

ORIGINAL ARTICLE

Exploring barriers and enablers of self-management behaviours in patients with diabetic foot ulcers: A qualitative study from the perceptions of patients, caregivers, and healthcare professionals in primary care

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Key Messages

- diabetic foot ulcers (DFUs) are complex and costly and will continue to be highly prevalent. Self-management is the cornerstone of preventing and delaying diabetic foot ulcer (DFUs). Yet, multifaceted factors impeding DFU self-management are unclear
- this study shows in-depth accounts of 28 key stakeholders (including patients, their family caregivers, and healthcare providers) perceptions of DFU self-management
- self-management behaviour is a multidimensional phenomenon, determined by the dynamic interplay of multifaceted factors related to personal beliefs, the healthcare system, relational and community societal factors, in which low personal beliefs including lack of control over ulceration and treatment, disease fatigue, and the low perceived threat of consequences, are the key individual barriers to DFU self-management. Poor patient-practitioner communication, financial constraints, and social stigma also hinder foot self-care practices. Motivation through personalised care, and family and community social support are the key enablers to facilitating DFU self-management behaviours
- the findings can be used to develop interventions for improving self-management for DFU management and prevention

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1 | INTRODUCTION

Diabetes mellitus (DM) is a serious threat to global health and diabetic foot ulcers (DFU) remains one of the most common complications of DM¹ affecting around 20 million people annually.² DFUs are complex to treat, take months or years to heal, and the recurrence rates remain high up to 40% within 1 year of healing.³ People with DFUs are at risk of prolonged healing times and hospitalisation, reduced quality of life^{4,5} and higher five-year mortality rates.³ Moreover, DFU is a causal factor for up to 85% of patients with diabetes who subsequently undergo lower extremity amputation^{3,6} and is a leading cause of global disability.² Singapore has the highest rate of diabetic lower extremity amputation (DLEA) in the world⁷ because of DFU and the trend is increasing.⁸ Additionally, DFU is a substantial clinical and economic burden to health systems in Singapore with escalating healthcare costs corresponding to more proximal amputation levels and high re-admission rates.⁹ Thus, understanding barriers to managing DFU is vital for improving patient care.

The vast majority of DFUs and DLEAs are preventable¹⁰ and failures or delays in timely treatment or self-care especially could explain the increasing trends. Foot self-care is pivotal to preventing DFU recurrence and reducing the rates of DLEAs,^{3,11-13} but it is often ignored.^{14,15} While important, education about foot care alone is often insufficient in improving self-care and preventing DFU recurrence.^{16,17} Patient-related cognitive and emotional factors, especially illness perceptions, are key determinants in facilitating or hindering appropriate foot self-care behaviours.^{18,19} A qualitative meta-synthesis review found that patients with DFU often presented poor understanding and low perceived risk for DFU, low perceived control over DFU occurrence, and inconsistent engagement in foot self-care.¹⁸ Misperceptions of DFU arise when patients have poor awareness of DFU presentation, causes of DFU and the consequences of poorly-managed DFU.¹⁸ Holding beliefs about diabetes, such as low control or influence on ulceration, are associated with poor engagement with self-care in DFU,²⁰ and has also been shown to adversely affect survival.²¹ A lack of perceived control in preventing further DFUs is related to the emotional and behavioural responses of individuals living with the threat of re-ulceration.²² Patients' perceptions of managing DFU may also differ from the standard of care guideline recommendations despite the perceived benefits of self-management.

Besides patient-related factors, system-level or healthcare provider (HCP)-related factors are equally important. Empathetic patient-provider communication characterised by sensitivity and rapport promotes openness and adherence

to self-care while insensitive communication has been found to increase patient dissatisfaction and lead to worse clinical outcomes.¹⁸ There is substantial discordance between patient and practitioner's impressions and expectations of foot self-care and significant gaps and barriers in the way foot-care recommendations are communicated to patients with diabetes in the clinical environment.²³ Prior studies, however, only included HCPs in tertiary care settings and focused on patients with diabetes without foot ulcer.^{24,25} Patients with DFU are predominantly cared for in primary care settings. It is therefore important to consider the needs and perspectives of primary care HCPs in DFU care in order to address barriers and improve patient adherence to recommended foot self-care practices.

Studies to understand DFU recurrence are relatively few and focused almost exclusively on patients' perspectives.¹⁸ Less emphasis has been placed on understanding the needs of family caregivers who are often involved in the DFU treatment process. Family caregivers support patients with DM self-care by administering treatment and rendering practical assistance (such as wound care or transport), promoting/encouraging patients' self-care and foot care behaviours through reminders and monitoring, synthesising, and communicating health information, and giving emotional support.²⁶⁻²⁸ The diverse and central roles that caregivers play in the patients' care underlie the complex and reciprocal influence between patients and caregivers. However, the perspectives of family caregivers and the interdependence of the two partners (patient and caregiver) are not well understood in DFU care.

Previous studies to understand the relationship between illness/health perception and DFU care and self-management behaviours mostly used quantitative methods.^{20,21,29} Qualitative research is well placed to understand how individuals experience and respond to particular situations and conditions regarding health and illness.³⁰ However, there is a paucity of qualitative research on illness perceptions and the interplay of individuals (patient-caregiver dyads) and system-level and HCPs factors regarding self-care behaviour in improving DFU care in primary care. Existing studies largely focused on patients with diabetes³¹⁻³⁷ rather than those with active DFUs. The findings from these studies cannot be extrapolated to patients with DFU as the perceptions of foot self-care behaviour may differ between patients with and without prior DFU. The interdependent perceptions in self-management of patients, their family caregivers, and HCPs are not well understood in DFU care. Several studies only reported the barriers to foot self-management from HCPs' perspectives alone.^{24,38,39} The perceptions of self-management behaviour among patients, caregivers, and HCPs may vary significantly.

