

Factors Influencing Fear of Progression in Patients with Diabetic Foot Ulcers: A Qualitative Study

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Abstract: This study aimed to explore the factors influencing fear of progression (FoP) and the lived experiences of patients with diabetic foot ulcers (DFUs), and to provide evidence to inform home-based foot care, psychological support, and continuing-care interventions. A phenomenological qualitative design, guided by the Common-Sense Model of Self-Regulation (CSM), was used. Fourteen patients with DFUs attending the wound clinic of the First Affiliated Hospital of Xi'an Jiaotong University between March and June 2026 were recruited using purposive and maximum-variation sampling. Semi-structured interviews were conducted. Audio recordings were transcribed within 24 h and analysed using Colaizzi's seven-step method. Three themes and eight subthemes were identified: stressors (fear of amputation and complications, substantial financial burden, and severe restrictions in daily life); illness beliefs (resigned acceptance with passive coping and accepting the illness with active coping); and needs (disease-related knowledge and psychological counselling, guidance for foot self-care, and social support). Fear was closely related to recurrent wounds, pain, functional limitation, financial strain, and negative beliefs about illness controllability. Professional guidance, family support, and compassionate care enhanced confidence in treatment. FoP in patients with DFUs is shaped by disease-related stressors, illness beliefs, and available support resources. In addition to wound management, healthcare professionals should dynamically assess psychological distress and risk of self-harm, provide individualised education, pain management, psychological support, and continuing care, and strengthen family and social support to improve patients' sense of control and self-care capacity.

Keywords: diabetic foot ulcer; fear of progression; Common-Sense Model of Self-Regulation; influencing factors; qualitative research

1. Introduction

Diabetic foot ulcer (DFU) is a serious chronic complication of diabetes and is commonly associated with peripheral neuropathy and/or lower-extremity peripheral arterial disease ^[1]. DFU is characterised by high incidence, recurrence, mortality, and healthcare resource use, imposing a substantial public-health burden on patients, families, and society ^[2,3]. It has been estimated that up to 34% of people with diabetes may develop a DFU during their lifetime ^[4]. In China, the 1-year recurrence rate after healing has been reported to be as high as 31.6% ^[5].

Fear of progression (FoP) refers to fear arising from concerns that illness may worsen or recur and result in adverse consequences for psychological well-being, physical function, and daily life ^[6-9]. Timely FoP interventions in people with diabetes and cancer have been reported to reduce psychological distress and improve quality of life ^[10,11]. However, research on FoP in people with DFUs remains limited, and no standardised intervention programme has yet been established.

The Common-Sense Model of Self-Regulation (CSM), proposed by Leventhal and colleagues, is an important social-cognitive framework ^[12]. It proposes that when health is threatened, individuals use cognitive and emotional self-regulation processes to interpret and manage their illness. CSM-based research in the DFU population remains scarce. Therefore, this phenomenological study used the CSM as its theoretical framework to explore the factors influencing FoP and the lived experiences of patients with DFUs, thereby informing targeted foot care, psychological support, and self-management

guidance.

2. Materials and Methods

2.1 Participants

Purposive sampling with a maximum-variation strategy was used. Patients with DFUs who attended the wound clinic of the First Affiliated Hospital of Xi'an Jiaotong University from March to June 2026 were recruited. Inclusion criteria were: (1) diagnosis of DFU according to the 2019 International Working Group on the Diabetic Foot (IWGDF) definition ^[13]; (2) age ≥ 18 years; (3) clear consciousness and adequate ability to communicate; and (4) voluntary participation. Patients with severe physical diseases, such as serious cardiac, cerebral, or pulmonary disease, or with psychiatric disorders or cognitive impairment were excluded. Sampling continued until data saturation was reached; 14 participants were ultimately enrolled. The study was approved by the Ethics Committee of the First Affiliated Hospital of Xi'an Jiaotong University (XJTU1AF2026LSYY-0080).

2.2 Methods

2.2.1 Development of the interview guide

An initial interview guide was developed according to the study aim and relevant literature. It was reviewed and revised by one qualitative-research expert and two clinical experts with associate senior titles or above and more than 10 years of DFU nursing experience. Two pilot interviews were then conducted, and the guide was further refined. The final guide included the following questions:

- 1) Please describe your concerns about the progression of diabetic foot disease.
- 2) If the disease worsens, what are you most afraid of, and why?
- 3) How severe is your fear, and how has it affected your work and daily life?
- 4) How do you try to relieve this fear? Please describe this in detail.
- 5) When you feel afraid, what situations make it particularly difficult to relieve that fear?
- 6) In such situations, what would you like people around you—family, friends, colleagues, and healthcare professionals—to do for you?
- 7) When the disease worsens, what actions would you like to take to reduce your fear?

