

RESEARCH ARTICLE

Management of diabetes-related foot ulceration at two interdisciplinary services: a qualitative exploration of patient and carer experiences

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Abstract

Aims To investigate patient and carer experiences of care at two interdisciplinary specialist services for the management of diabetes-related foot ulceration (DFU).

Methods Semi-structured interviews were conducted with patients experiencing DFU who attended a minimum of four appointments over three months, and their carers who attended at least two appointments. Purposive sampling was used to identify patients based on: gender; employment status; cultural and linguistic background; carer support; end-stage renal disease; and mental health diagnosis. Audio recordings were transcribed verbatim and analysed thematically.

Results We invited 25 patients to participate. Thirteen consented and were interviewed, along with three carers. Data sufficiency was achieved. Three themes and two subthemes were identified: *confident in care*; *care considered comprehensive* (subthemes: *education benefits* and *access is complex*); and *DFU is life changing*.

Conclusions This study adds to a limited body of previous evidence regarding DFU care experiences. The importance of feeling confident and care being comprehensive were highlighted. New insights were gained, including that receiving care for and living with DFU are part of the same experience which cannot be separated. These findings may guide interdisciplinary service planning and future research to improve care for people living with DFU.

Keywords diabetes-related foot ulceration, interdisciplinary team, qualitative.

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Introduction

Among patients with diabetes, the prevalence of diabetes-related foot ulceration (DFU) varies worldwide, ranging from 1–2% in Australia, 4% in the United Kingdom to approximately 10–30% in Africa, although inconsistent ascertainment methods may have influenced these findings.¹ The average age of those experiencing DFU is 62 years.²

For patients experiencing DFU, structured care from an interdisciplinary specialist service (otherwise known as a High Risk Foot Service [HRFS]) reduces the odds of major amputation by 40–60%^{3,4} and improves physical and mental quality of life.⁴ HRFS care is therefore encouraged. Evidence-based guidelines for HRFSs highlight the importance of timely referral intake, DFU local care, pressure offloading, infection

management, peripheral arterial disease management and a patient-centered approach.⁵⁻⁸

Patient-reported experience measures are essential in evaluating health service quality and performance, while supporting patient-centered care.⁹ Also, patient engagement in other settings has shown positive trends regarding patient outcomes and satisfaction, in addition to service productivity.¹⁰ Hence, a sound understanding of patient and carer priorities in DFU care may be beneficial in guiding future research and health service development to optimise patient engagement and outcomes. Previous investigation regarding experiences of, and priorities within, DFU care from Ireland,¹¹ the USA¹² and Australia¹³ identified the importance of accessibility, coordination, patient-centered care, communication and trust. However, two studies interviewed only male patients and excluded participants with limited English proficiency,^{11,13} and one included a cohort where the majority had already experienced lower limb amputation.¹¹ Therefore, this study aimed to investigate the experiences of care from a representative cohort of patients and their carers attending two public, interdisciplinary HRFSs.

Methods

A qualitative descriptive study was undertaken, using the principles of credibility, dependability, confirmability and transferability to support qualitative rigour.¹⁴ Semi-structured individual (patient) or dyad (patient and carer) interviews were conducted using an interview guide (Appendix 1). Questions were primarily based on recommended HRFS care⁵⁻⁷ and the interview guide was reviewed by clinicians prior to data collection. Interviews were conducted face-to-face in a clinic room or over the phone and all were audio-recorded. Interviewers recorded field notes during and after interviews. Debrief meetings among members of the research team were conducted regularly. Additional ulcer details, including recent progress and depth, were extracted from the medical records of the patient's most recent HRFS appointment prior to being interviewed.

To reduce confirmation bias, verbatim transcriptions, interviewer notes, member checking feedback and an inductive approach were used for thematic analysis.¹⁵ All participants were invited to engage in member checking following their interview; seven did so and one provided minor clarifying edits. Steps for data analysis included initial data familiarisation, early code generation, actively searching for themes, theme review and theme definition.¹⁵ Participant demographic details were summarised descriptively. Analysis was undertaken using NVivo 14 (Lumivero, Denver CO USA) and Excel (Microsoft Office, Redmond WA USA), primarily completed by SM, with review by members of the research team with qualitative expertise (SP, SD). This study was reported according to the consolidated criteria for reporting qualitative research (COREQ).¹⁶

We recruited participants who had recently experienced care from the HRFS through attending multiple appointments.