This study aimed to understand the barriers and enablers of managing DFU from the perceptions of various stakeholders in order to identify the potentially modifiable factors associated with suboptimal DFU care. These modifiable individual and/or dyadic factors could inform the development of tailored interventions or refinement of existing diabetes services in primary care.

2 | MATERIALS AND METHODS

2.1 | Study design

This study used a descriptive qualitative research design. We conducted individual interviews with patients with active DFU and their caregivers. We also conducted focus group discussions (FGDs) with HCPs who were involved in DFU care in the primary care setting.

2.2 | Ethics statement

Ethical approval for this study was provided by The National Healthcare Group Domain Specific Review Board ethics committee (Ref No. 2021/01074) and the Nanyang Technological University Institutional Review Board (Ref No. NTU IRB-2022-338).

2.3 | Sampling and recruitment

Purposeful maximum variation sampling was used to identify participants for the study from seven general primary care clinics between April and July 2022. These seven clinics serve the population in the central and northern parts of Singapore. We purposively sampled patients with active DFU to include individuals of different ages, genders, ethnicities, educational backgrounds, time since diagnoses, and other clinical baselines. Caregivers were sampled including spouses and children to gain an understanding of the barriers to DFU care from a wide variety of angles and provide a holistic view of DFU care. HCPs selected were those who were directly involved in the care of patients with DFU while trying to achieve a diverse representation among the various professions, for example, family physician, wound nurse, and podiatrist.

Patients and caregivers were recruited subject to the following inclusion criteria: age 21 years old and above; with active DFU receiving care in primary care settings (patients only) or providing/supporting care for a person with DFU (caregivers only), conversant in either English or Chinese. Those unable to give consent because of

cognitive or psychiatric diagnoses or only fluent in dialects were excluded. Inclusion criteria for HCPs were those providing care or consultation to patients with DFU at the primary care clinics for at least 6 months. Members of the research team and HCPs who do not provide care for DFU (eg, pharmacists and laboratory technicians) were excluded.

2.4 | Interview guide

Three interview guides were developed for the three stakeholder groups based on relevant literature and expert inputs (see Appendix A). They comprised non-directive, open-ended questions on the following topics: perceptions and experiences of DFU, understanding DFU treatment, challenges/concerns, emotions regarding DFU, needs/resources, and patient's behavioural responses. The interview questions were pilot tested on one participant of each group prior to the actual interviews. Questions and prompts were refined iteratively to enable topics that have not been previously identified to be pursued in subsequent interviews.

2.5 | Data collection

Informed consent was obtained prior to data collection. The face-to-face individual interviews were conducted in a private consultation room within the patient participant's primary clinic for DFU treatment by one interviewer who had prior experience in qualitative methodology and was effective in conducting semi-structured interviews in both English and Mandarin. Each interview lasted between 35 and 60 min with an average time of 45 min. Participants' sociodemographic and clinical characteristics were documented. Recruitment for individual interviews was stopped upon thematic saturation. Thematic saturation was accomplished when themes and subcategories in the data became repetitive and redundant such that no new information could be gathered by further data collection.

Two virtual FGDs (up to 90 min each) were conducted in English with two different groups of HCPs using a flexible topic guide with prompts. The zoom videoconferencing platform was used and FGDs were led by two facilitators: a senior researcher (KG) who has considerable expertise in qualitative methodologies and an HCP who has wound care experience and prior qualitative health services research. There was no prior relationship between the interviewers and interviewees for both individual interviews and FGDs. Field memos were kept during interviews and FGDs to record situations, ambience, and non-verbal communications, as well as the interviewer's thoughts, analytical notes,

and any potential biases. Care was taken to clarify points raised by all participants during each interview and verbal verification with each participant on the main points that the participants had shared during the interviews.

2.6 | Data analysis

Each interview and FGD was transcribed verbatim. The accuracy of the transcripts and translations (from Chinese to English) were verified by comparing them against the recordings. Transcripts were not returned to the participants for comments. Data from transcripts were analysed discursively using reflexive thematic analysis⁴⁰ and dyadic analysis⁴¹ and by exploring multiple perspectives on single events, rather than a single account. The analysis first took place at an individual level, and then at a dyadic level. Individual analyses are descriptive, moving to interpretive according to reflexive thematic and six-phase analytical process (ie, familiarisation with the data, generating initial codes/themes, reviewing/defining/naming themes, and producing report)⁴² as a set of guidelines, rather than rules, that were applied in a flexible manner to fit the data and the research questions.⁴⁰ Dyadic codes/summaries were created based on the codes/summaries for the individual pairs on how each pair addressed a particular problem. Further codes were developed from the dyadic analysis that reflected the pairs' experiences and needs rather than individual experiences.⁴³ All themes emanating from transcripts/codes/summaries were identified through both an inductive and iterative process. Data analysis began with reading and achieving familiarity with the transcripts for pre-analytical understanding. Next, the transcripts were coded line-by-line inductively and deductively to ensure important aspects of the data were not missed, while efficiently assigning codes using pre-established codes derived from the Social Ecological Model (SEM) framework.⁴⁴

The SEM is a theory-based framework for understanding the multifaceted and interactive effects of personal and environmental factors related to behaviours.⁴⁴ SEM is used as a foundation for planning and understanding the determinants of self-management behaviours in patients with diabetes.^{45,46} Current evidence reveals that the social impact, family, and health system factors of DFU are important factors for the management and prevention of diabetic foot diseases.^{26,47-49} Hence, the SEM framework was used to deductively map barriers and enablers of foot self-care behaviour across multiple levels of the healthcare system, such as individual, healthcare system, relational, and community social-cultural levels. The rationale for this framework application was to provide us with a robust platform to enable further exploration of factors that influence the adoption

of the findings across micro (individual), meso (healthcare system), and macro (relational and social-cultural) levels.

