

ORIGINAL ARTICLE

“When nothing happens, nobody is afraid!” beliefs and perceptions around self-care and health-seeking behaviours: Voices of patients living with diabetic lower extremity amputation in primary care

Xiaoli Zhu¹  | Mary Lee² | Evelyn AL Chew³ | Ling Jia Goh¹ | Lijuan Dong¹ | Bernadette Bartlam⁴

¹Nursing Services, National Healthcare Group Polyclinics, Singapore

²Health Outcomes and Medical Education Research, National Healthcare Group, Singapore

³Clinical Research Unit, National Healthcare Group Polyclinics, Singapore

⁴Family Medicine and Primary Care, Lee Kong Chian School of Medicine, Nanyang Technological University, Singapore

Correspondence

Xiaoli Zhu, Nursing Services, National Healthcare Group Polyclinics Singapore, 3 Fusionopolis Link, Nexus@one-north (South Lobby), #05-10, Singapore, 138543. Email: julia_zhu@nhgp.com.sg

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Abstract

Self-management and self-care are the cornerstone of diabetes care and an essential part of successfully preventing or delaying diabetes complications. Yet, despite being armed with the required information and guidance for self-management, self-care and adherence to foot self-care recommendations and compliance to medication among patients with diabetic foot ulcer and diabetic lower extremity amputations remain low and suboptimal. This study reveals in-depth account of nine such patients' beliefs and perceptions around their illness, their self-care, and their health-seeking behaviours. Patients living with diabetic lower extremity amputation displayed profound lack of knowledge of self-care of diabetes and foot and passive health-related behaviours. The overarching sense that "when nothing happens, nobody is afraid," points to a lack of motivation in taking charge of one's own health, whether this is with reference to treatment or care adherence, following recommended self-care advice, or seeking timely treatment. The Health Beliefs Model provides the theoretical framework for probing into the factors for the participants' suboptimal self-care and passive health-seeking behaviours. Two themes emerged from data analysis: profound knowledge deficit and passive health-related behaviours. The beliefs and perceptions around self-care and health-seeking behaviours for patients with lower extremity amputation are interpreted as the "ignorant self" with passive health-seeking behaviours. Patients with diabetes and diabetic foot diseases may benefit from personalized education, motivational interviewing, and family support.

KEYWORDS

amputation, diabetic foot ulcer, health-seeking, perceptions, self-care

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1 | INTRODUCTION

Diabetic foot and lower limb complications are a source of morbidity and mortality in people with diabetes, affecting 40 to 60 million people with diabetes globally.¹ Diabetic foot ulcers (DFUs) are the common complications of diabetes, and the number of people with DFU has grown exponentially over the past few decades,² with a high recurrence rate up to 40% within 1 year.³ More than 95% of diabetes management is self-care.^{4,5} Segall and Goldstein described self-care as comprising behavioural practices such as health maintenance, disease prevention, assessment of symptoms, self-diagnosis, self-treatment (non-medication treatments and self-medication), self-referral, consultation with non-medical (alternative) care practitioners, and the use of specialised medical care.⁶ Self-management has been identified as the cornerstone of diabetes care and an essential part of successfully preventing or delaying diabetes complications.^{1,7,8} According to the International Diabetes Federation, self-management is defined as “management of or by oneself and the taking of responsibility for one’s own behaviour and well-being.”¹ A structured self-management plan for patients with DM comprises insulin use (where appropriate), blood glucose monitoring, physical activity, and a healthy diet.¹ Foot self-care and self-management are the keys to the prevention and treatment of DFU.⁸ International Working Group Diabetic Foot Guidelines suggest that self-care and self-management refer to foot care interventions that the patient can do at home, consisting of foot inspection, foot skin care, nail care, appropriate footwear inspection, foot self-monitoring, and seeking professional treatment in a timely manner.⁸

DFU is a common precursor to diabetic lower extremity amputation (DLEA).^{9,10} DFU and DLEA result in physical dysfunction, emotional distress, and diminished quality of life^{1,11,12} and increase the risk of early death.¹ DLEA is a life-altering experience that requires physical healing, emotional recovery, and social adaptation to regain normality.¹² Pivotal to good self-care is patient education.¹³⁻¹⁵ However, despite provision of appropriate information and guidance, patients’ self-care is often suboptimal, and adherence to foot self-care recommendations and compliance to medication remains low.¹⁶⁻¹⁹ In addition, although early detection and referral of patients is crucial,²⁰⁻²² there are still a number of patients who delay reporting foot symptoms to health professionals, and up to 40% to 60% of amputations are related to patient delay.²³

Singapore has the highest rate of DLEA in the world,²⁴ and the trend is increasing.²⁵ A study in primary care found

Key Messages

- self-care is a key measure in prevention of diabetic foot and other complications. Yet, self-care and adherence to foot self-care recommendations among patients with diabetic foot ulcer and diabetic lower extremity amputation (DLEA) remain low and suboptimal
- this study reveals in-depth accounts of nine such patients’ beliefs and perceptions around their illness, self-care, and health-seeking behaviours. Patients living with DLEA displayed knowledge deficiency and passive health-related behaviour before amputation
- the overarching sense of their beliefs and perceptions around self-care points to a lack of motivation in taking charge of one’s own health. Patients with diabetes and diabetic foot diseases may benefit from personalized education, motivational interviewing, and family support

that more than half of patients with DFU showed poorly controlled DM; nearly 70% of current DFU patients had a history of previous DFU or diabetes-related amputation; and only 16% of them attended the recommended annual diabetic foot screening for DFU prevention.²⁶ Approximately one-third of patients with diabetes failed to adhere to treatments.²⁷ These findings suggest that patients’ engagement in self-care behaviours is low, making prevention of DFU and DLEA particularly challenging. An in-depth understanding of patients’ beliefs and perceptions around self-care and seeking healthcare support is essential in order to address these challenges.