Inclusion criteria were: patients experiencing DFU who attended a minimum of four appointments over three months at the Concord or Royal Prince Alfred Hospital HRFSs in Sydney Local Health District (SLHD), NSW Australia (Appendix 2 details the service setting), and their carers who attended at least two appointments; aged 18 years or older; having capacity and willingness to provide informed consent. Patients were purposively sampled on these characteristics: gender, employment status; from a culturally and linguistically diverse (CALD) background; received support from a carer; had end-stage renal disease; or had a known mental health diagnosis. Interpreter services were available to support participants from CALD backgrounds. Patients with a known mental health diagnosis were only invited to participate if their treating podiatrist felt that there was a low risk of increased stress related to study participation.

Eligible participants were approached in person at the HRFS or by phone, and provided with participant information sheets outlining the study aims. Interviews were scheduled for participants who provided informed consent. Where possible, prior relationship between the interviewer (SM or GF) and interviewee was avoided, as each interviewer primarily worked at one included HRFS, but interviewed participants who attended the other site. However, as both interviewers had worked in SLHD for many years, some participants had previously received clinical care from their interviewer. Nevertheless, participants seemed to speak openly while being interviewed. Both interviewers were experienced, female podiatrists and were trained to conduct these interviews.

Results

In total 25 patients were referred, of which 13 patients (Table 1) and three carers (Table 2) participated between August 2023 and July 2024, achieving data sufficiency. Reasons why referred patients did not participate included the researchers being unable to contact them or lack of interest. The median interview duration was 34 minutes (range 10–52 minutes). Interpreter support was required for one patient and their carer translated for them, as was their preference. Interview answers and topics raised by both patients and carers were consistent. Three themes were identified, presented in order of importance (based on a combination of anecdotal discussion frequency and tone of voice during interviews): *confident in care*; *care considered comprehensive*; and *DFU is life changing*. *Care considered comprehensive* included two subthemes: *education benefits* and *access is complex*.

1. **Confident in care:** feeling confident in their care and having a positive rapport with staff were essential.

Overall participants were confident in the care received at the HRFS: *"I've always had a lot of confidence in them ... I think I've come away feeling reassured [...] I think... this is the best I could be getting ... I'm, you know, really quite happy with their explanations and their confidence is good. Yeah, I find that reassuring" (P12). "They were careful ... they were*

Table 1. Patient demographics (n=13)

Patient ID	Sex	Age (years)	DM type	DM duration (years)	CALD	ESRD	Mental health diagnosis	Employed	Carer support	Current DFU (n)	Ulcer progress	Ulcer depth	PAD	Current infection	First or subsequent time accessing HRFS care
1	M	33	Type 2	2	No	No	No	No	No	1**	Amputated**	—	—	—	First
2	M	58	Type 1	40	No	No	No	Yes	No	1	Deteriorated	Superficial	No	No	Subsequent
3	M	73	Type 2	20	Yes	Yes	No	No	Yes	1	Improved	J/B	Yes	No	First
4	M	74	Type 2	24	No	No	No	Yes	No	1	Unchanged	Superficial	Yes	No	Subsequent
5	M	63	Type 2	28	Yes	Yes	No	No	Yes	1	Deteriorated	Superficial	No	Yes	Subsequent
6	M	75	Type 2	27	Yes	No	No	No	No	1	Improved	Superficial	No	No	Subsequent
7	F	63	Type 2	18	No	No	No	No	No	0 (healed)	Healed	—	—	—	First
8	M	83	Type 2	10	Yes	No	No	No	Yes	1	Deteriorated	Superficial	Yes	No	First
9	M	59	Type 2	10	Yes	Yes	No	Yes	No	>1	Improved	T/C	Yes	No	First
10	M	52	Type 2	15	Yes	No	No	Yes	No	1	Improved	Superficial	No	No	First
11	F	76	Type 2	15	No	No	Yes	No	Yes	1	Unchanged	Superficial	Yes	No	First
12	F	73	Type 1	49	No	Yes	No	No	Yes	>1	Improved	Superficial	Yes	No	Subsequent
13	F	83	Type 2	41	Yes	No	No	No	No	>1	Improved	Superficial	Yes	Yes	Subsequent
Summary	M: 9 (69%), F: 4 (31%)	73 (59–75), 33–83	Type 1:2 (15%), Type 2:11 (85%)	20 (15–28), 2–49	7 (54%)	4 (31%)	1 (8%)	4 (31%)	5 (38%)	0: 1 (8%), 1: 9 (69%), >1: 3 (23%)	I: 6 (46%), U: 2 (15%), D: 3 (23%), A: 1 (8%), H: 1 (8%)	S: 9 (69%), T/C: 1 (8%), J/B: 1 (8%)	7 (54%)*	2 (15%)*	First: 7 (54%), Subsequent: 6 (46%)