2.7 | Researcher's positionality and 'reflective lenses'

The researcher is a Senior Wound Nurse Clinician who has been largely involved in the treatment of patients with DFU within the public health primary care sector in Singapore and deals with complex cases of individuals with DFU in the healthcare cluster. The researcher's clinical experiences allow her reflective and thoughtful engagement with the data and the analytic process⁴⁰ to identify the barriers to DFU care and potentially modifiable targets for care intervention.

2.8 | Methodological rigour

Rigour was ensured through attention to study credibility, confirmability and dependability, and transferability.⁵⁰ Credibility was supported by the fact that the principal investigator (ZX) is a wound care nurse specialist and has long-term ongoing interactions and practical experience in caring for patients with DFU. She is thus familiar with issues faced by patients and their care processes. Additionally, the other researchers had prolonged engagement with the topic and used reflexive thematic data analyses. Regular study team debriefing was also conducted to improve the data analysis process. Confirmability was enhanced by the continual documentation of field notes and verification of transcripts and findings by the researchers. Dependability was achieved by having team members (ZX and PL) participate in the analysis process and identify similarities to enhance findings. Any disagreements were resolved with a third person until a consensus was reached. Transferability was supported through a detailed description of the study participants and the use of verbatim quotes to support themes. The findings are reported according to the consolidated criteria for reporting qualitative research (COREQ) guidelines.⁵¹

3 | RESULTS

3.1 | Participants' characteristics and sociodemographic

Twenty-eight individuals participated in the study including fifteen patients with active DFU, five family caregivers, and eight HCPs who consisted of three senior family

physicians, four wound care nurses, and one podiatrist. Five eligible patients declined to participate in the interview because of work/personal commitments after wound care in the clinic. No one dropped out of the study after the interviews were completed. The characteristics and sociodemographic information of all the participants are presented in Tables 1–3. Of the fifteen patient participants, the average age was 64.5 years; the average duration of diabetes was 22.7 years; the average duration of DFU was 6.5 months. All patient participants had a history of previous DFU, and up to 80.0% of them had a history of previous amputation. Toe ulcers made up 66.7% while plantar ulcers constituted 33.3% of the sample. The percentages of neuropathic DFU, neuro-ischaemic DFU, and ischaemic DFU were 60.0%, 33.3%, and 6.7% respectively.

3.2 | Summary of themes

The codes derived were organised into three interlinked superordinate themes based on the SEM. The first theme was those factors related to the barriers and enablers around the individual micro level, followed by the healthcare system meso level, and the macro level related to wider relational and community/society. The three superordinate themes were individual perceptions, healthcare system influences, and relational and community societal factors. The nine subthemes across micro- to macro-levels comprised six barriers (eg, lack of control over ulceration and treatment, disease fatigue, perceived low threat of consequences, poor patient-practitioner communication, financial concerns, and perceived social stigma) and three enablers (eg, motivation through personalised care, family support, and community social support). The interdependent superordinate themes and subthemes on barriers and enablers of managing DFU embedded in the SEM framework are displayed in Figure 1.

3.3 | Superordinate themes and subthemes

3.3.1 | Superordinate theme 1: Individual perceptions (micro-level)

Subtheme: Lack of control over ulceration and treatment (barrier)

The complexity of DFU resulted in a lack of perceived control over oneself to manage DFU which adversely affected patients' physical and emotional well-being. The experiences of living with DFU and heightened risks for amputation were viewed as uncontrollable. The constant threat of lower limb amputation made patients feel

distressed/powerless which ultimately impeded treatment adherence.

...My toe turned black... it's bad control of diabetes! It goes also to the clinic then referred me to hospital then said to chop off the thing. I was not in a good mental place during the time. I did not go to see doctor, even though I'm supposed to. It's self-destructing. I totally like gave up on myself... (Andy).

Patient participants with multiple episodes of re-ulceration and re-amputation expressed very low confidence in preventing their feet from getting DFU and viewed DFU as unpredictable. They felt vulnerable and powerless to manage DFUs and reported being overwhelmed by prolonged wound healing and frequent recurrence of DFUs. Lack of control over the DFU appearance and outcomes made both patients with DFU and caregivers harbour strong feelings of anxiety and worry about DFU prognosis, complications, and possible amputations and feel discouraged about foot self-care as healing and controls seemed elusive and non-feasible. Negative experiences (ie, fear, anxiety, and stress) might affect one's decision making in performing self-care.

..... they (foot ulcers) come on their own and cannot be prevented! If it (ulcer) wants to come, it will come. If it wants to turn badly, it'll turn out very badly. It cannot be prevented; it's been about 15 years, on and off... I am very worried about my wound if it will get worse, any broken skin. If it relapses, that's very horrible... Sometimes there are blisters... then fluid comes out became a wound, no choice! ... (sigh...). (Mary). ... we never know when it (ulcer) comes back. I cannot do anything... so many years... the only option was to bring her to see a doctor. I could only rely on the doctor, no choice! (sigh...) (Mary's husband).