2.2.2 Data collection

Semi-structured interviews were conducted until data saturation was achieved and no new themes emerged. The interviewer contacted participants in advance to arrange a convenient time. Interviews were conducted in the department teaching room. Before each interview, participants were informed of the study purpose and assured that all information would remain confidential. Audio recording began after informed consent was obtained. The interviewer observed and recorded non-verbal information, including facial expression, tone of voice, and body language; used repetition and probing to deepen the interview; and encouraged participants to express their views freely. Each interview lasted 20–30 min.

2.2.3 Data analysis

Within 24 h after each interview, recordings were transcribed verbatim and field notes were organised. Participants' demographic data and transcripts were coded, and non-verbal information was incorporated in the light of the interview context and field records. Data were analysed using Colaizzi's seven-step method ^[14]: (1) repeatedly reading the transcripts; (2) identifying statements relevant to FoP in patients with DFUs; (3) formulating meanings from recurrent significant statements; (4) clustering meaning units into themes; (5) providing a detailed description of each theme; (6) comparing and refining similar themes to develop final themes; and (7) returning the findings to participants for verification to enhance credibility.

2.2.4 Rigour

Before data collection, the interviewer received systematic training in qualitative research, held an international wound therapist certification, and participated in clinical wound dressing care. Trust was

established through patient and respectful communication during routine care. During interviews, the interviewer listened attentively and used a gradual approach to facilitate in-depth expression. Recordings were transcribed within 24 h and independently analysed by two researchers. Disagreements were discussed within the research group until consensus was reached. The final findings were returned to participants for confirmation. The entire process of data collection and analysis was supervised by a qualitative-research expert.

3. Results

3.1 Theme 1: Stressors

3.1.1 Fear of amputation and complications

As ulcer healing was delayed or impeded, fear of amputation and complications intensified. Concern about limb loss was particularly prominent, while the possibility of visual impairment and the uncertainty of recurrent infection also caused substantial physical and psychological distress. P4: "I am afraid that I will not be able to keep my foot; I am afraid of amputation." P6: "I am afraid of going blind, of not being able to see." P7: "I am afraid that it will not heal and that I will need an amputation. Amputation would make life inconvenient." (smiled bitterly). P9: "One of his feet has already been amputated... If it gets worse, won't he still face amputation?" (smiled bitterly). P10: "I try not to reach the point of amputation."

Living under the threat of complications and amputation could generate pessimism and undermine confidence in life. Fear of pain during dressing changes was also a major source of distress and negatively affected physical, emotional, and daily functioning. P1: "I feel that I may not survive. I am afraid that I will suddenly disappear, that I will be gone." (choked with sobs). P10: "I am afraid of the pain during dressing changes. Every dressing change is torture. I think that I would rather close my eyes and be gone than suffer like this." P12: "I hope it does not flare up so often. It is too torturous... diabetic foot has ruined her life. I hope she will not have to suffer any more." (tearful)

3.1.2 Heavy financial burden

The prolonged course of DFU treatment created a long-term challenge not only to physical recovery but also to family finances. Frequent dressing changes, expensive wound-care materials, and limited insurance coverage placed considerable direct financial pressure on participants. P4: "I work as a security guard. I have to swap shifts with others to come for dressing changes. I am afraid that my employer will dismiss me because of diabetic foot, and that I will lose my job." P5: "There really is not much money at home now... the financial pressure is great." P8: "He is a farmer and has no job. He uses his savings, and when that is not enough his children pay for him. What he fears most is the high cost." P10: "I worry that there will not be enough money for treatment. I also need other medicines and dressing changes. It costs a lot. Without insurance support, there is not enough money even for dressings." (looked worried)

Travel and accommodation for treatment away from home, together with reduced income due to functional limitation, further increased the financial burden. Participants also described guilt arising from their perceived inability to fulfil family responsibilities. P14: "Our hometown is in northern Shaanxi. It is inconvenient for my son to drive us here for dressing changes, so my spouse and I have stayed in a hotel near the hospital. It costs 90 yuan per night, and we have stayed for more than a month. I do not know when the wound will heal." P5: "Since I got this wound, I cannot do anything. I have been in hospital for more than a month and spent a lot of money. My children still need to go to school, and I cannot earn an income." (furrowed brow). P1: "I always feel that I am a burden, dragging down my family, my wife, and my children." P10: "I am afraid of burdening my wife and children. I am afraid that my wife cannot bear such financial pressure, and I do not want to add to the family burden."

3.1.3 Severe restriction of daily life

DFU affected physical function, family roles, and social participation. Impaired mobility directly limited daily activities; dietary changes also produced psychological strain because patients found it difficult to balance glycaemic control and adequate nutrition. P3: "I cannot move around like a normal person or travel far. Things I could do when I was well, I cannot do now." P9: "I just lie at home. I cannot move, cannot do anything, and cannot even cook." P6: "I used to walk 10,000 steps every day. Now I cannot walk, and it affects me psychologically." P11: "My diet has changed a lot. Now I do not dare to eat anything." P2: "I cannot eat too well, but I cannot eat too poorly either. It is very difficult to

find the balance.” P7: “My diet has changed a lot. I know I should eat lightly, eat less staple food, and eat more vegetables.”

