



ORIGINAL RESEARCH-CLINICAL SCIENCE

Reasons for (non-)adherence to self-care in people with a diabetic foot ulcer

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ABSTRACT

We aimed to explore reasons for (non-)adherence to self-care among people with diabetic foot ulcers, as well as barriers and solutions to improving their self-care adherence. We performed a qualitative study, recruiting people with a diabetic foot ulcer from a community diabetic foot clinic. Semistructured interviews were held with participants. Data saturation occurred after 9 and was confirmed after 11 participant interviews. Interviews were audio-taped, transcribed verbatim and analyzed using the framework approach. Findings were mapped and the World Health Organization's (WHO) adherence dimensions were applied to themes identified. The key themes identified were (1) participants performed recommended practices in self-care; (2) participants relied heavily on care support; (3) motivations for self-care came from "staying well"; and (4) there was a disparity between self-care knowledge and understanding. Barriers identified included poor mobility and visibility, difficulty wearing offloading devices or using wound dressings, and frustration with lack of progress. Solutions to improve adherence included integrating self-care as routine, improved education, more external help and improving visibility. All five WHO adherence dimensions played a role in (non-)adherence to diabetic foot ulcer self-care. We conclude that adherence to recommended diabetic foot ulcer self-care was limited at best, and reasons for nonadherence were multidimensional. Based on the factors related to (non-)adherence and the barriers and solutions described, we suggest clinicians obtain a broad view of a person's situation when aiming to improve self-care adherence.

INTRODUCTION

Diabetic foot ulcers affect 19%–34% of the people with diabetes in their lifetime and are associated with a significant increase in morbidity and mortality and a decreased quality of life.^{1–4} Best practice treatment of diabetic foot ulcers requires weekly or fortnightly outpatient visits in multidisciplinary foot clinics⁵ typically over several months.⁶ Yet, the majority of overall care actually takes place away from the multidisciplinary clinic in the person's home and is referred to as self-care.⁵ This diabetic foot ulcer self-care typically consists of wearing an offloading device at all times, changing wound dressings, and frequently checking the ulcer for infection or deterioration. For diabetic foot ulcers to heal, adherence to this self-care is crucial,^{7,8} but these recommendations have been described as extremely difficult.⁹

According to the World Health Organization (WHO), adherence to care is a multidimensional phenomenon, determined by the interplay of five sets of factors: social and economic, therapy-related, patient-related, health-system-related,

and condition-related factors.¹⁰ When applied to people with a diabetic foot ulcer, these dimensions can all be expected to play a role in self-care. For example: social and economic factors often concern limited health literacy and social support of patients with foot ulcers^{11–13}; therapy-related factors are the side effects of treatment, such as caused by offloading devices^{14,15}; patient-related factors involve the person's existing knowledge, skills, and beliefs of the benefits of care^{11,13,16}; health-system-related factors include the lack of reimbursements for offloading and dressings that are common in most nation's health systems¹⁷; and condition-related factors are often the other self-care components imposed by general diabetes care as well as concomitant depression.¹³

Despite its importance, adherence to diabetic foot ulcer self-care has received surprisingly limited attention in research and has focused primarily on the area of offloading.^{18,19} A systematic review on offloading interventions for diabetic foot ulcers recommended that "ways to improve adherence and to encourage patients to adhere should receive immediate attention from

clinicians and researchers”.¹⁸ Further, the first-ever prospective study on predictors of offloading adherence found that poor offloading adherence was mostly seen in patients who experienced postural instability and those with less severe ulcers.¹⁴ However, offloading is only one aspect of foot ulcer self-care, and other aspects along with the five sets of factors outlined by the WHO are yet to be investigated.

While very little attention has been afforded to adherence in people with foot ulcers, adherence to self-care in people without an ulcer has received a little more attention. For people at high-risk of ulceration (i.e., those in remission after healing of a diabetic foot ulcer^{1,20}), adherence has been studied in relation to preventative interventions, such as custom-made orthopedic footwear use or foot temperature monitoring at home.¹⁹ Systematic reviews show that the effects of such interventions are significantly enhanced in adherent patients.^{19,21} Observational studies on custom-made orthopedic footwear to prevent ulceration indicate that adherence is related to the perceived benefit of the footwear.^{22,23} For people at low-risk of ulceration, this concerns general self-care such as daily foot checks and washing and drying of toes, with nonadherence found to be related to poor illness beliefs or a lack of awareness.^{11,12,24,25} However, interventions to improve adherence have not been established to date.^{19,21} Furthermore, the self-care activities required for people at high-risk or at low-risk of developing diabetic foot ulcers are considered to be significantly different to the more urgent and extensive self-care required in people with a diabetic foot ulcer.