Previous studies to understand self-care and health-seeking behaviours of DFU mostly used quantitative methods.²⁸⁻³⁰ Qualitative research is needed in order to understand how individuals experience, give meaning, and respond to particular situations or conditions.³¹ However, qualitative research exploring patients’ beliefs and perceptions around self-care of DFU is relatively scarce, with those focused on patients’ overall experiences³² rather than behaviours related to self-care and health-seeking specifically. To our knowledge, there is no evidence in this field in Singapore. Therefore, the aim of this study was to explore beliefs and perceptions around self-care and the health-seeking behaviours of patients living with DLEA in primary care in Singapore in order to identify the implications for practice.

2 | THEORETICAL FRAMEWORK

Using a theoretically underpinned approach in qualitative research can extend its scope, enabling a yet more in-depth and robust explanation of the issues identified.³³ The Health Belief Model (HBM) is a health-specific behavioural cognitive model that was created to explain behaviours related to public health preventive services and adherence with medical prescriptions.^{34,35} The premise of the HBM is that individuals will take action to prevent or control a health problem if they perceive themselves susceptible to the problem, if they perceive the problem to be severe in nature and consequence, if they perceive that the action benefits them and produces a desirable outcome, and if they perceive few barriers to taking that action.³⁶ “Self-efficacy” and “cues to action” were added to the HBM by Rosenstock et al.^{35,37} “Self-efficacy” is a term first used by Bandura³⁸ to describe an individual's belief about his/her ability to perform the behaviour in question, while “cues to action” is the concept that has been widely observed as an important aspect triggering people's health-seeking behaviour and medication use. The latter includes internal (symptoms, past experiences) or external (healthcare workers, friends, relatives, mass media) cues.³⁹

In the HBM, the constructs of *perceived susceptibility* and *perceived severity* argue that people will be more motivated to behave in healthy ways if they believe they are vulnerable to a particular negative health outcome, and believe in the grave consequences of the disease.^{37,40} Perceptions of self-care behaviour include an individual's beliefs around the benefits of, and barriers to, undertaking health behaviours.⁴⁰ In this study, HBM was used to understand the ways in which self-care and health-seeking behaviours were or were not engaged with, and the impact on health and healing.

3 | METHODS

3.1 | Study design

This study adopted the methodological framework of Interpretative Phenomenological Analysis (IPA) to gain an “insider perspective” of lived experiences of participants by “giving voice” and “making sense” of the lived experience of a particular person.⁴¹ IPA is idiographic and has roots in phenomenology in that it does not attempt to produce an objective statement of the phenomenon itself but is committed to the detailed examination of a phenomenon as it is experienced and given meaning in the lived experience of a particular person.⁴¹ IPA aims to arrive at more general claims by cautiously

following a thorough analysis of individual cases.⁴¹ IPA is an interpretative process between the researcher and participant and draws upon the fundamentals of phenomenology, hermeneutics, and idiography.⁴²

3.2 | Setting and participants

The study was conducted in a primary health care in Singapore. Its six polyclinics serve a significant proportion of the population in the central and northern parts of Singapore and provide a comprehensive range of health services for the family, functioning as a one-stop health centre providing treatment, health promotion, and disease prevention.⁴³

Previous evidence has found that one-fifth of patients with diabetes die within the first year of their amputation.⁴⁴ Hence, participants who had undergone at least one episode of major or minor amputation due to diabetes in the last 12 months and underwent post-amputation wound care in polyclinics were recruited for the study. Patients who are below 21 years old, and with cognitive impairment and known mental illnesses were excluded from the study. Wound care nurses from the clinics screened and identified eligible patients. Ethics approval for this study was provided by the National Healthcare Group Domain Specific Research Board in Singapore (Ref No. 2018/00424).

3.3 | Data collection

A copy of the Participant Information Sheet was distributed to each individual potential participant for their consideration prior to participation by clinic staff. The interviewer then approached the willing participants and briefed them the aims of the study and answered their queries prior to obtaining the individual written consent.

Semi-structured interviews with a duration of 45 to 60 minutes each were undertaken and audio recorded. Field notes and reflexive diaries were also used to capture researchers' observations and interpretations. Collected audio interview data were de-identified and all transcripts were anonymised using unique identifiers to protect the privacy and confidentiality of the participants. Data were collected between September 2018 and January 2019.

3.4 | Data analysis

The analysis was conducted independently by all team members (ZX, ML, ECAL, GLJ, DL, and BB) following the guidelines set out by Smith, Flowers, and Larkin.¹⁹ Upon the initial reading of the first three transcripts, there was an

annotating phase of analysis. Descriptive, linguistic, and conceptual comments were noted, followed by identifying emergent themes within the text. As the present study focused particularly on the themes of self-care, particular attention was paid to participants' experiences of self-care and health-seeking behaviours. Similar themes repeated throughout the text were consolidated and given an appropriate theme title. The emergent themes were then clustered into sub-ordinate themes. Differences in opinion were resolved through discussion. Table 1 shows an example of analysis process. This process started after the first interview and was undertaken for each participant's interview. Once all nine interviews were analysed in this way, subordinate themes were compared by looking for convergences and divergences across each participant's lived experience to generate superordinate themes. The content of the interviews was checked with three participants to bolster trustworthiness.

4 | RESULTS

Two interlinked superordinate themes emerged from data analysis: profound knowledge deficit and passive

health-related behaviours (Figure 1). The beliefs and perceptions around self-care and health-seeking behaviours for patients with DLEA are interpreted as the "ignorant self," reflecting the language used by participants, with inadequate care.

4.1 | Profound knowledge deficit

The majority of the participants displayed a lack of basic knowledge of diabetes and foot self-care, the possible consequences of the diabetic foot diseases and the link between the two, regardless of age, gender, or ethnicity.

4.1.1 | Lack of knowledge of diabetes self-care

A female participant (P09) showed confusion about what diabetes is and how she developed diabetes. She believed she inherited diabetes from her mother and added that she had diabetes "overnight" because she indulged in sweet snacks. Lack of understanding of diabetes affected her decision-making and treatment adherence. Family members' advice outweighed medical advice on information resources for diabetes management. She assumed that she had to stop exercise because of the wound, which led to deterioration of her physical functionality.