For summary statistics, data are reported as median (IQR), range for continuous data, or n (%) for categorical data

Legend: A = amputated; CALD = culturally and linguistically diverse; D = deteriorated; DFU = diabetes-related foot ulceration; DM = diabetes mellitus; ESRD = end-stage renal disease; F = female; H = healed; HRFS = high risk foot service; I = improved; J/B = to joint or bone; M = male; PAD = peripheral arterial disease; S = superficial; T/C = to tendon or capsule; U = unchanged; — = not recorded.

Notes: *Data is missing for two participants in this column; **Patients who have recently undergone amputation of a previous DFU site may experience delayed post-surgical healing, in which case the post-surgical amputation site is treated as a new DFU.

slow, they were caring [...] So that's a good thing, you know what I mean? The staff are, you know, pretty 'A1' [good]... It doesn't matter who you get" (P9). In view of this confidence in their care, participants reported having shared what they had learnt, and one reported recommending that a friend be referred to the service.

A positive rapport between patients, carers and staff was valued, which supported patients feeling comfortable to ask questions and be involved in their care: "Everybody has been just very, very nice [...] If we're not sure of anything, we ask" (P11). "I just think they're a great team. Like I've seen a lot of them too. [...] They... know what they're doing. They do a good job. Like I said, they're very friendly" (P1). However, one patient reported disappointment and stress when they raised a concern which they felt was not well supported: "But I was complaining to the girls that the toe ... was hurting me, every night ... it was strangling me ... because there was an ulcer underneath the nail that nobody saw it until I lost my shit" (P7). This patient was subsequently admitted for acute care where comprehensive management was provided.

2. Care considered comprehensive: there were many aspects of HRFS care which could feel overwhelming. Some patients sought a simple explanation to provide grounding and comfort. Two subthemes were identified: *education benefits* that described the importance of understanding DFU, complexities of putting education into practice and the necessity for consistency; and, *access is complex* that detailed various aspects of booking and attending both HRFS and external appointments.

Overall, appreciation for the comprehensive nature of care at the HRFS was expressed: "It's helpful [...] What's the best, [dressing], the rest of the stuff they use ... Like, when it's going backwards, when it's improving ... [Interviewer] So it sounds like they've kind of got everything?... [Patient] Yeah" (P1).

Participants valued interdisciplinary team members, both within and external to but linked with the HRFS. Having interdisciplinary team members working together was particularly valued, such as when a patient's podiatrist worked with the HRFS team: "...they've worked well together.

I tell you what, he has been good. He's been in contact with the clinic and they with him" (P12). Participants also expressed gratitude for additional team members including administrative staff who aided with HRFS appointment bookings or facilitated phone discussion with HRFS clinicians if they had a concern, and district nurses who aided with dressing changes between HRFS appointments. One patient also reported being supportive of students assisting in their care, believing in the value of student learning.

Continuity of care was valued across outpatient and inpatient settings. An example was a patient who was well known to the HRFS outpatient clinic and received inpatient review during an unrelated admission: "The people from the foot clinic came and saw me in the ward [...] which I thought was wonderful [...] I don't quite know how they even found out that I was in, but I was quite sick there for a while" (P12).

Some participants found aspects of DFU care overwhelming: "I remember when they debride the first time on the heel, and said, oh...just a small debride, and then you look at a photo and...it's like a well" (P9). Most participants valued being actively involved in and having options in their care: "They gave me the options ... yeah, it was good" (P10). However, some participants felt that they did not have options in their care due to the nature of their condition: "You get to a point when you're getting fed all sorts of stuff and it's like ... I don't want to hear anymore because whatever you're telling me, it's not helping me" (P7).