The WHO urges that people are not solely responsible for treatment adherence, and research into this topic needs to encompass a broad and in-depth perspective incorporating these various dimensions.¹⁰ With adherence to diabetic foot self-care being a multifactorial and complex process and influenced by individual experiences and the places where people live, better understanding of diabetic foot ulcer self-care adherence requires research with a range of methods, both qualitative and quantitative, to reflect the multifactorial nature of adherence.^{10,13} This can also be seen from a qualitative study in this population, where disruptions and adaptations during foot ulcer care are described.⁹ The rich descriptions from this study underline the importance of qualitative methods; however, since they did not investigate self-care adherence, nor any of the factors or dimensions related to self-care, qualitative research on this topic remains needed. With the lack of research on the multiple factors of diabetic foot ulcer self-care adherence, and the various dimensions that play a role, we chose to perform a qualitative study in this area. The aim of this study was to explore reasons for (non-) adherence to self-care among people with diabetic foot ulcers, and their practical and contextually tailored solutions for improving self-care adherence.

METHODS

Study design

We performed a qualitative study using face-to-face semistructured interviews, using the framework approach.²⁶ The study protocol was approved by the Prince Charles Hospital's Human Research Ethics committee (HREC/17/QPCH/14).

All study procedures were in accordance with the Declaration of Helsinki.

Participants

People aged 18 years or above with a diagnosis of type 1 or type 2 diabetes mellitus and a foot ulcer (“full-thickness lesion of the skin below the malleoli”⁵), and who owned a smartphone, were eligible to participate. Owning a smartphone was an inclusion criterion as this study was a part of a larger research project investigating the development of a smartphone application.²⁷ Demographic details were obtained from the participant via self-report before the start of the interview and confirmed with the information as recorded by their podiatrist in the validated Queensland High Risk Foot Form clinical record during their last visit to the clinic.²⁸

Development of interview guide

A 40-item, semistructured interview guide was developed. The systematic nature of the framework approach allowed for the interview guide to be structured to align with the various aspects and factors of diabetic foot ulcer self-care. For the purpose of this study, the WHO definition of self-care was used: “the ability of individuals, families, and communities to promote, maintain health, prevent disease, and to cope with illness with or without the support of a health-care provider” (<https://apps.who.int/iris/handle/10665/205887>).

The interview guide was piloted with two persons not included in the study, to ensure validity and feasibility. The final version of the interview guide consisted of two sections: participant's self-care practices and use of smartphone technology. Only the section on self-care was used for this study and comprised 23 items across 3 subsections: (a) current self-care practices (11 items), (b) barriers to and facilitators of self-care (6 items), and (c) personal ideas on strengthening treatment adherence (6 items). See Appendix for the interview guide.

Procedures

Participants were recruited from the diabetic foot clinic of the Chermide Community Health Centre in Brisbane, Australia. Patients meeting eligibility criteria were informed of the study by their podiatrist, and when interested invited to participate by the research team. Based on previous experience,^{22,29} it was expected that 10–12 participants would suffice for this qualitative study; data saturation was reached after 9 participants and confirmed after 11 participants.²⁶

Interviews were held in a private room within the diabetic foot clinic, with only the participant and the investigator present. Before the start of the interview, the study was again explained to the patient. Patients then provided informed consent. All interviews were held by the same investigator (LS), who was trained before the start of the study by two experienced qualitative researchers (JvN and BP). Interviews lasted approximately 60 minutes. Interviews were voice-recorded digitally and transcribed verbatim by one investigator (LS), while this investigator also made notes during the interview. All data were stored securely, in line with the university's data storage policies.