...my mum has diabetes, so I have it...actually initially I don't have...it's because I finished all the New Year snacks [which are high in sugar]!...then diabetes came doctor told me that I have to take (insulin) injection (insulin) for my diabetes...I didn't want to take it [injections] – because my mother told me before, once you get the needles, you will have to do it forever...because there's a wound, so I don't do exercise...that's why my legs have no strength... (P09)

Another participant (P06) showed a misconception about appropriate diet after he had undergone amputation. He

TABLE 1 An example of data analysis process

Patient's verbatim transcript	"...After the nail came off...(long pause)...I think for two or three days, then...I thought when the bleeding stops...it could heal by itself. But then, I got a fever after that...I went to A&E (accident and emergency in hospital)" (P03)
Researchers' exploratory comments	Did not seek immediate treatment after nail injury, why? (<i>Descriptive comments</i>) Assume healing will take place without treatment? (<i>Descriptive comments</i>). <i>Long pause</i> during interview revealed unwillingness to actively respond to foot injury? (<i>Linguistic comments</i>). The delayed decision to seek treatment and hesitancy (<i>long pause</i>) are passive behaviours (<i>Conceptual comments</i>)
Emergent themes	Failure in treatment seeking Late for treatment
Clustered emergent themes to sub-ordinate themes	Failure in timely treatment seeking
Super-ordinate theme	Passive health-related behaviours

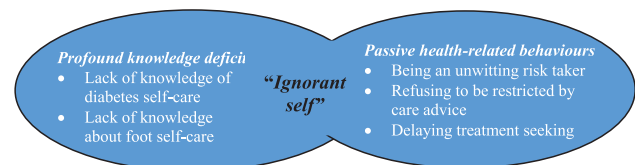


FIGURE 1 The essential meaning of the "ignorant self" embodies profound knowledge deficit and passive health-related behaviours

was aware of restrictions on carbohydrate intake, according to the care advice from healthcare providers, but he seemed confused about what healthy diabetic dietary options were. He was perplexed by various dietary suggestions, yet he did not seem to be motivated to find out more. His passive confusion turned into a way of living and self-care behaviours that were not only mistaken but also detrimental to his diabetes.

...the doctor said I should eat less carbohydrate...So now...I have stopped eating rice...I started taking biscuit, bread instead... (P06)

4.1.2 | Lack of knowledge about foot self-care

During the interviews, most participants said that they sustained a foot injury but did not realise they had a wound until it got infected. The symptoms they expressed were suggestive of diabetic neuropathic foot syndromes with poor foot sensation, which concealed the severity of the ulcers until they became infected. Failure to perform the recommended daily foot self-examination for the diabetic neuropathic foot was evident. Some participants were also unaware that their footwear should be closed-end covered shoes instead of slippers, a lack of awareness that could leave them susceptible to traumatic foot injury leading to further amputations.

...the slippers I am wearing...I injured my toe but didn't realize that...because sometimes I knocked but didn't know where I knocked, how I knocked my foot...now it became swollen. I don't know why... (P07)

Such limited understanding played a key role in the journey leading to amputation. One participant saw foot self-care as necessary. However, his perceived barrier was that he could not see underneath his foot, which prevented him from performing foot self-care. He subsequently sustained a foot blister. Instead of seeking immediate treatment advice from healthcare professionals, because of a lack of knowledge, he de-roofed the blister, which ultimately turned into a foot infection. Eventually, his foot partially amputated as a result.

...I am supposed to do self-check-up? Very hard to check foot because I cannot see underneath of my foot...there was a blister on my toe and I cut the skin of the blister area...the blister was infected...I got fever and was sick like this...they (doctors) asked me to do X-ray of my foot, the

bones were all not good already, need to be removed (sad laugh)... (P06)

4.2 | Passive health-related behaviours

In all of the discussions, participants described that their foot had produced a wide range of symptoms, including callus, blisters, swelling, fever, and malodorous wounds. These symptoms are in line with clinical descriptions of diabetic foot diseases, particularly moderate to severe foot infection. However, these symptoms are not always taken seriously by participants as signs of "critical foot" conditions due to passive health-seeking attitudes.

4.2.1 | Being an unwitting risk-taker

Several participants did not see the seriousness of poorly controlled diabetes prior to foot amputation. One participant (P02) understood the normal range of blood glucose level but did not seek treatment when his blood glucose was abnormally high until amputation was unavoidable. He was distracted by work commitments and his personal life priorities, and underestimated the seriousness of his foot condition. His lack of knowledge culminated in the amputation of two toes.

...I had diabetes long ago...but I have never taken any diabetes medicine, you know...I just take it (diabetes) as normal...because I need to upgrade my (work-related) skills... focus on my work trainings and career...I wanted (blood glucose level) 7 to 8 (mmol/dl) but that time (before amputation) mine was 15 (mmol/dl)... (P02)

A female participant (P07) reflected that she was aware of foot self-care practice but did not perform recommended proactive foot self-care. She admitted that constant reminders by relatives helped her to remember to perform foot self-examination.

...I'm supposed to check (self-examine) my feet every day...sometimes I am busy...only do it when my daughter always says "Mother, you need to check your toes"... Actually. She said every time after you shower, you should check your toes...I always forget...then that's it... (P07)

A participant (P05) who had undergone two episodes of amputation shared that he refused to comply with advice

from healthcare professionals as he had a strong personal belief that these were “pointless” and “useless.” However, he eventually admitted that his foot amputation was attributed to his lack of understanding, highlighting also the need for a more nuanced approach to information giving than written text.

...Yes, they gave me a lot of these (pamphlets), the small booklet and one file talking about this diabetes and how I should go across and take care of. But I didn't read... When it comes to reading all these kinds of... let me tell you frankly...I'm not that type of people who like to read things...even the (softcopy in) hand-phone, I hate to read all those message here...In fact, receiving this does not necessarily tell me well...it's not necessary for me, I am a bit self-educated on diabetes (laughs)...well it (foot ulcer) is not a sudden discovery...in fact, I was very ignorant of this (ulcer)... (P05)

A participant (P03) who had his first episode of digital toe amputation after having diabetes for three decades said that healthcare professionals' educational advice “falls on deaf ears.” Diagnosed in his youth, the disease did not affect his daily life for a long time, giving him a sense of invincibility and therefore refusal to be restricted by the disease; he believed that there would not be severe consequences and could not imagine himself being hospitalised and undergoing amputation.

