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"I Never Thought They Would Ever Take Off My Toes": A Qualitative Illness Trajectory Study in People With Diabetic Foot Syndrome

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ABSTRACT

Diabetic foot syndrome (DFS) can be prevented, but due to various obstacles preventive measures can only be implemented inadequately. Person-centred care forms the foundation for effective support measures. However, the current lack of a longitudinal perspective on patients' Illness trajectory hinders the development and provision of tailored support. The aim was to describe the illness trajectory experienced by patients with DFS. To investigate the research question we used a qualitative design based on the 'Interpretive Description' and conducted a purposive sample of individual interviews in a university hospital's wound outpatient department. Data were analysed according to Braun and Clark's reflexive thematic analysis using the illness trajectory model as a theoretical framework. We included 12 patients with diabetic foot ulcers and recorded wound duration, number of ulceration recurrences and rate of amputation. We identified six illness trajectory-relevant phases: (1) silent or non-apparent diabetes mellitus (DM); (2) occurrence of the first wound: present DFS; (3) needing inpatient treatment; (4) from a mosquito emerges an elephant; (5) being in outpatient treatment and experiencing wound-free periods and (6) the occurrence of recurrences. Participants stated both self-management and care coordination behaviours regarding their treatment. However, due to knowledge gaps, misunderstandings or a desire for 'normalcy' and independence from the healthcare system as they juggled multiple comorbidity-related responsibilities, they often acted contrary to behavioural recommendations. 'Silent diabetes' is not always prioritised in disease management.

1 | Background

Diabetic foot syndrome (DFS) is a late complication of diabetes mellitus (DM) [1]. It involves all pathological changes to the foot of a person with DM [2]. Diabetic foot ulcers (DFUs) usually result from reduced pressure/pain sensitivity in the context of diabetic polyneuropathy, often in combination with peripheral arterial disease [3]. Overall, 15%–25% of people with DM eventually develop DFS, adding considerably to DM's personal and societal burdens. In 2020, the European prevalence of DFS was 5.1% [4, 5]. DFU treatment is associated with high healthcare costs [6]. In England, the costs for associated care (including amputations) in 2014–2015 were estimated at between £837 and £962 million—almost 1% of the entire National Health Service

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Abbreviations: APN, advanced practice nurse; DFS, diabetic foot syndrome; DFU, diabetic foot ulceration; DM, diabetes mellitus; ID, interpretive description.

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Summary

- A person-centred care approach is pivotal in the prevention and treatment of diabetic foot ulcers.
- The experience of 12 patients with diabetic foot ulcers was used to describe the illness trajectory. We identified six illness trajectory-relevant phases. Participants stated both self-management and care coordination behaviours regarding their DFS treatment and multiple comorbidity-related responsibilities. Due to knowledge gaps, misunderstandings or a desire for 'normalcy' and independence 'silent diabetes' is not always prioritised in disease management.
- We recommend compassionate and appreciative communication and the identification and consideration of the needs, perspectives and expectations of patients and their families in the context of all present illnesses.

Budget for that year [7]. With appropriate treatment, roughly 77% of DFU patients heal within 1 year [8]. However, recurrence rates are high: 40% in the first year, 60% within 3 years and 65% within 5 years [8, 9]. Approximately 50% of the associated ulcers become infected; and of those, 15% lead to at least one amputation—further amputations being common [4, 10]. For affected individuals, ulcers and associated amputations not only present a major health problem through to higher mortality rate [6] but also impair daily living activities. They lead to restricted mobility and changes in social roles and are a source of physical dysfunction, emotional stress and reduced quality of life [6, 11–13]. Many amputees report that amputation-related physical impairments lead to a feeling of dependency and powerlessness [12].

However, DFUs are preventable. It is estimated that at least 75% of all such ulcers could be avoided through high-quality preventive action [6]. The International Working Group on the Diabetic Foot (IWGDF) guideline identifies five key elements of effective prevention, including educating patients and their families and ensuring that appropriate footwear is worn routinely. The most important of these behaviours include daily foot inspection and foot hygiene, that is, avoiding behaviours that put the foot at risk (e.g., walking barefoot), wearing appropriate footwear, reporting any abnormalities immediately to healthcare professionals and receiving regular foot examinations from healthcare professionals [14]. But implementation of these preventive behaviours is often insufficient [6, 15]. In addition to cognitive or physical limitations, reasons include a lack of knowledge regarding DFUs' preventability and the fact that early symptoms are often barely visible or tangible. More problematically, as many patients do not fully grasp that they have a dangerous chronic condition, they neither sufficiently prioritise nor adhere fully to the preventive measures [6, 12, 13, 16–18]. Currently, no clear evidence indicates which patient education measures are most successful [19, 20]. In a 2023 umbrella review, Alshammari et al. found that most educational measures are based on a single intervention. It remains unclear to what extent these can reduce the development of foot wounds and improve patients' knowledge and behaviour. Complex interventions based on multiple measures appear to be more successful [20].