Data analysis

We used the framework approach for analysis of the semistructured interviews undertaken in this qualitative study.²⁶ Three (LS, BP, JvN) investigators were involved in data analysis. The complete framework approach for data analysis consisted of:

1. Familiarization: By listening to interviews, transcribing data, and reading and rereading transcripts. Notes taken during interviews supplemented these transcripts.
2. Thematic framework identification: Preliminary codes and themes were developed for relevant sections of data and revised to include emergent concepts or themes. After three interviews, codes and themes were discussed between the three authors to reach consensus.
3. Indexing: Data from all transcripts were indexed using generated codes and categories. Data were coded through SaturateApp, a web-based tool for collaborative qualitative analysis (available at www.saturateapp.com). After each interview, codes were checked for saturation. Data saturation occurred after nine and was confirmed after eleven interviews.
4. Charting: The coded data were summarized and charted. Pertinent sections of data were copied and placed under thematic headings, with reference to the pages and lines in the transcripts.
5. Mapping and interpreting data: Associations between themes and explanations for the data were investigated by mapping and interpretation. Findings were mapped and interpreted within the themes identified; the WHO adherence dimensions (social and economic factors; therapy-related factors; patient-related factors; health-system related factors; condition-related factors¹⁰) were applied to each theme.

Finally, all themes and interpretations were discussed between all authors, until consensus was reached in the findings.

RESULTS

Participants

Characteristics of the participants are displayed in Table 1. Of the eleven participants, ten were male, ages ranged from 43 to 74 years. Six had type 2 diabetes and five had type 1 diabetes. Median duration of their diabetic foot ulcer was 12 months, ranging from 3–84 months, and most ulcers were on the plantar surface of the foot.

Section 1: Current self-care practices

Four themes were identified related to participants' current self-care practices and their adherence to these practices. The themes and their mapping to the WHO dimensions are summarized in Table 2 and described below with additional details and quotes to illustrate.

Theme 1: Recommended and alternative self-care practices

The first theme identified concerned recommended and alternative self-care practices. Together, participants described

Table 1. Participant characteristics (*n* = 11)

Characteristics	<i>N</i> (%) or Median (range)
Gender	
Male	10 (91%)
Female	1 (9%)
Age	
(Years)	53 (43–74)
Education	
High school	4 (36%)
Associate diploma	6 (55%)
Degree	1 (9%)
Occupation	
Employed	5 (45%)
Unemployed	2 (18%)
Retired	3 (27%)
Student	1 (9%)
Diabetes	
Type 1	5 (45%)
Type 2	6 (55%)
Diabetes complications	
Peripheral neuropathy	11 (100%)
Retinopathy	4 (36%)
Nephropathy	1 (9%)
Ulcer location	
Hallux–plantar	4 (36%)
Hallux–medial	2 (18%)
Metatarsal heads	3 (27%)
Midfoot–plantar	2 (18%)
Ulcer duration	
(Months)	12 (3–84)

the six key self-care practices that are recommended in the international guidelines,⁵ namely, dressing changes, checking of feet, wearing the offloading device, ensuring cleanliness, moisturizing and preventing excessive moisture.

“...I’m changing the dressing every second day, and give the foot a good wash in the shower prior...” (P1)

“...change the dressing, then we wash with saline solution, put fresh dressings on and tape it down, and put a bit of semi-compressed felt on...” (P4)

“Make sure you do regular checks of your foot, every night.” (P6)

Although participants recognized the importance of some of these six key self-care practices, no single recommended self-care practice was mentioned by all participants. Further, low rates of adherence were typically reported for these self-care practices, most frequently for wearing offloading footwear at all times (see further theme 4) or checking the ulcer. As such, adherence to all key recommended self-care practices can be interpreted as limited.

Table 2. Themes, WHO dimensions, and codes in relation to 'Current self-care practices' (section 1)

Theme	WHO dimensions	Codes (N)
1. Recommended and alternative self-care practices	Social and economic Therapy-related Patient-related Health-system-related Condition-related	<i>Recommended self-care practices:</i> Dressing changes (10) Checking of feet (5) Wearing offloading device (3) Ensuring cleanliness (6) Moisturizing (7) Preventing excessive moisture (4) <i>Alternative self-care practices:</i> Fingers to check (2)
2. Reliance on care support	Social and economic	Dependent on caregivers (6) Partially dependent (4) Independent (1)
3. Motivations for self-care	Social and economic Therapy-related Patient-related factors	<i>Aim to stay well:</i> Not to lose limb (5) Maintain stable foot ulcer (2) Not attend podiatry appointments (1) Recovery (6) Optimizing day-to-day activities (6)
4. Self-care knowledge and understanding	Therapy-related Patient-related Health-system-related	Clear information from prescribers, but at times confusing (8) Inadequate information (3) Not wearing offloading at all times (8) Wearing soft footwear to "protect" (2) Using antiseptics to clean (3)

Note: *N* = number of participants where this was coded in data analysis. The total within one theme can exceed 11, because some participants provided more than one response within one theme.