...having diabetes for 30 years, of course, doctors have been talking to me for a number of times and giving me advice about food, or about care advice. But it's one ear in, one ear out...I didn't take it seriously because nothing happens yet. When nothing happens... nobody is afraid...because (they) don't see the negative consequences... (P03)

4.2.2 | Refusing to be restricted by care advice

Some participants said they intentionally disregarded having diabetes, and ignored self-care advice about, for example, regular blood glucose home self-monitoring even when the glucometer device was available to them. One participant (P03) said that he refused to be confined by diet restrictions and other lifestyle limitations. He believed that diabetes and its complications were

unavoidable and he had to accept the consequences with regrets.

...I am very seldom to check my blood glucose.... even though I had the machine (glucometer). I don't want to measure because I don't want to find out the readings, ignoring it. I mean basically it's trying to run away from the fact that your sugar might be high. Because if what happens, if you measure and if it's high, you become stressed by it. That you cannot eat food which you like. So, as I said, these are sometimes regrets in life that you have to take it along...It's something (pause, slowly) that is beyond my control. I mean, even though I should have controlled my diabetes better, but some of these things...will just come along the way.... Despite taking precautions. So (pause) I am having this amputation now... (P03)

4.2.3 | Delaying treatment seeking

Linked to this, was delayed treatment seeking. Several participants were unaware of their foot ulceration until their foot was swollen and could not fit into shoes. One female participant (P07) did not notice her foot wound until it turned malodorous and attracted the interest of her dog. She then further delayed seeking immediate medical advice because of family commitments. The belief that her foot wound was not severe enough to consult the doctor eventually resulted in an amputation.

I got a Jack Russell (dog), he come and smell my toe...I thought, (laugh) why are you smelling my toe? (slight laugh) then only I looked at the bottom of my toes and saw my injury there...guess what I did next? (slight laugh)...I attended a bangle ceremony...when I reached home and tried 3 pairs of slippers, (the foot) cannot go in (because of swelling). Then I went to hospital A&E (accident & emergency department). They did X-ray of my foot and said that they had to take out the toes... (P07)

Two male participants (P02 and P03) who underwent first-time amputation had waited until a fever broke out before seeking emergency care in the hospital. By then, the infection was extensive and one of them lost two toes. Even then, he did not understand the association

between his deteriorating foot condition and not seeking timely advice, continuing to attribute it to new shoes.

...It's happened on the first day of Hari Raya...I visited relatives wearing a pair of new shoes (pause)...I saw a wound on my foot when I reached home...I just leave it, wait and see how...In the next morning, I checked again and saw some sort blisters on my foot. ...I just washed it and left it like that (did not seek treatment) until I got fever... (short rueful laugh)...the new shoes caused that... (P02)

Another participant (P03) thought that there was no urgency in seeking help for his nail wound, since the bleeding had stopped. However, this inaction resulted in swelling, infection, and finally, a toe amputation. His knowledge was limited about causes, management, and prevention of DFUs. Despite being detected early, his foot nail wound was left untreated until it developed into a systemic infection, making the amputation inevitable.

...After the nail came off...(long pause)...I think for two or three days, then...I thought when the bleeding stops...it could heal by itself. But then, I got a fever after that...I went to A&E (accident and emergency in hospital) (P03)

5 | DISCUSSION

This article presents the first in-depth account of amputees' beliefs and perceptions around their self-care and health-seeking behaviours in Singapore. Patients living with diabetic lower extremity amputation showed lack of knowledge and passive health-related behaviours, which held them back from preventing complications. The overarching sense is that "when nothing happens, nobody is afraid," pointing to a reluctance to self-management and a lack of motivation in taking charge of one's own health, whether with reference to treatment or care adherence, recommended self-care advice, or in seeking treatment for diabetes and DFU care. A state of unawareness and a lack of knowledge about self-care shaped their decision-making as risk-takers who refused to be restricted by clinical advice and to seek help. We now discuss these findings in the context of the HBM, in particular, beliefs and perceptions of susceptibility to severe disease, and beliefs and perceptions of benefits and barriers to self-care and health support. We then examine the links

between knowledge and self-care before examining the implications for practice.

5.1 | Perceived susceptibility to and perceived severity of DFU and DLEA

Previous work reported that the level of knowledge underpins a person's beliefs about health and illness and thus determines health-related behaviours.^{12,45,46} Levels of knowledge and awareness of diabetes and diabetes-related foot diseases shape patients' beliefs and perceptions regarding their susceptibility to the disease and are key factors in health care-seeking practices.⁴⁷ In the present study, participants' low perceived susceptibility and severity attributed to low perceived threats to the consequences of diabetes that shaped their passive health-related attitudes, which was in contrast with the findings from recent studies from Singapore researchers. Those findings claimed that the most frequently used sources of health information for patients with diabetes were advice by healthcare professionals and pamphlets from hospitals/clinics.²⁷ Most older people who live alone develop self-coping mechanisms to meet their healthcare needs rather than seek formal medical consultation.⁴⁸ Inadequate knowledge is often attributed to why people with diabetes do not undertake foot self-care practices.⁴⁹ However, in our study, many participants ignored self-care advice from healthcare professionals and refused to receive educational pamphlets from healthcare institutions. Our participants' tendency to "being a risk-taker" and "refusing to be restricted by care advice" reflect participants' perceived low susceptibility to and perceived low severity of wound deterioration and amputation. Consequently, instead of seeking immediate medical treatment for a new acute foot wound or a torn nail, the wound was left unattended, resulting in an amputation. There appears to be a relationship between the pre-amputation attitudes of lower perceived threat uncovered in this study and the likelihood of eventual amputation, with important implications for how information is structured, delivered, and understood.