HCPs commented how the low control over healing, made a motivation to follow self-care low as efforts seemed futile and unproductive.

... because they already thought their wound is becoming the biggest trouble and challenge in their life. I feel like, instead of coping (with it), they are trying to run away from it. (HCP3).

Subtheme: Disease fatigue (barrier)

The couple participants recounted feeling fatigued because of the complex unpredictable prognosis of their

TABLE 1 Characteristics of patients with active diabetic foot ulcers who participated in individual interviews (N = 15).

Patient name ^a	Age	Race	Gender	Marital status	Highest education level	Employment	Occupation (if retired or unemployed, note last employment)	Duration of DM (years)	Duration of DFU (months)	History of DFU	History/Level of Amputation	Location of Wound	Type of DFU ^c
John	62	Indian	Male	Married	Secondary school	Retired	Security officer	30	13	Yes	Yes, transmetatarsal	Plantar and transtatarsal head	Neuropathic DFU
Tan	64	Chinese	Male	Divorced	Primary school	Unemployed	Electrician	14	3	Yes	Yes, toe	Toe post-amputation site	Neuropathic DFU
Steve	70	Malay	Male	Married	Secondary school	Unemployed	Taxi driver	35	24	Yes	Yes, left BKA**	Toe	Neuropathic DFU
Rahim	55	Malay	Male	Married	Secondary school	Unemployed	Taxi coordinator	10	2	Yes	Yes, Toe	Plantar and metatarsal head	Neuropathic DFU
Andy	46	Chinese	Male	Single	Junior College	Employed	Video editor	8	3.5	Yes	Yes, toe	Toe	Neuro-vascular DFU
Sophie	63	Chinese	Female	Married	Primary school	Unemployed	Coffee shop assistant	40	2	Yes	Yes, toe	Toe	Neuropathic DFU
Mary	71	Chinese	Female	Married	Primary school	Unemployed	Housewife	21	2	Yes	Yes, right BKA ^b	Toe	Neuro-vascular DFU
Quek	70	Chinese	Male	Married	Primary school	Retired	Driver	23	2	Yes	Yes, toe	Toe	Neuro-vascular DFU
Mike	56	Chinese	Male	Single	Primary school	Unemployed	Security manager	22	4	Yes	Yes, toes	Toe	Ischaemic DFU
Wilson	73	Indian	Male	Married	Primary school	Employed	Cleaner	30	4	Yes	No	Plantar	Neuropathic DFU
Robert	58	Indian	Male	Married	Primary school	Employed	Security manager	21	6	Yes	Yes, toe	Plantar	Neuropathic DFU
Tina	59	Malay	Female	Married	Secondary school	Unemployed	Food company clerk	21	6	Yes	No	Plantar	Neuropathic DFU
George	70	Eurasian	Male	Married	Bachelor	Employed	Security manager	22	24	Yes	Yes, transmetatarsal	Plantar and transtatarsal head	Neuropathic DFU
Cherry	87	Chinese	Female	Married	No formal education	Unemployed	Housewife	21	3	Yes	No	Toe	Neuropathic DFU
Gary	63	Chinese	Male	Married	No formal education	Unemployed	Maintenance worker	22	3	Yes	Yes, toe	Toe post-amputation site	Neuro-vascular DFU

^aPseudonyms were used to preserve the anonymity of the patients.

^bBKA: below-knee amputation.

^cDFU: diabetic foot ulcers.

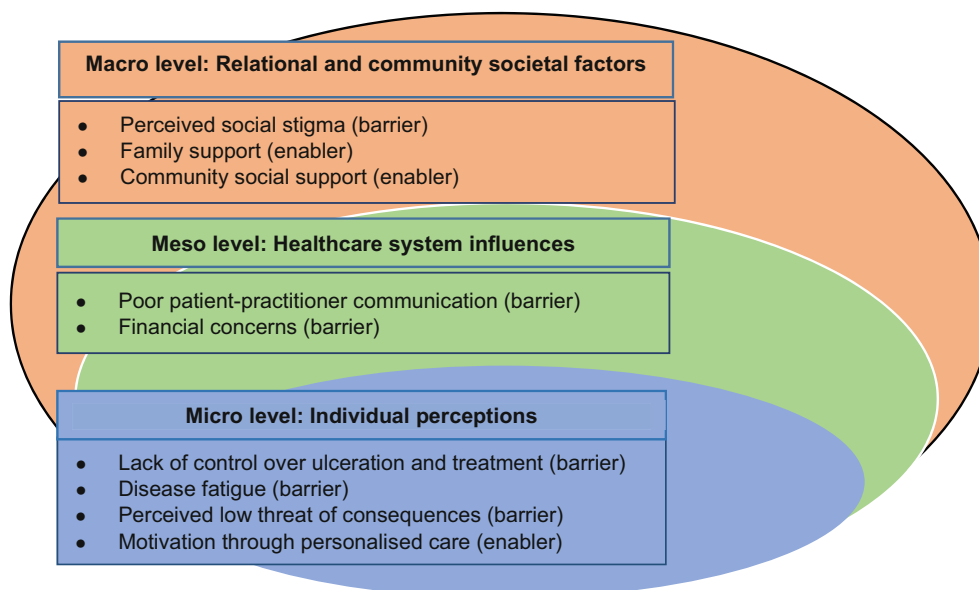
TABLE 2 Characteristics of caregivers of patients with diabetic foot ulcers who participated in individual interviews (N = 5).