"No, no, I take them [offloading device] off and wear slippers around the house." (P10)

"No [I don't check my ulcer frequently], I must say I'm a bit slack with it because the position [...] it's in such a difficult spot." (P11)

In addition, the participants used an array of alternative self-care practices that are not recommended, some with the potential to cause serious harm or complications. For instance, some participants described using their fingers to feel the wound area to determine if it had reduced in size or healed without describing any hygiene measures before or afterwards.

"And I also feel ... to see if there's anything tender, using my fingers." (P2)

Theme 2: Reliance on care support

The second theme identified was reliance on caregivers for self-care. We found a strong reliance on the need for caregivers to provide assistance to adhere to self-care practices. Most participants were dependent on family (mainly their partner) or paid caregivers, who were cited as an "essential

component" in maintaining their self-care practices. Of the six participants who indicated they were completely dependent on caregivers, four suggested they were completely unable to provide any self-care themselves when their caregivers were unavailable. In such instances, those participants described the need to approach other caregivers such as external family members, paid caregivers, or they would even go back to the diabetic foot clinic for simple dressing changes.

"My wife does it all. I just lay down and she looks after it." (P10)

"If it does need a little changing [when caregiver is not around], I'll try to arrange to get down here [the diabetic foot clinic]." (P8)

Theme 3: Motivations for self-care

The third identified theme concerned motivations for self-care practices. The notion of "staying well" was a common motivation among participants. This was, however, interpreted differently by participants. For some, staying well meant not having their affected limb amputated, and this was described as their primary motivation for self-care. Others described an

acceptance that returning to a state without a foot ulcer was unlikely and considered staying well as maintaining an uninfected ulcer. The third notion of staying well concerned participants pointing to actual recovery as their motivator.

"Trying not to lose another toe. I don't want to lose any more past my foot. I want to try to keep them all." (P6)
"I'd be happy if I just get check-ups in order to maintain it... I don't think I can ever get to the point where it will disappear completely." (P5)
"I'm going for a kidney transplant and naturally the ulcer has to be healed before that." (P11)

Apart from the aim to stay well, another motivator was optimizing day-to-day activities. This was described by participants as wishing to restart their day-to-day routines through hobbies, work, and family activities.

"I want to be able to run around with my family and do things. I want to be able to work." (P3)
"The hassle is that you can't just go swimming with your kids, like you know, at the beach? Which you want." (P8)

Theme 4: Self-care knowledge and understanding

The last theme concerned self-care knowledge and understanding, where we found a disparity between the two. Most participants reported to possess self-care knowledge, but from the interviews it became clear that this understanding was predominantly related to dressing changes. For other aspects of self-care it was often missing or inadequate, especially when related to offloading.

"You should never be walking around barefoot. So even when I'm upstairs, that's why I keep a pair of socks on." (P8)
"Well, in terms of offloading, I put a bandage on my foot to offload pressure" (P7)

Participants had received their self-care information predominantly from their health-care practitioner, and when asked directly they indicated they perceived the information as clear and adequate, and they described a trusting relationship. However, participants also described receiving confusing and conflicting self-care information. Potential areas of confusion included the type of wound dressing or moisturizer to be applied and, again, appropriate offloading.

"...people here are saying that I really should have an open sandal [i.e.: post-operative sandal] but all the other information on diabetes and particularly with neuropathy, you should wear closed-in shoes..." (P2)
"I don't understand what they meant when the podiatrist said to me – 'have you got a cast on your foot?' I'm thinking have I got a broken foot? [...] But nobody ever asked me whether I know what it meant by a cast." (P9)

To gain further insight into participants' knowledge, we asked them about the advice they would give other patients in their situation. Most participants cited advice consistent with recommended self-care practices, reflecting adequate knowledge, especially in relation to the frequency of dressing changes and daily foot checks. However, misconceptions and inadequate understanding of proper self-care practices were reflected in participants' descriptions of their adherence to offloading. This was most pronounced in relation to the necessity of wearing offloading devices at all times, as clearly illustrated by this participant:

"I wear it [offloading device] everywhere, everywhere, EVERYWHERE. Everywhere. But well, at home ...I walk around in my socks." (P3)

Section 2: Barriers to self-care adherence

We identified four barriers to self-care adherence. The barriers and their mapping to the WHO dimensions are summarized in Table 3 and described with additional details and quotes to illustrate below. The facilitators identified based on section 2 of the interview were overlapping with the solutions as identified from section 3. We have therefore combined these in section 3, as practical solutions.