5.2 | Perceived benefits and perceived barriers to health-related behaviours

In line with the findings from a previous study,⁴⁶ most participants did not perform the recommended foot self-care; they believed that foot ulcers were unavoidable and difficult to detect in the early stage, and that amputations were unpreventable. Some of the participants were aware of foot complications (ie, blisters and bleeding nails) but

underestimated the levels of the risk and seriousness of the condition, assumed that “it could heal by itself” (P03) and decided to leave it untreated. In agreement with the findings from the literature,⁵⁰ most of our participants also admitted to taking chances with their foot health as several of them purposely ignored foot self-care advice, disregarded medical advice for self-care, or delayed seeking treatment. Their self-evaluation and belief of the recommended self-care behaviours as impinging their ability to maintain and enjoy “normal life,” led them to take the risk of ignoring their diabetes altogether. Quite possibly, the benefits of treatment adherence were not fully appreciated then because they did not know what they potentially stood to lose. Our participants' perceived barriers to self-care and health-seeking, such as work commitment and “difficult to self-check foot,” were associated with lack of knowledge and resulted in passive health-related behaviours. Ramifications of passive health-related behaviours, including delayed health-seeking behaviour, were influenced by individuals' health beliefs. Some participants were aware of the recommended self-care advice by healthcare professionals but refused to be restricted by the constraints of diet intake and footwear, adherence to foot self-care practices. This health belief was related to their underrating the perceived benefits of self-care health practice.

5.3 | Linkage between patient knowledge and self-care behaviours

The HBM posits that an individual is likely to perform a behaviour if he/she perceives a threat from a disease or health condition. Threat perception is based on two beliefs: the perceived susceptibility of the individual to the disease and the perceived severity of the consequences of the disease for the individual. HBM also proposes that an individual is likely to perform a behaviour if he/she perceives that performing the behaviour will supposedly reduce the negative health outcome. Behavioural perception is based on two beliefs: the perceived benefit or efficacy of the target health behaviour and the perceived barriers to performing the target behaviour. In the present study, both patients' perceived threat (ie, *left foot wound untreated or late for health-seeking*) and perception of behaviours (ie, *foot self-care and health-seeking behaviour*) were the consequences of knowledge deficiency and passive health-related behaviours (inactive practice). Preventing diabetic foot complications, understanding the risk factors, and having the ability to manage complications outside of the clinical encounter are an important part of a diabetes foot self-care programme in which effective foot care interventions include both foot

care knowledge and foot care practices.⁵¹ Helping patients improve in self-management of diabetic foot diseases to improve clinical outcomes requires improving both knowledge and self-care practice.

In the present study, lack of knowledge resulted in low perceived threats regarding the consequences of diabetes and DFU, affecting self-care practice and health-seeking behaviours. Most of our participants, irrespective of ethnicity, gender, age, and episodes of previous amputation, failed to identify warning signs of foot wound deterioration, which resulted in delayed treatment. This lack of knowledge resulted in a lack of self-care and a passive engagement with health-related behaviours. Educational interventions respecting patient's autonomy and focusing on empowerment and engagement is recommended to facilitate change from passivity to active engagement in self-care, in order to achieve optimum outcomes.

These findings revealed that most participants failed to identify foot ulcer infection at an early stage, which led to amputation. This is similar to the findings from a previous study, which reported participants precipitating amputation were unable to apprehend the risk of ulceration or infection and lacked awareness of the risks posed by traumatic foot injuries.⁵² A systematic review found that even when knowledge of appropriate foot care behaviours was present, perceived barriers, such as their impingement on everyday activities, precluded adherence.⁵⁰ While the literature reports that early detection of initial foot ulcer prevents delayed treatment,²¹ most of our participants were unable to detect the presence of a foot problem, and others took chances and ignored the new foot wound. Their self-care beliefs were marked by both lack of knowledge and passive health-seeking attitudes, which had, in turn, arisen from low perceived susceptibility and low perceived severity of the consequences of uncontrolled diabetes, low perceived benefits, and increased perceived barriers to self-care and health-seeking.

5.4 | Implications for practice: opportunities for educational and behavioural intervention

With rising healthcare costs and a shortage of infrastructure and medical professionals, Singapore's healthcare model is shifting its emphasis, relying less on hospital care and more on community and home care.⁵³ Diabetes illness belief is indirectly correlated to overall self-management.⁵⁴ Healthcare professionals, including wound care nurses, hold a pivotal position in advocating a self-care management model that promotes autonomy for

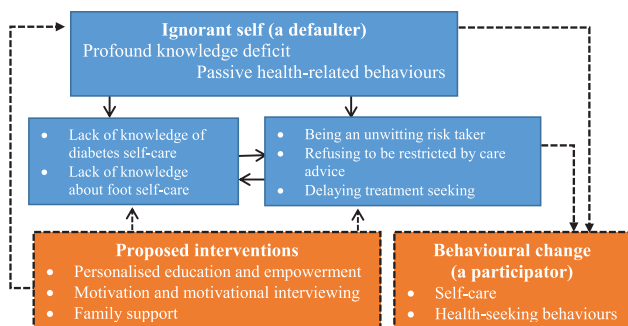


FIGURE 2 Beliefs and perceptions around self-care and health-seeking behaviours from patients living with DLEA and the proposed interventional framework for behavioural change. DLEA, diabetic lower extremity amputation

individuals with DFUs.⁵⁵ Most importantly, patients have to make their own decisions about diabetes management and diabetic foot care. This work supports existing literature arguing that diabetes patient care needs to move to a patient-centred philosophy based on self-efficacy, self-management, and empowerment,⁵⁶ and DFU prevention must be tailored to the individual patient.⁵⁷