Relationship to patient* (pseudonym)	Age	Race	Gender	Employed	Occupation (if retired or unemployed, note last employment)
Steve's wife	66	Malay	Female	Unemployed	Housewife
Mary's husband	74	Chinese	Male	Unemployed	Construction worker
George's wife	44	Chinese	Female	Employed	Retail clerk
Cherry's daughter	65	Chinese	Female	Unemployed	Housewife
Gary's son	27	Chinese	Male	Employed	Clerk of public sector

TABLE 3 Characteristics of HCPs of patients with a diabetic foot ulcers in primary care who participated in focus group interviews (N = 8).

Study ID	Age	Gender	Profession	Years of service in healthcare	Years of service in primary care	Accumulated years of service in taking care of DFU ^a
HCP1	36	Female	Wound nurse	12	5	5
HCP2	40	Female	Wound nurse	16	10	10
HCP3	34	Female	Wound nurse	12	5	5
HCP4	50	Female	Physician	25	19	6
HCP5	37	Male	Physician	12	7	6
HCP6	37	Male	Physician	12	7	7
HCP7	35	Female	Wound nurse	13	6	5
HCP8	37	Male	Podiatrist	13	9	13

^aDFU: diabetic foot ulcers.

**FIGURE 1** The interdependent superordinate themes and subthemes on barriers to and enablers of managing DFU embedded in the Social-Ecological Model across micro- to macro-levels.

wound requiring frequent clinic visits for wound treatment and emotional exhaustion related to slow healing. Some patients with plantar ulcers and multiple episodes of re-ulceration/re-amputation with prolonged healing chose to let go of any efforts or avoided active engagement

in treatment. The unpredictability of their illness treatment left them feeling physically and mentally exhausted resulting in a sense of hopelessness and powerlessness in their future life. They appeared to have low treatment efficacy and were less motivated in participating in active

self-care practices and performing their caregiving role leading to a sense of resignation and disease fatigue.

...controlling diet made me loss appetite and coming for wound dressing made me feel exhausted! I am very worried that I will give up any time. So I'm now very laid back, do whatever I want! ... now is 2 years! I'm losing patience already so you know, I'm like just letting it go... I got no more hope... The most challenging task, activities for self-care is to accept the fact that I need to come back here for wound dressing... (sighs) that is the biggest problem! twice a week, every week. And now it's 2 years! If 2 years that hole cannot heal, I do not see how few months gonna help. Just let it be... (sigh...) (George).

Sometimes I feel exhausted but what to do? I am his wife... His wound has been there for so long... it seems no way to heal... (sigh...) It has been many years facing the challenges and living with him with a longstanding wound with many episodes of recurrence. I am already numb and have no high expectations on him. Whatever will happen, will happen... (George's wife).

Subtheme: Perceived low threat of consequences (barrier)

Patient participants, despite knowing the importance of diabetes and foot self-care, underestimated the seriousness, susceptibility, and threat of the consequences of their health conditions and took risks for non-adherence to treatment advice. Although she was equipped with good knowledge, her low perceived threat of consequences affected her decision-making in good adherence to self-care advice likely because of the chronic nature of DFU leading to low motivation.

Because sometimes like "oh okay," because nothing happened. I knew I got diabetes, I knew I cannot take sugar. But when I drank coffee with sugar, nothing happened, you know my feet are okay. You know my legs and feet do not give me any problems. When I get new wound, it healed. I always said, nothing one [it's nothing], it's okay to drink coffee with sugar... but now I cannot think like that already... (Tina).

HCP participants also shared some patients' 'carefree' attitudes reflecting the perceived low threat of DFU, which subsequently made them view the treatment of

severely infected DFU as a lower own (self) priority despite placing strong demands for urgent DFU care from their HCPs.

"They really do not care! They do not see that this is severe enough. His toe already turned to gangrene and the whole foot become swollen and gangrenous... he does not know what's the priority in their life... the foot already like this but still taking a risk and want to go home to pack their things first instead of going to hospital (emergency department) instantly... (HCP3).

Subtheme: Motivation through personalised care (enabler)

Patient participants raised the importance of personalised consultation(s), trust, and committed relationships with HCPs. They reported that more personalised consultations encouraged them to take an active role in foot self-care. They were very keen to see the same wound nurse not only for wound care but also to get personalised support and/or individualised motivation to live well with their chronic foot conditions.

I'm just hoping that the same wound nurse can continue to dress my wound and motivate me ... The way she works, she wants to make me live. So it makes me very embarrassed that I do not want to live. So if I do not help myself, I'm gonna give her more work. Yes! That's the word, guilty! (George).

HCP participants also felt that DFU services needed more personalisation and to move away from rigid content delivered uniformly for all patients towards a more tailored one that aligns better with patient values and priorities.

I think, instead of pouring more resources into like blanket education, maybe we can look into how we impart that education on self-care... perhaps targeting it and individualising it to that patient. And then harmonising that with what the patient is passionate and motivated about... (HCP6).

Many patient participants felt that simple words of encouragement and affirmation from their HCPs validated their effort(s) on ulcer healing and prevention and made them feel more motivated to keep going.

I just wanted to hear that "hey, your wound is improving!"... I guess the positive outlook

helps us a lot. ...that totally like elevates you from distress. You would not think too negatively, you would not think so depressing, it's like, at least you know it's improving, you'll survive! ... at least, it helped me lift up a bit. So, it's still hope! It's just stick to your strict control of diet control or all these things, there's still hope... (George).

3.3.2 | Superordinate theme 2: Healthcare system influences (Meso-level)

Subtheme: Poor patient-practitioner communication (barrier)

Patient participants expressed frustration and some dissatisfaction with patient-practitioner communication. Negative interactions undermine motivation to self-care and follow treatment recommendations.