While participants were providing feedback regarding ways to improve their DFU care, it became apparent that some sought explanation and meaning to provide grounding and comfort. For example, some participants expressed a feeling that faster management in aspects of their care may have improved their DFU outcome, however inconsistencies in their stories suggested that they were seeking a simple explanation during a complex experience. For example, one patient reported that after a long period of time attending the clinic for care of their ulcer, their ulcer started improving. This improvement started shortly before a surgical debridement, which was planned when the ulcer was not yet improving. However, the patient then suggested: "It possibly could have been [surgically] debrided sooner" (P12).

Table 2. Carer demographics (n=3)

Carer ID*	Age (years)	Approximate hours per week providing care	Only carer or other carers also involved in the patient's care	Relationship with the patient
3	64	40	Only carer	Family member
8	58	4	Only carer	Family member
11	56	35	Only carer	Family member
Summary	58 (57–61), 56–64	35 (20–38), 4–40	Only carer: 3 (100%)	Family member: 3 (100%)

For summary statistics, data are reported as median (IQR), range for continuous data, or n (%) for categorical data

*Carer and patient in a dyad have the same ID number

Education benefits were a consistent aspect of care considered comprehensive. Overall feedback regarding education was positive and avoiding complex terms was appreciated: “At least they ... explain everything in plain English so you can understand ... Rather than using medical terms. [...] They’ll tell you exactly what’s happening, what we’re doing, and they ... explain the whole situation” (P9).

Most participants reported feeling supported to gain an understanding of their DFU: “It was really good. Like they explained to me ... where my pressure points are ... Like obviously explained the shoes and stuff like that [...] the fact that they had it on a computer ... showed me where most of my pressure’s going through ... It’s all good to have that information” (P1, describing their experience with in-shoe pressure assessment). However, one participant reported feeling that better education early during their DFU journey was needed: “But, nobody ever sat me down and said you really need to take control, which I should have” (P7).

Overall, participants expressed understanding the education provided by the HRFS. While this education was sometimes difficult to put in practice, the associated benefits were acknowledged: “What a pain in the arse [...] going to the toilet ... or having a shower [...] But it worked” (P9, describing their experience with negative pressure wound therapy).

Sometimes participants did not have capacity to follow HRFS education, particularly resting to support offloading, even though they understood the reasons why. This was the case regardless of employment status. For example, one patient was not working but helped to care for his young grandson: “[Interviewer] Has the foot clinic asked you to rest or to try and avoid too much walking? [Patient] Uh, yes, [laughter]. [Interviewer] How are you going with that? [Patient] Some days it’s good. Other days, it’s not [...] sometimes I take the little bloke to preschool [...] Take him up the road, you know?” (P6). Recommendations from the HRFS sometimes led to safety concerns which patients had to negotiate, including finding offloading boots slippery on wet floors, and back pain related to wearing them. Of note, it is standard practice within these HRFSs to assess safety in the clinic when implementing and monitoring offloading. If safety concerns arise, patients are advised to cease any recommendations immediately and contact the service.

Most participants reported consistency in the education and recommendations received which was appreciated, however some reported feeling stressed if there were inconsistencies, both within and external to the HRFS: “I don’t want to hear ... two opinions [...] But who do I believe now?” (P5). Participants also noted that there was a lot to learn regarding DFU care and as such, learning occurred gradually over time.

Overall feedback from participants identified that HRFS access is complex, another consistent aspect of care considered comprehensive. Flexibility in booking HRFS appointments around other commitments was valued.

Feelings about the importance of appointments running on time varied, with some understanding when appointments ran late, while others reported frustration due to other factors, such as timed street parking and the risk of receiving a parking ticket. Some participants experienced difficulty with physically accessing the service, owing to parking, the need to walk to the clinic rooms, and difficulties using public transport: “About the longest walking I do is from where I park” (P10). Numerous participants valued not feeling rushed during their HRFS appointments: “And they’re nice about it ... they’ve got no rush to do it, you know, they give you time to sit you down and say ... would you like this” (P9). Participants were generally satisfied with their frequency of appointments, and appreciated the option of attending more regularly if they were concerned: “I don’t think that any more frequent ... appointments were or are needed; not unless some emergency will occur, which we all hop[e] it won’t” (C8). Participants appreciated the streamlined process from initial referral to the HRFS, to preparation for discharge and the associated care coordination around ongoing maintenance.