The HBM is a relevant practice model for clinical work with individuals struggling with behaviour change for better self-care or health-seeking. Self-care behaviours require support and motivation for patients to engage in the desired behaviours and achieve the sustained adoption of health-seeking behaviours and optimal, health-supporting lifestyle choices.⁵⁸ Patients who experienced less distress caused by diabetes reported stronger self-efficacy beliefs.²⁷ A person-centred approach includes respecting patient autonomy and encouraging collaborative decision-making, thus helping patients with DFU to engage in self-care and facilitate ulcer prevention and healing.^{59,60} A central tenet of the HBM is that individuals are more likely to change behaviour if there is increased perceived severity and susceptibility of disease, increased appreciation of perceived benefits of treatment, and minimisation of barriers.⁶¹ We agree that it is important to assess individual beliefs and plan care and education accordingly⁴⁶ as health beliefs are affected by knowledge levels and determine health-seeking behaviours. We therefore propose a behavioural educational interventional framework (Figure 2), which echoes and builds upon the current literature^{35,62} and our findings to address both knowledge deficit and passive health-related behaviours for patients with diabetes and DFUs in primary care. Such an interventional framework would incorporate both personalised education and motivation as cues to actions and include elements that resemble the components of care programmes for patients with diabetic foot diseases. The framework

would seek to improve patients' knowledge on self-care and health-seeking behaviours, drawing on motivational strategies.

6 | STRENGTHS AND LIMITATIONS

This research is the first study that revealed beliefs and perceptions around self-care and health-seeking behaviours based on the in-depth account of amputees living with post-amputation wounds in primary care in Singapore. This study could be replicated to other primary care settings with a broader range of participants to increase its transferability. It draws on interviews with a limited sample, and more work is needed to explore the contexts and impacts of socio-demographic variables, such as ethnicity, age, gender, education, and comorbidities.

7 | CONCLUSIONS

The study reveals the multifaceted beliefs and perceptions around self-care and health-seeking behaviours for patients living with DLEA in primary care in Singapore. The study also provides an important insight that health beliefs, at the heart of which are patient beliefs and perceptions, shape decision-making in self-care and health-seeking. Patients with diabetes and diabetic foot disease may benefit from the proposed interventional framework underpinned by the HBM aimed at knowledge improvement and behavioural change in primary care. Further work is needed to identify the components of such a behaviour change model and its acceptability to patients and clinicians.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHOR CONTRIBUTIONS

Zhu Xiaoli: Study design, data analysis, and manuscript preparation; **Goh Ling Jia:** study design and data analysis; Evelyn Chew AL: data collection and data analysis; **Dong Lijuan:** study design; all authors: data verification, revision and approval of the final manuscript.

DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions

ORCID

Xiaoli Zhu  <https://orcid.org/0000-0003-3406-6203>

REFERENCES

- IDF Diabetes Atlas, 9th Edition Committee. Karuranga S, Malanda B, Saeedi P, Salpea P, *International Diabetes Federation: Diabetes Atlas (Ninth edition 2019)*. 9th ed. International Diabetes Federation; 2019. <https://www.diabetesatlas.org/en/resources/>.
- Zhang P, Lu J, Jing Y, Tang S, Zhu D, Bi Y. Global epidemiology of diabetic foot ulceration: a systematic review and meta-analysis. *Ann Med*. 2017;49(2):106-116. <https://doi.org/10.1080/07853890.2016.1231932>.
- Armstrong DG, Boulton AJM, Bus SA. Diabetic foot ulcers and their recurrence. *N Engl J Med*. 2017;376:2367-2375. <https://doi.org/10.1056/NEJMr1615439>.
- Bullen B, Young M, McArdle C, Ellis M. Overcoming barriers to self-management: the person-centred diabetes foot behavioural agreement. *Foot*. 2019;38:65-69. <https://doi.org/10.1016/j.foot.2019.01.004>.
- Wagner J. Behavioral interventions to promote diabetes self-management. *Diabetes Spectr*. 2011;24(2):61-62. <https://doi.org/10.2337/diaspect.24.2.61>.
- Segall A, Goldstein J. Exploring the correlates of self-provided health care behaviour. *Soc Sci Med*. 1989;29(2):153-161. [https://doi.org/10.1016/0277-9536\(89\)90163-9](https://doi.org/10.1016/0277-9536(89)90163-9).
- Inzucchi S. Management of hyperglycemia in type 2 diabetes, 2015: a patient-centered approach. 2015;38:140-149. <https://doi.org/10.2337/dc14-2441>.
- Bus SA, Lavery LA, Monteiro-Soares M, et al. *IWGDF Guideline on the Prevention of Foot Ulcers in Persons with Diabetes*; 2019. www.iwgdfguidelines.org. Accessed October 24, 2019.
- Bakheit HE, Mohamed MF, Mahadi SEDI, et al. Diabetic heel ulcer in The Sudan: determinants of outcome. *J Foot Ankle Surg*. 2012;51(2):152-155. <https://doi.org/10.1053/j.jffas.2011.10.032>.
- Zubair M, Malik A, Ahmad J. Incidence, risk factors for amputation among patients with diabetic foot ulcer in a north Indian tertiary care hospital. *Foot*. 2012;22(1):24-30. <https://doi.org/10.1016/j.foot.2011.09.003>.
- Vileikyte L, Pouwer F, Gonzalez JS. Psychosocial research in the diabetic foot: are we making progress? *Diabetes Metab Res Rev*. 2020;36(S1):1-5. <https://doi.org/10.1002/dmrr.3257>.
- Zhu X, Goh LJ, Chew E, Lee M, Bartlam B, Dong L. Struggling for normality: experiences of patients with diabetic lower extremity amputations and post-amputation wounds in primary care. *Prim Health Care Res Dev*. 2020;21(e63):1-10. <https://doi.org/10.1017/S146342362000064X>.
- Adiewere P, Gillis RB, Imran Jiwani S, Meal A, Shaw I, Adams GG. A systematic review and meta-analysis of patient education in preventing and reducing the incidence or recurrence of adult diabetes foot ulcers (DFU). *Heliyon*. 2018;4(5):614. <https://doi.org/10.1016/j.heliyon.2018.e00614>.
- Goodall RJ, Ellauzi J, Tan MKH, Onida S, Davies AH, Shalhoub J. A systematic review of the impact of foot care education on self efficacy and self care in patients with diabetes. *Eur J Vasc Endovasc Surg*. 2020;60(2):282-292. <https://doi.org/10.1016/j.ejvs.2020.03.053>.
- Dorresteijn J, Kriegsman D, Assendelft W, Valk GD. Patient education for preventing diabetic foot ulceration. *Cochrane Database Syst Rev*. 2014;12:1-45. <https://doi.org/10.1002/14651858.CD001488.pub5>.
- Bus SA, van Netten JJ. A shift in priority in diabetic foot care and research: 75% of foot ulcers are preventable. *Diabetes Metab Res Rev*. 2016;32:195-200. <https://doi.org/10.1002/dmrr.2738>.
- Gaurang Vyas V. Comparison study of compliance with medication and foot care in type 2 diabetic patients. *J Diabetes Metab*. 2015;6(9):1-3. <https://doi.org/10.4172/2155-6156.1000593>.
- Chappidi M, Chidambaram P, Sivananjiah S, Somanna SN. Non-adherence to foot-care activities and its associated factors among patients with type 2 diabetes mellitus in an urban area of South India: a cross sectional study. *Int J Community Med Public Heal*. 2018;5(12):5089. <https://doi.org/10.18203/2394-6040.ijcmph20184745>.
- Wasnik RN, Marupuru S, Ahad Mohammed Z, Rodrigues GS, Sekhar Miraj S. Evaluation of antimicrobial therapy and patient adherence in diabetic foot infections. *Clin Epidemiol Global Health*. 2019;7:283-287. <https://doi.org/10.1016/j.cegh.2018.10.005>.
- Smith-Strøm H, Iversen MM, Igland J, et al. Severity and duration of diabetic foot ulcer (DFU) before seeking care as predictors of healing time: a retrospective cohort study. *PLoS One*. 2017;12(5):e0177176. <https://doi.org/10.1371/journal.pone.0177176>.
- Bus SA, Lavery LA, Monteiro-Soares M, et al. *IWGDF Guideline on the Prevention of Foot Ulcers in Persons With Diabetes*. The International Working Group on the Diabetic Foot; 2019.
- Schaper C, Van Netten JJ, Apelqvist J, Bus SA, Hinchliffe RJ, Lipsky BA. *IWGDF Practical Guidelines on the Prevention and Management of Diabetic Foot Disease*; 2019. www.iwgdfguidelines.org. Accessed October 25, 2020.
- van Battum P, Schaper N, Prompers L, et al. Differences in minor amputation rate in diabetic foot disease throughout Europe are in part explained by differences in disease severity at presentation. *Diabet Med*. 2011;28(2):199-205. <https://doi.org/10.1111/j.1464-5491.2010.03192.x>.
- Singapore: One of world's highest for diabetes-related leg amputations | The Independent Singapore News. <https://theindependent.sg/singapore-one-of-worlds-highest-for-diabetes-related-leg-amputations/>. 2017. Accessed October 11, 2020.