... a senior consultant using words like "I hope you get better"! If you hope I get better, then I'm a dead duck. Then she said "why?" You are the doctor, you do not hope I get better, you should make me better!! You know, if you hope then what's left of me? Since then, I've stopped seeing doctors for my diabetes (angry face) ...I feel that doctors should take a course in how to talk to patients! (George).

Patient participants value empathy and emotional connections in their health care interactions. They expressed that empathy from HCPs was key to allowing them to share their concerns so that they can be addressed or at least be understood. This would help them to be more open to considering changes in their behaviours.

... When you talk to your patient, you must touch their heart! If you touch their heart, they will let you know everything. Being patient and showing empathy, you do not need to ask, they will tell you all their story. If you nurse or doctor, do not understand your patients, it's very hard for you to communicate with your patients and have them listen to your advice! (Steve).

Majority of HCP participants noted the limited consultation time as a critical barrier to the in-depth discussion(s) with patients. Empathetic communication was recognised by both patients and HCPs but the latter group felt that in-depth communication was hindered by time restraints.

...there's very little time allocated to see the patients and we do not have sufficient time to evaluate what's happening to the patients... I wish I can do all these on my own and then follow-up on the same patient but...logistically it's not easy because of limited consultation time per patient. Overall, not enough time has been put in for care of patients with diabetic foot ulcers (HCP5).

Subtheme: Financial concerns (barrier)

Many patient participants expressed their concerns and dissatisfaction with the costs of the prescribed off-loading shoes. They described the cost as a financial constraint and barrier which likely hindered their adherence to footwear advice from their HCPs.

(off-loading) shoes are expensive \$200! What is this?! ... I do not understand why they are expensive! Those are basic needs for self-care and should be subsidised! The problem is money... (Tan)

The financial constraint was further confirmed by HCP participants who recounted stories of many of their patients being put off by the high costs of therapeutic footwear.

...Once they found out the price of the off-loading shoes, they got a shock. And then they said... "Oh, maybe this is less priority." They pushed this part (footwear advice) backwards... (HCP8).

3.3.3 | Superordinate theme 3: Relational and societal factors (macro level)

Subtheme: Perceived social stigma (barrier)

Some patient participants expressed that prescribed footwear was ugly and stigmatising. They felt embarrassed and stressed about being judged by people around them because of the prescribed footwear.

I used to wear high heels. Then suddenly I need to change everything. So like, all of a sudden. The doctor advised me, must wear this shoe, recommended this shoe. To me like, "must I wear this? So ugly!" when people look at my shoes, putting away all my shame is not easy... (Tina).

Patient participants felt ashamed and stigmatised to live with diabetes. They were particularly sensitive to

others' judgements about having diabetes. Those social judgements and biases about diabetes and obesity had a negative impact on their mental health and hurt their feelings. The hurtful stigmatisation and the negative perspectives left them feeling tough to internalise it, espousing negative views of themselves. They described that patients with DFU need support from society to improve their self-care behaviours.

I feel diabetes very shameful, "you got diabetes!" You know that kind comments. Diabetes so what? I know my life sucks... I think self-care all these things are like need help from society. It does not help that it's like society treats diabetics like, you go outside, and diabetes is like ostracised and all these things. Because I'm fat. Since I was young I was this size, I was ostracised all the time. It is tough and will take a long time for me to like, do not care about opinions from other people..." (Andy).

Subtheme: Family support (enabler)

As shared by patient participants, their family members were an important source of emotional and practical support in dealing with DFU. Family members took on the responsibility for several tasks for their loved ones especially when patients themselves were no longer able to perform because of their amputation and other medical conditions. This was confirmed by the dyad participants.

I had a problem to reach my foot for daily check-up. My husband helped me take photos of the bottom of my foot and toes and show me the photos for me to check on my foot for any cuts or wounds (Mary).

Reminding her to take medication and her insulin jabs every morning, helping her to take photos of her foot to let her inspect her foot daily... those are my daily routine and I am like her family doctor... she needs my help and emotional support towards her health and self-care (laugh) ... (Mary's husband).

Subtheme: Community social support (enabler)

Positive social influence appeared to be an important determinant of the self-management behaviour of the patient participants we interviewed. Patient participants reflected that the government had provided more support in recent years to empower people with the knowledge and skills to be better informed about how to monitor and care for their diabetes.

...we got plenty of education resources from government and society, newspapers, also TV programs, internet and everything to show us what is diabetes and complications like diabetic foot and how to take care of them. We also got free diabetes health screening in our community..." (Steve).

Patient participants also shared their observations about the positive social influence of healthy living related to diabetes diet advice. This appeared to have a positive impact on lifestyle change towards improved self-management for individuals with diabetes and foot complications.

...healthy living becoming a norm in society ... Suddenly I see a lot of people asking for all these (sugar-free drinks). So I know Singapore is becoming a health conscious country already! Same to the foot self-care... the feet are the most important thing, so wearing shoes is safer, much safer" (Rahim).

4 | DISCUSSION

The recognition of the challenges related to diabetes care has led to the widespread implementation of various support programmes for patients. While these programmes have generally been effective and acceptable by patients,⁵² the rates of adherence to foot care remain sub-optimal and foot care is still not sufficiently prioritised by patients despite the serious repercussions.^{9,15} Most importantly, despite the availability of specialised diabetes care for DFU in primary care in Singapore and other settings, and the timely identification and treatment of individuals with DFU in the community, the incidence of diabetes-related amputation caused by DFU remains alarmingly high.⁵³ To better understand the barriers faced by patients with DFU, this study combined interview data from patients, family caregivers, and HCPs to delineate the barriers faced by patients with DFU so as to identify actionable targets for refinement of existing services and the development of DFU specific interventions in the primary care settings.

