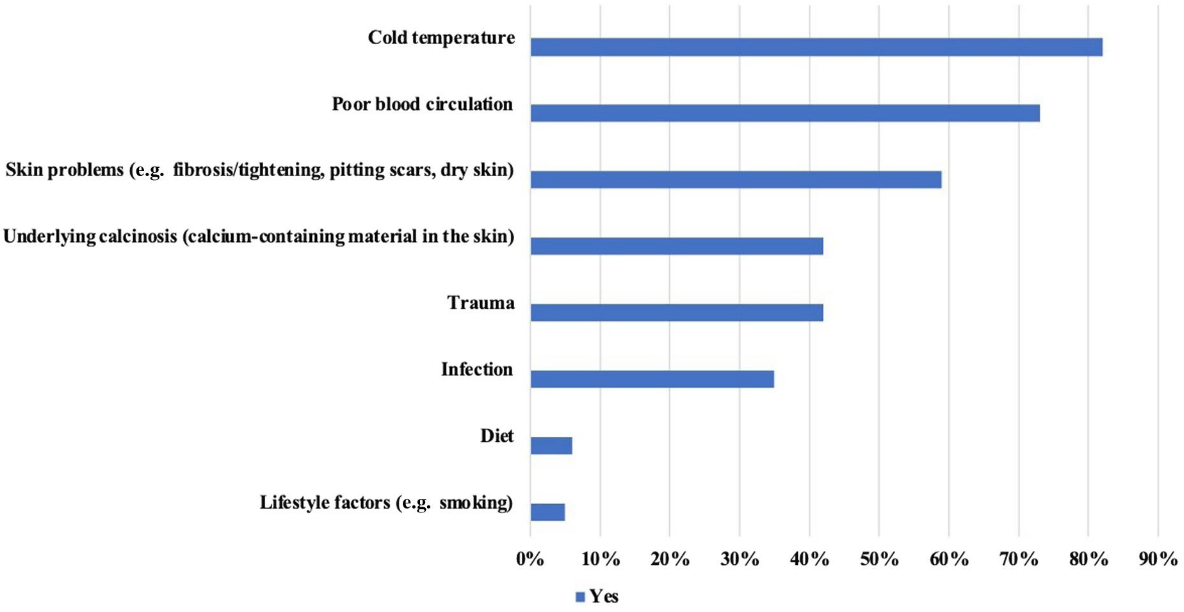

Figure 1. Respondents' perceived factors that may delay digital ulcer healing

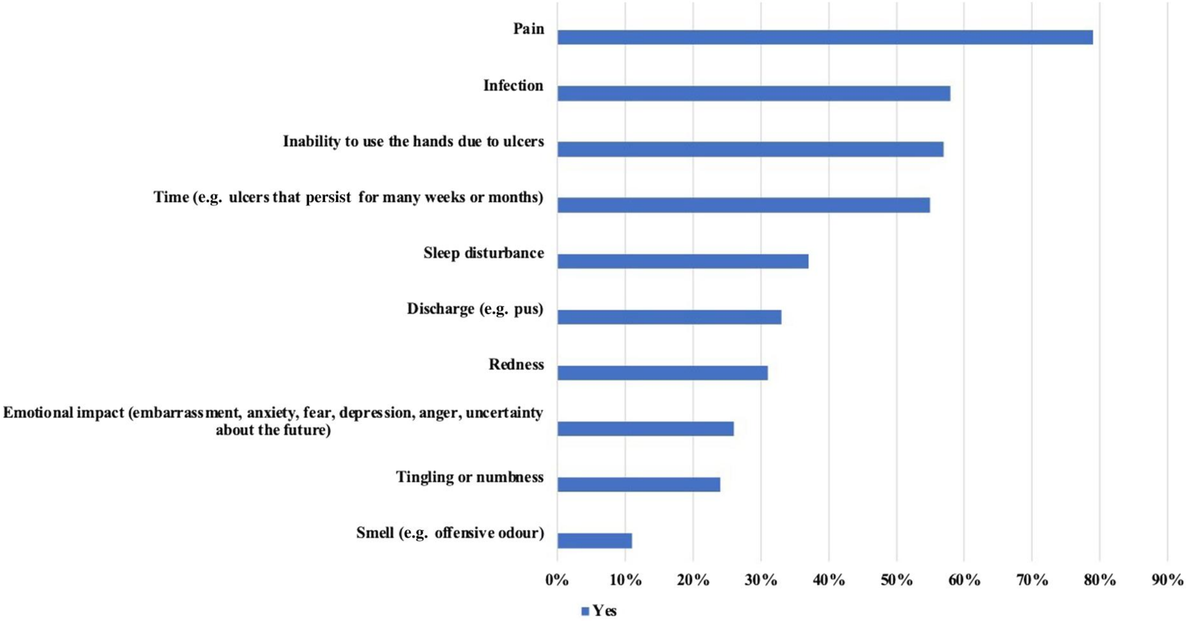

Figure 2. Respondents' main reasons for seeking advice from health-care professionals for digital ulcers

modified (e.g. through avoidance of cold exposure, smoke cessation, and therapeutic intervention) to reduce the extent of skin sclerosis. In addition, we have identified patients' priorities and potential reasons why patients with SSc would consider changing their DU treatment strategy. As could be expected, a local/wound-based approach was preferred, and oral therapies were preferred to i.v. administration (which often requires day hospitalization), while invasive surgical intervention was considered to be a last resort. Future research should address the integration of patient preferences in a shared decision-making model for the treatment of DUs in SSc, and of patient-reported outcomes in the development of potential new therapies [21].