25. Yee A, Yap CW, Saxena N, Lin L-K, Heng BH. Diabetes-related lower extremity amputations in Singapore. *Proc Singapore Healthc.* 2017;26(2):76-80. <https://doi.org/10.1177/2010105816663521>.
26. Zhu X, Olsson M, Bajpai R, Lim VH, Goh LJ. Factors associated with healing outcomes in primary care patients with diabetic foot ulcers: a retrospective study in a multi-ethnic sample. *Adv Skin Wound Care.* 2020; In Press.
27. Zhang X, Foo S, Majid S, Chang YK, Dumauual HTJ, Suri VR. Self-care and health-information-seeking Behaviours of diabetic patients in Singapore. *Health Commun.* 2020;35(8):994-1003. <https://doi.org/10.1080/10410236.2019.1606134>.
28. Sari Y, Upoyo AS, Isworo A, et al. Foot self-care behavior and its predictors in diabetic patients in Indonesia. *BMC Res Notes.* 2020;13(1):38. <https://doi.org/10.1186/s13104-020-4903-y>.
29. Li R, Yuan L, Guo XH, et al. The current status of foot self-care knowledge, behaviours, and analysis of influencing factors in patients with type 2 diabetes mellitus in China. *Int J Nurs Sci.* 2014;1(3):266-271. <https://doi.org/10.1016/j.ijnss.2014.05.023>.
30. Chin Y, Huang T, Hsu BR, Weng L, Wang C. Factors associated with foot ulcer self-management behaviours among hospitalised patients with diabetes. *J Clin Nurs.* 2019;28(11-12):2253-2264. <https://doi.org/10.1111/jocn.14822>.
31. Pope C, Mays N. In: Pope C, Mays N, eds. *Qualitative Research in Health Care, 3rd Edition.* 3rd ed. Oxford: Blackwell/BMJ; 2006.
32. Alfaqih MR, Kusnanto K, Padoli P. Systematic review a systematic review: the experience of patient with diabetic foot ulcers. *J Nurs.* 2020;15:120-128. <https://doi.org/10.20473/jn.v15i2.18995>.
33. Collins CS, Stockton CM. The central role of theory in qualitative research. *Int J Qual Methods.* 2018;17:1-10. <https://doi.org/10.1177/1609406918797475>.
34. Janz NK, Becker MH. The health belief model: a decade later. *Heal Educ Behav.* 1984;11(1):1-47. <https://doi.org/10.1177/109019818401100101>.
35. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the health belief model. *Heal Educ Behav.* 1988;15(2):175-183. <https://doi.org/10.1177/109019818801500203>.
36. Rosenstock IM. The health belief model: explaining health behavior through expectancies. *Health Behavior and Health Education: Theory, Research, and Practice.* The Jossey-Bass health series. Hoboken, NJ: Jossey-Bass/Wiley; 1990:39-62.
37. Rosenstock IM. Why people use health services. *Milbank Mem Fund Q.* 1966;44(3):94-127. <https://doi.org/10.2307/3348967>.
38. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Adv Behav Res Ther.* 1977;1(4):139-161. [https://doi.org/10.1016/0146-6402\(78\)90002-4](https://doi.org/10.1016/0146-6402(78)90002-4).
39. Glanz K, Rimer BK, Viswanath K. In: Glanz K, Rimer BK, Viswanath K, eds. *Health Behavior and Health Education: Theory, Research, and Practice.* 4th ed. San Francisco, CA: Jossey-Bass; 2008.
40. Tanner-Smith EE, Brown TN. Evaluating the health belief model: a critical review of studies predicting mammographic and pap screening. *Soc Theory Heal.* 2010;8(1):95-125. <https://doi.org/10.1057/sth.2009.23>.
41. Smith JA, Flower P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research.* London: Sage Publishing; 2009.
42. Peat G, Rodriguez A, Smith J. Interpretive phenomenological analysis applied to healthcare research. *Evid Based Nurs.* 2019; 22:7-9. <https://doi.org/10.1136/ebnurs-2018-103017>.
43. National Healthcare Group Polyclinics. https://www.nhgp.com.sg/About_Us/. Accessed April 30, 2020.
44. Linette Lai. Singapore “has 2nd-highest proportion of diabetics”, Health News & Top Stories—The Straits Times. The straitstimes. <https://www.straitstimes.com/singapore/health/hospital-data-shows-one-in-5-diabetics-who-had-lower-limb-amputation-died-within-a>. 2015. Accessed January 21, 2018.
45. Hjelm K, Bard K. Beliefs about health and illness in Latin-American migrants with diabetes living in Sweden. *Open Nurs J.* 2013;7:57-65. <https://doi.org/10.2174/1874434601307010057>.
46. Hjelm K, Apelqvist J. Influence of beliefs about health and illness on self-care and care-seeking in foreign-born people with diabetic foot ulcers: dissimilarities related to origin. *J Wound Care.* 2016;25(11):602-616. <https://doi.org/10.12968/jowc.2016.25.11.602>.
47. Hjelm K, Beebwa E. The influence of beliefs about health and illness on foot Care in Ugandan Persons with diabetic foot ulcers. *Open Nurs J.* 2013;7(1):123-132. <https://doi.org/10.2174/1874434601307010123>.
48. Lee JMG, Chan CQH, Low WC, Lee KH, Low LL. Health-seeking behaviour of the elderly living alone in an urbanised low-income community in Singapore. *Am J Physiol Regul Integr Comp Physiol.* 2020;133(1515):260-265. <https://doi.org/10.11622/smedj.2019104>.
49. Harvey JN, Lawson VL. The importance of health belief models in determining self-care behaviour in diabetes. *Diabet Med.* 2009; 26(1):5-13. <https://doi.org/10.1111/j.1464-5491.2008.02628.x>.
50. Coffey L, Mahon C, Gallagher P. Perceptions and experiences of diabetic foot ulceration and foot care in people with diabetes: a qualitative meta-synthesis. *Int Wound J.* 2019;16(1):183-210. <https://doi.org/10.1111/iwj.13010>.
51. Bonner T, Foster M, Spears-Lanoix E. Type 2 diabetes-related foot care knowledge and foot self-care practice interventions in the United States: a systematic review of the literature. *Diabet Foot Ankle.* 2016;7:29758. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4761684/pdf/DFA-7-29758.pdf>.
52. Feinglass J, Shively VP, Martin GJ, et al. How “preventable” are lower extremity amputations? A qualitative study of patient perceptions of precipitating factors. *Disabil Rehabil.* 2012;34(25):2158-2165. <https://doi.org/10.3109/09638288.2012.677936>.
53. Khalik. Parliament: Key shifts needed to keep healthcare system sustainable, says Gan Kim Yong, Politics News & Top Stories—The Straits Times. The Straits Times. <https://www.straitstimes.com/politics/parliament-key-shifts-needed-to-keep-healthcare-system-sustainable-says-gan-kim-yong>. 2017. Accessed January 4, 2021.
54. Quek J, Tan G, Lim K, Yap CK, Wong M, Soon J. Diabetes distress and self-management in primary care in Singapore: explorations through illness perception. *Int J Community Med Public Heal.* 2019;6(2):473. <https://doi.org/10.18203/2394-6040.ijcmph20190166>.
55. Costa IG, Pilar Camargo Plazas M, Tregunno D. Rethinking self-care management for individuals with diabetic foot ulcers. *Wounds Int.* 2017;8(12):22-25. <https://www.woundsinternational.com/resources/details/rethinking-self-care-management-fo>