Our study findings indicated that perceptual and emotional processes namely the interplay of low perceptions of control, low perceived threat, and disease fatigue hindered patients' DFU management by triggering emotional and physical exhaustion and low motivation to adopt DFU self-care recommendations. Many of the study participants had prior DFU experience with a prolonged journey of DFU care and reported a low perception of control

over ulceration and treatment outcomes. Similar to prior work,^{20-22,36} our participants reported low personal control over ulceration and treatment outcomes. They felt that ulcers were unpredictable and uncontrollable, and recounted their personal or indirect/vicarious experiences of multiple episodes of re-ulceration and/or amputation. The persistent wounds and their poor outcomes fuelled low control perceptions and adversely affected emotional and physical well-being and demotivated their adherence to treatment. Emotional distress and emotional vulnerability were reported which further eroded motivation towards treatment. Most notable was however the link between low control to disengagement from treatment, such as low foot self-care behaviours,^{20,36} which is consistently related to poor prognosis including survival.²¹ The struggle of regaining control after amputation has been highlighted in recent qualitative work.⁵⁴

The intensive and prolonged treatment protocols for DFUs, and the slow healing rate of DFUs not only fuelled low control perceptions but also triggered disease fatigue. Disease fatigue was vividly discussed by all participants, especially among those with plantar/trans-metatarsal head ulcer(s) with prolonged wound healing and multiple recurrence/re-amputations requiring long-term wound care. Fatigue has been studied extensively in the context of chronic diseases⁵⁵ like diabetes,⁵⁶ and more recently in coronavirus infection.⁵⁷ It was thought to comprise of physical, cognitive, and emotional aspects but it is not well understood in relation to DFU. Study findings indicated that disease fatigue was more than physical experience and symptoms and included cognitive and emotional exhaustion with DFU that dampened patients' motivation towards self-management and foot care.

It is of note that although most study participants had a prior history of DFU and/or direct /indirect experience(s) of amputation, the majority of those interviewed reported low perceived threat (eg, severity and/or susceptibility) for the serious complications of DFU which undermined foot self-care as repeatedly shown in previous studies.^{14,20,36,37} It is possible that patients with DFU who typically have multiple comorbidities or even end-stage kidney disease may not view DFU as threatening as other DM complications. As noted by qualitative review, patients often view amputation as a rare DM complication and do not consider wounds as a major cause of concern.¹⁸

Besides individual beliefs and perceptions, interpersonal and system factors were also important. Poor patient-practitioner communication and strained interactions as shared by the study participants discouraged treatment adherence. The importance of empathetic communication and forming emotional connections/rapport with HCP teams have been identified by a recent qualitative meta-synthesis

review¹⁸ as critical for fostering a sense of trust and motivation towards treatment. HCP participants in our study also recognised the value of good communication but often felt disempowered by time constraints.^{48,58} Another interpersonal barrier to DFU care was the perceived stigma, especially with regard to specialised footwear and appearance.^{1,52,53} Patient participants felt embarrassed and worried about being judged for their appearance with customised therapeutic footwear and often chose not to follow the footwear advice increasing the risk for poor healing and re-ulceration. Financial constraints were also noted as costs^{33,48,49,59} related to footwear and transport for foot treatment hinder treatment adherence.

While strained interactions hindered adherence, personalised care emerged as a key enabler. Patients reported that personalised wound care consultations made them feel motivated towards treatment through personalised care. Patients especially noted that seeing the same HCP (eg, wound care nurse) was not only for wound care but also getting personalised support/motivation from the attending HCP to encourage/empower them to live well with their chronic foot conditions. Personalised care approach is the key to the chronic care model and personalised care planning refers to the negotiated discussion (or series of discussions) between a patient and an HCP to clarify goals, options, and preferences to develop an agreed plan of action based on the mutual understanding for self-management improvement.⁶⁰ Personalised care may enhance DFU care through a collaborative process in which the patient and HCP discuss treatment or management goals for self-management improvement.

As consistently documented in the literature,²⁶⁻²⁸ family support was pivotal and family caregivers were identified as the key allies in DFU management. Family caregivers provide both practical assistance and emotional support for patients with DFU.^{26,28} In addition, patients also acknowledged the importance of community social support. Supportive family and community networks may mitigate emotional distress, buffer disease fatigue and enhance patient resources and self-management hence programmes aimed to build or mobilise these networks may be warranted.

A main strength of this study is the triangulation of perspectives of key stakeholders in DFU, that is, patients, their caregivers, and HCPs which allowed a more in-depth understanding of the challenges of DFU management in primary care. In addition, the adoption of SEM theory helped formalised connections across micro to macro levels and the dynamic interplay of various multifaceted factors in DFU. We also conducted explorative dyadic analyses to contrast and combine the perspectives of patient and family caregivers in each dyad. These dyadic analyses hold promise for deepening and

broadening the content, as well as for the trustworthiness of our findings.⁴¹

Finally, a number of limitations need to be considered. Our purposive sampling method did not manage to recruit any patients with first-episode DFU. Further work is needed to understand comprehensively the illness perceptions of patients with new-onset DFU in order to prevent new DFU occurrence. There were a small number of caregiver participants in the study, as most of our patient participants did not have an accompanying caregiver(s) for wound treatment in the participating clinics on the interview day. Future studies should consider conducting interviews in the home of participants as this may allow for greater inclusion of dyad samples compared with the clinical setting.