Our survey benefited from the responses from a large, international cohort of SSc patients; however, there are important considerations. Our survey data was not subject to confirmatory clinician diagnosis or chart review, including the underlying diagnosis of SSc. Furthermore, there is a potential selection bias by using social media as the method for survey distribution: not all patients have access to social media, and these patients might be of more advanced age or have a lower level of education; in addition, patients with more severe hand disability (e.g. severe flexor contractures) might not been able to complete the digital form for the survey, and patients with more severe DU disease could have been more keen to participate. Using only English posed a further limitation.

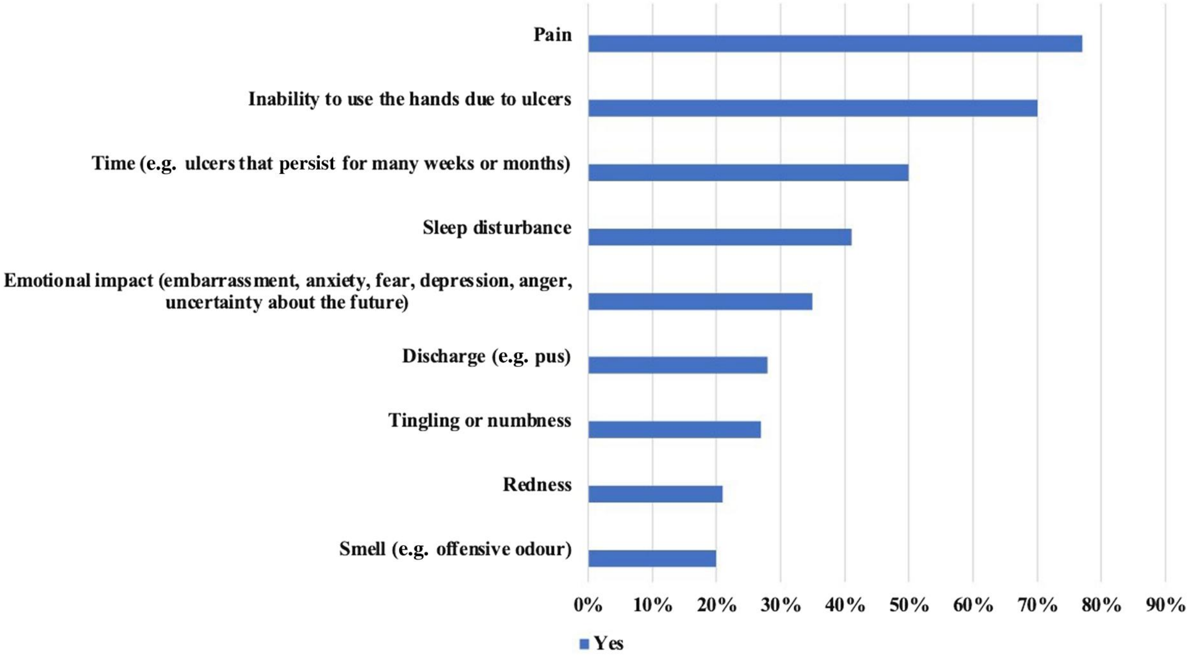

Figure 3. Reasons why respondents would consider changing digital ulcer treatment

In conclusion, our survey data exposed the lived morbidity from SSc-DUs and many currently unmet needs. Patients reported a limited access to rheumatology specialist wound care services, as well as a significant variation in the procedures used for local DU management. A remarkable number of patients had access only to private care, paving the way for further discrimination, considering the impact of DUs on working ability and thus on family income. Wound bed preparation using debridement is often neglected, and peri-procedural pain management is inadequate. Furthermore, patient education is far from universally received. Patients as research partners can provide novel insights into DU pathogenesis, and this should be further explored. We have identified the priorities and reasons patients with SSc would consider changing their DU treatment strategy, and these can inform a shared decision-making model for the treatment of DU disease in SSc. Shared decision-making would certainly have a huge impact on the emotional well-being of patients, also improving their adherence to home therapies. In some cases, the decision-making could be shared between the patient, the clinician and the caregiver, because some patients cannot travel alone due to the severity of the DU.

Supplementary material

Supplementary material is available at *Rheumatology* online.

Data availability

Sharing of the data underlying this article will be considered on reasonable request to the corresponding author.

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