Some participants described a transition from being family caregivers to being care recipients. This role reversal reduced their sense of value and increased the burden on their families. Mobility problems also reduced outings and social contact, contributing to isolation and loneliness. P4: “Life is certainly inconvenient. I need someone to take care of me for everything.” (looked helpless). P5: “My spouse is very troubled by this illness and says that after I recover, she wants to divorce me.” (despondent). P3: “I am afraid that people will laugh at me. I do not dare to go out. I do not want others to know this private matter, so I do not want to leave home.”

3.2 Theme 2: Illness beliefs

3.2.1 Resigned acceptance and passive coping

The prolonged and uncertain treatment course could lead to a resigned and passive coping style, especially when treatment did not achieve the expected effect or ulcers recurred shortly after healing. Repeated setbacks fostered negative illness perceptions and weakened participants’ willingness to seek solutions actively. P1: “I think about not living any more every day. I want to jump from a building.” P11: “I feel completely discouraged and only want to be free. I feel that life has no meaning every day.”

P10: “After a long time, I do not care any more. The disease will go as far as it goes.” (looked helpless). P11: “I do not want to trouble my children. I do not tell my family anything. I have lived long enough; I do not care any more.” (expressionless).

3.2.2 Accepting the illness and active coping

With time and accumulated treatment experience, some participants developed a more positive illness framework and shifted from passive endurance to active engagement. They reported confidence in professional treatment and a willingness to cooperate with care. P2: “At my age, I have thought it through. I still have confidence. I have always believed in the First Affiliated Hospital of Xi’an Jiaotong University. They can treat my foot, and the dressing changes are effective.” (gave a thumbs-up). P7: “This hospital is very professional. They said it was not too serious. As long as you cooperate with treatment, it will improve later.” P8: “When I think too much, I become very afraid. But when I think it through, there is nothing else to do. I already have the disease, so I should be treated and have dressing changes when needed.” P14: “Medicine has advanced. There are many good treatments and imported medicines. Medical care in China is good; I believe in medicine.” (smiled)

3.3 Theme 3: Needs

3.3.1 Needs for disease knowledge and psychological counselling

Participants commonly reported inadequate knowledge of DFU causes and treatment plans, as well as a strong need for psychological counselling and emotional support during the prolonged recovery process. P5: “When I am ill, I do not tell my children or family. I keep enduring it by myself, and then it gets delayed and becomes serious.” P4: “I did not pay attention before. I only took it seriously after my foot broke down. I did not know diabetes could cause foot ulcers, and doctors where I live never explained it. If someone had told me earlier, I would certainly have controlled my blood glucose well.” P6: “He is old and stubborn and does not listen to advice. He never checks his blood glucose. What we say does not work; he only listens to doctors.” P5: “I roughly know that this medicine is anti-inflammatory, but I really do not know the rest. You are professionals, and I want to hear you explain it.” P13: “If blood glucose is high, the wound will not heal; if it is low, there is not enough nutrition. I really do not know what to do.” P14: “I hope healthcare professionals can talk with him more and provide more psychological comfort.”

3.3.2 Need for DFU self-care guidance

The complexity of DFU care placed substantial demands on patients’ self-care skills. Management of exudate and dressing replacement required professional knowledge, and many patients and family members felt unable to perform these tasks safely. P14: “My wound smells very bad and keeps leaking. The gauze is wet the day after I go home from a dressing change. My spouse does not dare to change it; I do not know how either, and it keeps falling off. I can only come to the hospital and ask Dr Li to change it.” (frowned). P13: “I hope healthcare professionals can tell us more about diabetic foot, such as what to do in daily life, diet, and exercise. Then we will feel more certain.” P8: “It keeps recurring.

Doctors at the township hospital do not dare to change the dressing. We do not dare to do it at home either. It is far and inconvenient, so we can only come here every so often.” (looked helpless)

3.3.3 Desire for social support

The complexity and chronicity of DFU created physical, psychological, and social pressures, resulting in a strong need for multifaceted support. Participants valued emotional comfort from friends, affordability of medical supplies, and professional and compassionate support from healthcare providers. P6: “I like walking, chatting with friends while walking, travelling, and calling friends on the phone.” (smiled). P7: “That silver dressing is very expensive—280 yuan for one piece. It would be better if insurance covered it, so it could be cheaper.” P1: “At first I felt just so-so. Later I met Dr Li. He changed the dressings carefully, was patient, and spoke warmly. With my family’s and Dr Li’s encouragement, I slowly adjusted and kept going.”