Barrier 1: Poor mobility and visibility

Most participants cited that their limited mobility in combination with the location of their ulcer (most often on the plantar surface of their foot) resulted in poor accessibility to and visibility of their ulcer. This limited their ability to check their ulcer and conduct wound-dressing changes themselves.

"The main thing is not being able to actually see under the foot...like I'm just approximately putting it [the dressing] in the position I think it is." (P11)

Barrier 2: Difficulty wearing offloading devices at all times

Another challenge was wearing offloading devices, as they seemed to impose limitations on everyday activity. Participants also experienced complications from wearing offloading devices, as well as some instability while wearing them.

"Like at the moment because of three days a week I'm at college, that's obviously difficult. You can't do that [wear offloading device] there and I'm driving, so it's even harder." (P3)
"Just because of the way my foot is, I'd be rubbing my ankle against the moon boot ... then we'll start the whole thing over again." (P7)

Barrier 3: Difficulty with using wound dressings

Having to use wound dressings posed challenges, in relation to being able to care for one's foot hygiene (i.e., wound

Table 3. Themes, WHO dimensions, and codes in relation to ‘Barriers to self-care adherence’ (section 2) and ‘Solutions to improve self-care adherence’ (section 3)

Barriers	WHO dimensions	Codes (N)
1. Poor mobility and visibility	Patient-related	Limited mobility (6)
	Condition-related	Ulcer location (9)
2. Difficulty wearing offloading devices at all times	Social and economic	Limited in participation (6)
	Therapy-related	Causing complications (4)
	Patient-related	Difficulties donning/doffing (1)
	Health-system-related	
	Condition-related	
3. Difficulty with using wound dressings	Social and economic	Shower adaptations (3)
	Therapy-related	Keeping dressing in place (3)
	Patient-related	Purchasing dressings (2)
	Health-system-related	Availability of dressings (1)
4. Frustration with lack of progress	Therapy-related	Chronicity of ulcer (3)
	Patient-related	Frustration with caring (3)
	Condition-related	
Solutions		
1. Integrating self-care as daily routine	Therapy-related	Make it a routine (7)
	Patient-related	
	Condition-related	
2. Better education	Therapy-related	Education for carers (3)
		Support dressing packs (1)
3. External help	Social and economic	More informal caregivers (5)
	Health-system-related	Better access to paid caregivers (3)
4. Improving visualization of and accessibility to the ulcer	Social and economic	Involving family members (5)
	Therapy-related	Use aids (3)
	Patient-related	

Note: N = number of participants where this was coded in data analysis.

dressing needs to stay dry while showering), with keeping the dressing in the correct place at the location of the foot ulcer, but also socioeconomically in purchasing or in the numbers available to them.

“So, keep the foot dry – so the foot can go into a plastic bag. Tape it up, bend it over and then you roll (over) the top so that (there are) no seepages.” (P9)

“We had a lot of problems with them [wound dressings] coming off all the time, because it’s in high pressure zone... by the time I got home, the one they had put on had fallen off.” (P3)

Barrier 4: Frustration with lack of progress

The last challenge identified was participants’ frustration with the lack of progress despite being adherent to self-care. This was described mostly in terms of the chronicity of their wound. This lack of progress threatened longer term adherence, especially in participants feeling they were adhering to all self-care practices in addition to regular podiatry visits.

“I try to be positive but there was a period when I was really frustrated about it and upset. Because every time the dressing came off, [the ulcer] got worse.” (P2)

“...I was coming here every week and I just wasn’t getting any better. I was staying off my feet like I was told and I was getting annoyed with it.” (P3)

Section 3: Solutions to improve self-care adherence

We identified four practical solutions to improve self-care adherence. The solutions and their mapping to the WHO dimensions are summarized in Table 3 and described with additional details and quotes to illustrate below.