Participants expressed gratitude in being able to access the HRFS: “You’re just pretty fortunate to be alive today that you can go and make these appointments, and they can fix these things or keep these things under control” (P4). One participant appreciated the presence of other patients while attending the HRFS and the knowledge that she was not alone in her journey. This patient was not interested in further social opportunities (such as group classes or online forums), but valued the connection she felt in seeing other patients attending the HRFS: “You do realise that you’re not the only one that’s got issues like that... [Interviewer] Have you valued that?... [Patient] I have [...] Because I don’t know anyone else [...] that helped me” (P12).

Participants were generally accepting of and understood the need for extra assessments outside of the HRFS, however long wait times were sometimes noted. They preferred if these assessments were collocated with the HRFS or close to home.

3. DFU is life changing: considered the life changes, emotions and long journey of living with DFU.

Participants reported many life changes associated with DFU, including inability to complete previous tasks and needing to complete new tasks. While some reported neutral acceptance, these changes were mostly negative: “It changed my life in many ways ... Like, I couldn’t drive, I couldn’t walk properly ... I still have balance problems” (P7). Participants also reported that DFU was associated with changes for those around them: “My husband’s my carer and ... he’s been doing everything for me” (P12).

New emotions were experienced while living with DFU, including helplessness, frustration, and fear: “He was scared that it might get worse” (C3). Emotions were generally negative, especially if patients experienced pain as part of

their DFU journey: *"I had so much pain there, I couldn't walk on my foot with the ulcer"* (P9). Things were considered in perspective if the patient's DFU had not improved recently, while emotions were positive following recent DFU improvement: *"It's much, much better than it was before [...] oh my God, it's a big difference ... in a good way"* (C3). Likewise, emotions were generally negative following unplanned hospital admissions and positive following planned admissions. Emotions were also negative and stress reported when patients experienced more than one DFU at a time: *"I thought, oh, God, not another one"* (P2).

Participants also reported self-reflection as part of their journey with DFU, which particularly included self-blame and uncertainty, likely related at least in part to loss of protective sensation: *"Obviously I'm not doing it quite right because today, they said, 'That callus has built up which means you've been getting pressure on it' [...] I've just got to concentrate and think more about everything I do"* (P4).

The long journey of DFU was acknowledged, such as one patient who discussed aspects of their DFU care which had occurred eight years earlier. Generally, disappointment accompanied the long journey of DFU, however participant resilience was also highlighted: *"Haven't done too well over the last three months, but just got to keep at it"* (P4).

Having previous experiences of DFU influenced participant expectations of later DFU outcomes: *"I just thought they would just do what they normally do, patch it up and it'll be healed [...] because of all the previous experience, everything was fixed up fairly quickly. This one is just sort of [...] lingering"* (P2).

As patients experienced DFU in addition to other health conditions, managing everything was sometimes overwhelming but other times accepted as part of life: *"Because we've got so much on the plate with other things ... I'm confused as to who, what ... and with those little details"* (C8).

Discussion

This study achieved a thorough exploration of patient and carer experiences in DFU care. Overall, participants felt confident in their care, and that their care was comprehensive. A new finding was that receiving care for and living with DFU are part of the same experience which cannot be separated.

Confident in care was consistently a top priority during interviews. Feedback was generally positive which was appreciated from a service perspective, however findings were also clinically valuable, as confidence in care is central to positive care experiences for those with chronic illness, and in supporting them to feel confident regarding their future.¹⁷ The importance of confidence in care aligns with other studies regarding DFU care, where trusting¹³ and building rapport¹¹ were also priorities. Constructive feedback was received from a patient who reported DFU related

pain which she felt was not well managed. Consequently numerous practical changes were made locally in our HRFSs to reduce the risk of a similar situation recurring. Challenges are recognised in the field of DFU care and pain management, such as a lack of DFU validated pain assessment tools.¹⁸ However, pain management remains important, as wound-related pain is experienced by up to 75% of patients with DFU.¹⁸

Care considered comprehensive highlighted the value of continuity in care and reiterated the importance of personalised care^{12, 13} which is well-coordinated,¹² without feeling rushed.¹² However, the current study also provided new insight regarding the complexity of having DFU, including patients who sought grounding and comfort through a simple explanation (as indicated by inconsistencies during interviews) such as 'this should have happened faster'. This suggests that patients and carers may benefit from increased early support (further discussion below).