- r-individuals-with-diabetic-foot-ulcers Accessed November 4, 2019.
56. Harvey JN. Psychosocial interventions for the diabetic patient. *Diabetes Metab Syndr Obes.* 2015;8:29-43. <https://doi.org/10.2147/DMSO.S44352>.
 57. Ousey K, Chadwick P, Jawien A, et al. Identifying and treating foot ulcers in patients with diabetes: saving feet, legs and lives. *J Wound Care.* 2018;27:S1-S52. <https://doi.org/10.12968/jowc.2018.27.Sup5.S1>.
 58. El-Osta A, Webber D, Gnani S, et al. The self-care matrix: a unifying framework for self-care. *Self-Care Adv Study Underst Self-Care.* 2019;10(3):38-56. <https://selfcarejournal.com/article/the-self-care-matrix-a-unifying-framework-for-self-care/> Accessed December 28, 2020.
 59. Swanson V, Maltinsky W. Motivational and behaviour change approaches for improving diabetes management. *Pract Diabetes.* 2019;36(4):121-125. <https://www.practicaldiabetes.com/article/motivational-and-behaviour-change-approaches-for-improving-diabetes-management/> Accessed December 4, 2020.
 60. Price P. How can we improve adherence? *Diabetes Metab Res Rev.* 2016;32:201-205. <https://doi.org/10.1002/dmrr.2744>.
 61. Becker MH. The health belief model and sick role behavior. *Health Educ Monogr.* 1974;2(4):409-419. <https://doi.org/10.1177/109019817400200407>.
 62. Karimy M, Araban M, Zareban I, Taher M, Abedi A. Determinants of adherence to self-care behavior among women with type 2 diabetes: an explanation based on health belief model. *Med J Islam Repub Iran.* 2016;30(1):368. <http://mjiri.iums.ac.ir> Accessed November 3, 2020.

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