To our knowledge, this is the first qualitative study conducted in Singapore that revealed the interdependent perceptions of patients, caregivers, and HCPs on DFU self-management in primary care. Low personal beliefs including low personal control over ulceration and treatment, disease fatigue, and the low perceived threat of consequences were the key individual barriers to DFU self-management, particularly for patients with an ulcer with prolonged healing and complex prognosis. Poor patient-practitioner communication, financial constraints, and social stigma also hindered foot self-care practices. Motivation through personalised care, family, and community social support were key enablers to DFU self-management behaviours. The findings can be used to develop interventions for improving self-management capabilities in the context of DFU management and prevention in primary care.

AUTHOR CONTRIBUTIONS

Research idea and study design: Konstadina Griva, Xiaoli Zhu, and Eng Sing Lee; data collection: Xiaoli Zhu and Phoebe X.H. Lim; data analysis/interpretation: Xiaoli Zhu, Phoebe X.H. Lim, and Konstadina Griva; supervision or mentorship: Konstadina Griva and Eng Sing Lee; manuscript drafting and revision: Xiaoli Zhu, Konstadina Griva, Eng Sing Lee, Phoebe X.H. Lim, Yee Chui Chen, and Frederick H. F. Chan.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT


The data that support the findings of this study are available from the corresponding author upon reasonable request.

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APPENDIX A: INTERVIEW GUIDE

A.1 | Interview guide and probing questions for patients with DFU

1. How have you been coping with your daily self-care of living with an active foot ulcer (or a healed ulcer)?
2. What are you currently doing to look after yourself and manage your diabetes self-care? Could you tell me
 - a. Out of all these DM self-care tasks, which one(s) would you say you are doing the best with? (Please tell me more about that...)
 - b. Which/what do you have the most questions or concerns about self-care for diabetes? What are the areas that you feel may need more fine-tuning/some improvement?
3. What about looking after your feet?
 - a. What are you currently doing to look after your feet?
 - b. How important is foot care for you in terms of your diabetes?
4. Could you please share with me about your understanding of diabetes and diabetic foot ulcers (DFU)? Could you please elaborate more on that? For example, what is your perceived susceptibility of DM to DFU or amputation? What is your perceived severity of diabetes and DFU?
5. Please tell me more about your understanding of self-care, for example, self-foot inspection, self-wound care, compliance to treatment advices including oral medication, attending appointments and footwear advice, etc.
6. What are some of your concerns, if any, about your foot care? Any difficulties/challenges you are facing with it? Tell me more... (what makes ... this hard for you?) What are your HCPS worried about ...? What are you worried about?
7. What might help you with your foot care, especially those foot care tasks that may be more difficult/challenging for you?
8. What more do you think others (family and healthcare providers) could do to support you towards better self-care?
9. How (else) could your family/ HCPS support you with your foot care? What are your hopes/expectations?
10. What would make you decide/ think you need to seek treatment and advice for your foot wound? For example, what are the warning signs and symptoms of foot wound deterioration that alert you to seek treatment immediately? When/how/where to seek treatments (eg, immediately after foot skin breaks down)?

11. What do you think you and others could have done to prevent you from developing a new diabetic foot ulcers?

A.2 | Interview guide and probing questions for caregivers (family members) of patients with DFU

1. Please share with me your thoughts on taking care of your relative with a diabetic foot ulcers. Could you please elaborate more on that?
2. Please tell me more about your experiences of supporting your relative with an active or healed DFU. What tasks if any did you support him/her with? For example, self-foot inspection, self-wound care, compliance to treatment advices including oral medication, attending appointments and footwear advice, etc.
 - What part(s) of his foot care do you find the most challenging? Why?
 - What do you think you manage the best and what would you need more help with? Why?
3. What may be of help to you with your role as caregiver, especially to improve the probability of success? For example, improving your relatives' foot self-care as much as possible?
4. Based on your experience, what do think are the main difficulties for your relative in looking after his/her foot ulcers? Could you please elaborate more on that?
5. What do you think others (healthcare providers) can do better to support you and your relative who is living with an active foot ulcer (or a healed ulcer) towards better self-care?
6. What do you think you and others could have done better to prevent your relative from developing a new diabetic foot ulcers or ulcer recurrence?

A.3 | Interview guide and probing questions for healthcare providers of patients with DFU

1. Please share with me your thoughts on taking care of patients with diabetes and diabetic foot ulcers. Could you please elaborate more on that?
2. Please share with me your experience with providing care for patients with DFU. What are the most challenging parts of HCPS? Why?
3. How would you describe your interactions with DFU patients? What works well and supports DFU care and what may often backfire? What do you find the most challenging part of these communications/interactions?
4. What is the role of a patient in foot care? How important and what may get in the way of good self-care?

5. In terms of foot care recommendations which parts do you think are the most challenging for your patients? What may be the reasons for this? For example, self-foot inspection, self-wound care, compliance to treatment advices including oral medication, attending appointments/seeking treatment, footwear advice, etc.
6. What/how will help you to increase the likelihood of success in promoting patient's self-care and self-management?
7. How have you been coping with your daily work in supporting and caring for patients who are living with an active foot ulcer (or a healed ulcer)?
8. What do you think patients and family caregivers can do better to achieve better self-care?
9. What do you think you and others could have done better to prevent them from developing a new diabetic foot ulcers or ulcer recurrence?