Solution 1: Integrating self-care as daily routine

The first solution to improve adherence described was the importance of integrating self-care into their daily routine, allowing participants to keep on top of self-care practices. Many participants identified that self-care should be seen as being similar to bathing or brushing one’s teeth.

"It's a case of I've gotta get in and do it, and that's what I do. So it's kind of a routine... yeah it becomes more automated." (P5)

Solution 2: Better education

Several participants cited the importance of routine advice and education on recommended self-care practices for themselves and their caregivers, and pointed to a lack of education available. A participant suggested the development of "support dressing packs" (including education on how to use it), to assist in wound-dressing changes.

"They could ... maybe offer some training. You know, to the spouse or person who's going to do it and show them how to do the dressings and the changes." (P8)

Solution 3: External help

With strong reliance on caregivers to provide self-care, external help was a priority for many participants. Increasing the number of informal caregivers (family or friends), as well as access to paid caregivers (in the form of domiciliary visits), were identified as key solutions to being adherent to self-care.

"You can get nurses in the home who come every second day to my house to do my dressing." (P7)

Solution 4: Improving visualization of and accessibility to the ulcer

With the challenge of limited visibility of the ulcer (challenge 1), several methods were suggested as solutions to improve visualization of and accessibility to the foot ulcer. Some methods focused solely on the participant and involved simple tools, while others indicated better involvement of caregivers would be the solution.

"I use a mirror if I'm concerned, just to see generally the foot where I had the amputation." (P5)
"...you've got to get someone else involved ... The practice here, or your partner or wife, or best friend... just to make sure it's not getting any worse." (P7)

Different self-care categories of participants

While coding, we identified that participants' behavior could be categorized into two discrete groups in relation to their (non-)adherence: behavior indicating a lack of awareness of appropriate self-care practices (participants with codes primarily in relation to theme 4, barrier 1 and solutions 2 and 4), and behavior indicating a lack of motivation in following through with self-care practices (participants with codes primarily in relation to theme 3, barrier 4 and solution 3). The first group primarily consisted of participants describing a poor understanding of what appropriate self-care actually

was, but had a motivation to adhere to these if they knew what they were. The second group consisted of participants who were unable and unwilling to perform the self-care themselves. These were the participants who were frustrated with their lack of progress, for whom their foot ulcer was only a small part of their disease, or who perceived the inconveniences of self-care outweighed any (future) benefits of expedited healing. We identified barriers to self-care adherence in the first group concerning therapy-related factors (complexity of treatment) and patient-related factors (knowledge and skills), while for the second group, it was a combination of all five WHO dimensions.

DISCUSSION

While the importance of adherence in diabetic foot ulcer care is widely acknowledged in clinical practice, research in this field remains limited.¹⁹ As a result, there is no guidance available for the clinicians to improve adherence in daily clinical practice.²¹ From our qualitative study, we found that adherence to recommended diabetic foot ulcer self-care was limited at best, and factors from all WHO domains seemed to play a role. The findings from this study confirm that adherence is a multidimensional phenomenon.¹⁰ To improve self-care adherence, multidimensional interventions may be needed, depending on an individual's situation. In clinical practice, this could start by considering the relevance of each of the five domains of the WHO adherence framework for an individual, to determine the most pressing domains and the most readily available solutions to improve their self-care adherence. As an example of such a structured assessment, we will relate our findings in this discussion to the WHO adherence domains, as well as the broader literature.

Social and economic factors play a major role in diabetic foot ulcer self-care adherence and this takes various forms. The most important here is the reliance of patients on caregivers for their self-care, in line with experiences described in another study.⁹ The personal circumstances of patients should therefore always be taken into account and access to paid caregivers should be improved. Another economic factor was the burden caused by the necessity of wearing offloading devices at all times. This could take extreme forms, as described previously in a case report where a patient chose to undergo early major amputation over prolonged offloading with the chance of ulcer healing in order to facilitate quick return to work.³⁰ Developing offloading devices suitable for various jobs may positively influence adherence.