4. Discussion

4.1 Multiple disease-related stressors are important sources of FoP in patients with DFUs

Patients with DFUs feared amputation, visual loss, recurrent infection, pain, and delayed healing. Amputation was associated with anticipated losses in mobility, self-care, family roles, and social participation. Because DFU recurrence remains common and previous ulceration increases future risk, these concerns have a realistic basis; however, persistent worry without effective coping may develop into FoP [15-18].

Some participants expressed thoughts indicating anxiety, depression, hopelessness, or possible self-harm. People with diabetic foot disease are vulnerable to anxiety and depressive symptoms [19]. Clinicians should therefore assess fear, depression, and hopelessness at admission, during recurrence or prolonged treatment, and at follow-up. Persistent insomnia, severe self-blame, treatment refusal, or suicidal thoughts require immediate psychological crisis assessment, mental-health referral, and family-supported safety planning.

Painful dressing changes also intensified fear and treatment avoidance [20-22]. Pain should be assessed before procedures, with appropriate analgesia, comfort measures, and clear explanations of expected sensations. Financial costs, travel expenses, lost income, functional limitations, and fear of burdening family members may further undermine confidence and adherence. Clinicians should assess financial and insurance needs, connect patients with community and social resources, and encourage appropriate activity, social contact, and collaborative family participation in care.

4.2 Different beliefs about illness controllability shape coping responses

Patients’ beliefs about DFUs shaped fear and coping. After recurrent wounds, prolonged treatment, or poor outcomes, some concluded that DFUs were incurable or no longer worth managing. These beliefs reduced help-seeking, promoted treatment avoidance or discontinuation, weakened perceived control, and intensified FoP. Others believed that standard treatment could improve their condition and actively engaged in dressing changes, glycaemic management, and follow-up [23-25]. Their fear remained but was directed towards practical self-care. Thus, perceived controllability and treatment effectiveness are central determinants of coping.

Consistent with the Common-Sense Model, beliefs about consequences, duration, and controllability influence emotions and health behaviours [26]. Clinicians should assess beliefs at admission, recurrence, or treatment difficulty; correct assumptions that cure is impossible, amputation inevitable, or care burdens the family; and explain that glycaemic control, foot inspection, offloading, early management of abnormalities, and regular follow-up can reduce deterioration.

Self-efficacy can be strengthened through achievable goals, including daily sole inspection, avoiding barefoot walking, appropriate footwear, and prompt care for redness or exudate [27]. Clinicians should recognise completed self-care behaviours and co-develop feasible plans reflecting patients’ lifestyles, families, and preferences. Skilled wound care, compassionate communication, and reassurance may further sustain treatment engagement and acceptance [28].

4.3 Responding to needs for knowledge, self-care, and social support is essential for relieving FoP

Patients with DFUs often reported uncertainty about disease causes, glycaemic control, nutrition, wound healing, and treatment plans. Some recognised complication risks only after ulceration, whereas others lacked confidence in medication use or dressing changes because treatment rationales were unclear. Such knowledge gaps may increase illness uncertainty and FoP. Education should address individual concerns and explain links between glycaemic control, nutrition, foot inspection, warning signs, and wound healing. Illustrated materials, demonstrations, videos, repeated explanations, and teach-back may improve understanding, particularly among older adults and people with limited health literacy.

Patients also needed professional guidance for managing complex, exuding, malodorous, or frequently dressed wounds. Specialist clinics, telephone or online follow-up, and enhanced primary-care training could strengthen wound assessment, referral decisions, and post-discharge continuity. Patients and families should receive clear instructions on safe home-care tasks and warning signs requiring urgent attention. Family and peer support can assist with foot care, follow-up, emotional coping, and loneliness. Those living alone or with visual, mobility, financial, or family-support limitations require targeted assessment and assistance. Although remote monitoring may improve continuity, it should complement rather than replace timely, compassionate professional care.

5. Conclusion

FoP in patients with DFUs is influenced by multiple factors. Amputation, complications, pain, financial burden, and restriction of daily life constitute major stressors; beliefs about illness controllability influence passive or active coping; and inadequate disease knowledge, limited self-care capacity, and insufficient family and social support further increase uncertainty and fear. In addition to wound treatment, healthcare professionals should dynamically assess psychological status and risk of self-harm, provide individualised education, pain management, psychological support, and continuing care, and strengthen family participation and social support. These measures may improve patients' sense of disease control and self-care capacity, reduce FoP, and improve long-term rehabilitation experiences. This study was limited to the patient perspective and did not include family members, caregivers, or healthcare professionals. Future studies should use multiple perspectives and quantitative methods to examine associations among stressors, illness beliefs, social support, and FoP and to inform full-course psychological-behavioural interventions for people with DFUs.

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