Regarding education and access, firstly the importance of early education about the serious nature of DFU was raised. For consideration, mortality rates for patients with DFU are comparable to mortality rates for patients with numerous cancers,¹⁹ which naturally changes our thoughts of approach to DFU care education and raises questions such as 'should we be talking about survival early on', as would be expected with a cancer diagnosis? A comprehensive review of this topic, and seeking patient and carer feedback to guide future approaches to early education in DFU care, are indicated. Secondly, the current study added to knowledge regarding the burden of offloading devices,¹³ identifying practical details regarding struggles (for example due to fulfilling other commitments including supporting family) and safety concerns (such as related back pain). Considering offloading's impact on the patient is important²⁰ and associated research to clarify the patient's priorities early during DFU care (for example healing vs quality of life) may be beneficial. Thirdly, the participant in the current study who appreciated seeing other patients while accessing the HRFS and knowing she was not alone in her journey was insightful. Although no other participants in the current study reported similarly, as HRFS clinicians we recognise in practice that patients sometimes seem to enjoy chatting with one another while waiting for appointments, and the importance of social support¹¹ is acknowledged.

The third theme of *DFU is life changing* was somewhat of a surprise, given that we aimed to learn about patient and carer experiences in DFU care. This theme highlighted that receiving care for and living with DFU are part of the same experience which cannot be separated, and emphasised the take home message of respecting and supporting the patient in their DFU journey. The impact of life changes,¹¹ stresses¹¹ and the long term nature of DFU¹³ should also be recognised. While the resilience of participants was identified in the current study, healthcare providers should also note the ongoing struggles they face.

Aspects of each theme from the current study suggest that additional support early on may be beneficial, such as for those who felt that they did not have options in their care and particularly considering the overall impacts of living with DFU. Increased early support could potentially be provided by social workers and psychologists, however this support is not available in most HRFS settings. Of note, limited research and inconsistent findings regarding the role of psychological interventions for patients with foot ulcers²¹ highlight the complexity of living with DFU.

A strength of the current study was representation across each of the included purposive sample and ulcer characteristics. However, only one patient with a known mental health diagnosis participated. During recruitment we noted that patients with a mental health diagnosis were less likely to meet this study's inclusion criteria relating to attending HRFS appointments, so a more flexible inclusion would be recommended for such patients in the future. Additionally, while considering potential participants to include in this study, we noted that some HRFS patients who we knew well and suspected were facing mental health struggles did not have a recorded mental health diagnosis. Unfortunately, patients experiencing mental health struggles without confirmed diagnoses does occur among patients with diabetes.²² Also, patients with mental health struggles experience associated impacts, which include, but are not limited to, a compromised capacity to participate in their treatment.²² As such, screening for mental health comorbidities among patients with DFU and access to related support resources would likely be helpful. Finally, both interviewers were female owing to staffing and availability. In future studies, including a male interviewer may be beneficial and facilitate further interview discussion, particularly with male participants.²³

Conclusions

This study found that patient and carer priorities in DFU care included feeling confident and care being comprehensive. New insights were gained regarding these themes, including the importance of pain management, participants seeking a simple explanation within a complex situation for comfort, early education during DFU management and practical reasoning behind difficulties in implementing prescribed offloading. The final theme of the current study identified that DFU is life changing, with new insight that receiving care for and living with DFU are part of the same experience which cannot be separated. Overall, these findings can be used to guide future research and service improvement, to support DFU care which aligns with patient and carer priorities.

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Conflict of interest

The authors declare no conflicts of interest

Ethics statement

Ethics approval for this project was received from the Sydney Local Health District Ethics Review Committee (Royal Prince Alfred Hospital Zone): 2022/ETH01861.

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Author contribution

Author contributions: conception and design SMM, GF, VN, HBM, CS, SD, SSP; acquisition and analysis of data SMM, GF, SD, SSP; interpretation of data SMM, SD, SSP; and manuscript drafting SMM, SD, SSP. All authors provided important intellectual content during manuscript revision and approved this final manuscript for publication.

Appendices

The two appendices can be found in the online version at woundpracticeandresearch.com

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