Therapy-related factors concern the complexity and longevity of diabetic foot ulcer self-care. Rather than one action, recommended self-care consists of multiple parts, and all need to be performed daily and over long periods of time. This has been described in another study as "extremely difficult."⁹ Our findings partly confirm this, but take the research one step further by also describing facilitators and participants' solutions to this barrier. However, it is important to realize, for both researchers and clinicians, that this is an additional task, implied by the presence of the foot ulcer, on patients who are already caring in a complex and erratic environment.³¹ Of the various therapy-related factors, we found adherence especially challenged in relation to wearing offloading devices. The role of instability, as recently identified by Crews and colleagues,¹⁴ was confirmed in our study. Even

more striking was participants' limited understanding of the need to wear offloading at all times, especially at and around home. This is in line with studies on preventative footwear, where adherence at home was significantly lower compared to outside the house.³² When educating people with a diabetic foot ulcer, clinicians should ensure that the person actually understands the education.¹³ Furthermore, the development of specific home-offloading devices to improve adherence could be undertaken in future research.

Patient-related factors identified concern their understanding, skills, and motivation in self-care adherence. Skills to perform self-care can be challenging with the limited visibility and accessibility of one's foot. Tools to better visualize the plantar portion of the foot, for example with dedicated smartphone photos and applications,²⁷ need to be developed in future research. Motivation to adhere to self-care was often related to negative goals, such as a fear of amputation, and based on a biomedical model of illness. Participants more often described their foot ulcer and avoiding potential infection, hospitalization or amputation than social or familial factors as motivators. This might explain the frustration expressed by participants, as negative goal-setting can be harder to maintain. In clinical practice, it could be worthwhile for clinicians to not stress the negatives and increase the fear of amputation, but rather focus on patients' social or familial goals, and emphasize these during the course of treatment.

Health-system-related factors concern the availability and reimbursement of dressings and offloading devices, as well as the education provided by the practitioners. Regarding the first, it is important to note that the diabetic foot ulcer population is often experiencing financial challenges,^{17,33} as indeed described by some of the participants in this study. All essential components of self-care should be made available to patients, as the long term consequences of amputation are much more expensive and healing of foot ulcers is not only cost-effective, but cost-saving.³⁴ The health-system should also facilitate the education of individuals and, probably even more important, their carers. The confidence expressed in clinicians by participants in this study also stresses an important route to improve adherence via the health-system, as others have shown that the quality of the relationship between patients and providers of care correlates with adherence.¹⁰

Finally, condition-related factors were seen in the comorbidities people have to deal with that hinder their self-care, and in the large number of self-care practices they already need to perform on a daily basis.

Overarching from the themes and domains, we could categorize participants' behavior in two groups: behavior indicating a lack of awareness and behavior indicating a lack of motivation. The first group seemed to have an inadequate understanding of the self-care information presented to them, which could have undesirable influences on wound-healing outcomes.^{12,35} The second group appeared to resist self-care recommendations owing to a repertoire of factors encompassing biomedical, social, and psychological aspects. For these patients, interventions based on motivational interviewing may be an important avenue to pursue in future research and practice.³⁶ However, more research is needed to pinpoint if this categorization is reflective in the population.

This study was limited by its qualitative design, and the results should be seen as hypothesis-generating, not testing.²⁶ Another limitation was participant selection. As this was a

qualitative study, we did not aim for a representative population of participants. Compared to an average population of people with diabetic foot disease, we had an overrepresentation of people with type 1 diabetes, while we did not include immigrants or people identifying themselves as indigenous.³⁷ Furthermore, all included participants were diagnosed with peripheral neuropathy. While the majority of people with diabetic foot ulcers have neuropathy,⁶ the missing ability to feel their feet may cause specific patterns of (non-)adherence. The conclusions from the current study are therefore specifically applicable to those people with neuropathy only. We were also limited by not doing a formal assessment of health literacy and socioeconomic status of quality of life.

For clinical practice, the findings of this study mean the following: As stressed by the WHO, people cannot be seen as solely responsible for taking their treatment: social, economic, and health-system factors all affect their behavior and capacity to adhere to diabetic foot ulcer self-care. People's ability to adhere to mutually agreed treatment as optimally as possible is compromised by multiple barriers. To improve adherence, and thereby improve ulcer healing outcomes, it is important that all factors and barriers are considered when discussing adherence with a patient, and that all are studied when investigating adherence-improving interventions.¹⁰ Development of a framework to assist clinicians in structured assessment would be a good first step toward adherence-improving interventions. Until such a framework or specific interventions are developed, we recommend clinicians support their patients in trying to address and remove any barriers to treatment adherence. Clinicians can focus their education on clear and simple messages, tailored to the individual.¹³ It is important to check whether these messages have been truly understood, which goes beyond a person's ability to reproduce the knowledge.¹³ And while clinicians may not change a person's social or economic situation, it is important to know what access to care your patient has when away from the clinic.

In conclusion, we found that adherence to recommended diabetic foot ulcer self-care was limited at best, and reasons for nonadherence were multidimensional. Based on the barriers and solutions described, we suggest clinicians obtain a broad overview of their patient's situation to improve self-care adherence, including their mobility and visibility, their social situation and the presence or absence of external help, and their difficulties with wearing offloading devices and using wound dressings. Using structural assessment of these factors related to self-care adherence, clinicians may assist people with a diabetic foot ulcer in finding solutions to improve their adherence, and thereby also improving their ulcer healing outcomes.

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CONFLICTS OF INTEREST

The authors declare that they have no conflict of interest.

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APPENDIX

Semistructured interview guide used in the study “Reasons for (non-)adherence to self-care in people with a diabetic foot ulcer”

INTRODUCTION

- i. Welcome and thank participant for taking time to come for interview
- ii. Introduce researcher
- iii. Discuss aims of interview:
 - a. Learn how patients care for their foot ulcer away from the clinic and obtain ideas on how we can improve patient’s management
 - b. Get feedback on a prototype mobile app
- iv. Ground rules:
 - a. No right or wrong answers, just opinions, and experiences
 - b. Honest feedback on mobile app prototype, be critical, not about agreeing - > I want to understand if this is something that would work for you
 - c. Phones on silent
- v. Mention that clearance has been received from ethics and for patient to read and sign consent form.
- vi. Before we start, do you have any questions about this study?
- vii. Is it ok to start recording?
- viii. Ask about demographic details: age, occupation, education level, living situation (alone or with someone else), type I or II diabetes and effects of diabetes (e.g. peripheral neuropathy).

SECTION 1: CURRENT SELF-CARE PRACTICES

1. How long have you had your foot ulcer for?
2. What is your aim? What would you like the foot to be in 6 months?
3. Can you please tell me about what you do at home to care for your feet and foot ulcer?
4. Do you think diabetes is related to your foot wound?
5. Does anyone help you in your ulcer care? How do they assist you in your care? Probe more: What do you do if your carer is not available? Would you still do it yourself or leave it (i.e., the dressing) there?

6. Can you talk to me about what you did to your foot yesterday? When you last changed the dressing/wore the offloading device ...? Can you talk to me about it? Is this how you normally do it? Probe probes: Do you wear an offloading device (“special footwear provided by your clinician”)? If not, are you aware of it? Why do you not wear it?
7. What do you know about caring for your feet and foot ulcer at home?
8. Is there any information about caring for your feet and foot ulcer you find confusing? In what way?
9. Is there anything you do that helps you most with your foot ulcer care?
10. Have your health-care practitioners informed you about foot ulcer care away from the clinic? Possible probe: What do you think about the information?
11. Has your foot ulcer self-care changed over the course of having your foot ulcer? Could you elaborate?

SECTION 2: BARRIERS TO AND FACILITATORS OF SELF-CARE

1. You mentioned ... as a barrier/facilitator, can you tell me more about this?
2. What other difficulties or barriers do you have at home when you change your dressing/wear offloading device/...? What did you do to address this challenge?
3. How would you describe your experience caring for your foot ulcer?
4. What would you say are some struggles that you currently face in daily diabetic foot ulcer selfcare?
5. You mentioned earlier that you had some negative experiences caring for your foot ulcer. Would you care to elaborate? What is happening now in your care? Possible probe: for example, if patient has to take time off work, how has this affected the patient then? What has your foot ulcer care prevented you from doing or participating in?
6. You mentioned earlier that you had some positive experiences caring for your foot ulcer. Would you care to elaborate? What is happening now in your care?

SECTION 3: PERSONAL IDEAS ON STRENGTHENING TREATMENT ADHERENCE

1. What can clinicians do to make it easier for you to adhere to your treatment?
2. Is there any advice you would give to a fellow diabetic foot ulcer patient on how to care for their feet and ulcer?
3. What are some of your motivations for adhering to treatment?
4. You mentioned _____ as a barrier. What would be some solutions to overcome that barrier?
5. You mentioned _____ as a positive experience. What could be done to strengthen that experience?
6. You mentioned _____ as a negative experience. How could it have been done differently?