For people with chronic illnesses, the WHO recommends the concept of person-centred care. As the name implies, this approach is centred on people's health needs and expectations rather than diseases. Person-centred care operates from the perspectives of individuals and families, responding to their needs and preferences and empowering them to make decisions [21]. The biggest barriers to the implementation of the concept are a health system focused on acute care, a lack of patient involvement in decisions and inadequate communication skills and disease-related attitudes. In addition, there is a lack of appropriate vision in healthcare institutions and necessary standards as well as instruments and their substantiated evidence [22].

Managing diabetes and DFS requires a lifetime of work. Therefore, it could be helpful for person-centred care to know the illness trajectory from the patient's perspective. The concept of the illness trajectory is suitable for this purpose [23, 24]. The object of an illness trajectory is not to describe the physiological progression of an illness, but to systematically lay out the active role that patients and relatives can play in managing that progression, including the overall organisation of their work and the associated burdens. The specific stages and phases of the illness trajectory can be visualised on a curve [23, 24]. Each part of the curve corresponds to a particular management phase (x-axis). This corresponds to a set of necessary coping tasks as well as a degree of dependency (y-axis). By visualising the illness trajectory of people with DFS, the care team can help them maintain their quality of life. An illness trajectory is very individual and cannot be generalised; still, people affected by the same disease can have similar crises and experience a similar progression [23, 24]. The illness trajectory model has already been adapted to various chronic diseases, including HIV or cancer [25, 26]. However, there is currently no knowledge about the Illness Trajectories of people with a DFU. Visualising the illness trajectory of people with DFS can help care teams mainly in acute settings to focus less on those people's illnesses and more on their health needs and expectations and thus can help to make care more person-centred through deriving appropriate measures from it.

Therefore, our research question is: How do people with DFS experience their illness trajectory?

2 | Methods

This study is reported according to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist for qualitative research [27]. It was approved by the local Ethics Committee (Ethics Commission of Northwest and Central Switzerland, Project ID 2021-01494).

2.1 | Design

We investigated the research question using a qualitative design based on the 'Interpretive Description' (ID) [28] and a purposive sample with individual interviews. This research approach, which assumes that reality is multiple, subjective and created by individuals, enables a multitude of insights and perspectives from people in an increasingly dynamic context. ID was designed to create ways of understanding clinical phenomena that yield applications, which is why it is—amongst other disciplines—suitable for nursing practice [28].

2.2 | Context and Sample Selection

Data were collected in the outpatient wound clinic of a Swiss University Hospital. To include people with diverse experiences and perspectives, our sample selection aimed for a heterogeneous group with maximum variation regarding age, gender, comorbidities, duration of existing DFUs, recurrence rate, self-management and quality of life [28]. Patients were included if they were treated in the hospital's outpatient wound clinic, were aged > 18 years, spoke German and had at least one acute DFU. Those who were incapable of giving informed consent or were unable to participate in data collection due to an acute deterioration in their general condition were excluded. Participants were recruited via a personal enquiry by their wound expert (JW) during their treatment. After 12 interviews the research group decided that enough data had been collected to draw the necessary conclusions and any further data collection would no longer produce any insights with added value.

2.3 | Data Collection

The guided individual interviews took place between September 2021 and April 2022. These consisted of open questions about the illness trajectory and were conducted by one person (SL) in a suitably quiet, private room. Field notes were taken, audio recordings made and transcriptions later made. To ensure the sample's heterogeneity, each participant's current quality of life was recorded using the 'Wound Quality of Life (Wound–QoL)' questionnaire [29]. This measures disease-specific health-related quality of life in patients with chronic wounds and has sufficient validity and reliability [30]. Wound–QoL scores range from 0 to 68 points, with higher scores corresponding to lower disease-specific health-related quality of life [31]. Additionally, foot-related self-care was recorded using the 'Frankfurt Catalogue of Self-Care Activities–Prevention of Diabetic Foot Syndrome (FAS-PräDiFuss)' [32]. Scores range from 0 to 76, with higher scores indicating adequate disease-related self-care. The FAS-PräDiFuss is a valid and reliable instrument for practice and can be used to measure disease-related self-care for the prevention of DFS, which we wanted to demonstrate in our population [33].

To obtain the most complete information possible, all data collection instruments were sent to the patients before the interviews.

Socio-demographic (e.g., age and gender) and clinical data (e.g., type of diabetes, duration of wound, amputations and comorbidities) were extracted from patients' clinical records.

2.4 | Data Analysis

The data were analysed by an interprofessional research team, first according to Braun and Clark's reflexive thematic analysis in six steps (Table 1) [34, 35], then as part of an iterative analysis process [35]. For this process, we used the MAXQDA (version 22.2.1) analytical software package. Subsequently, to represent the themes systemically, we used Corbin and Strauss' trajectory model as a theoretical frame of reference. We used frequencies, means and medians to describe our sample.

TABLE 1 | Reflexive thematic analysis in six steps.

Braun und Clarke's six steps of thematic analysis [34, 35] and the authors' roles	
1. Familiarisation with data	The interviews were transcribed by the first author (SL) and subsequently read and listened to several times to develop an overall understanding of the data. Initial ideas for codes were noted.
2. Generation of codes	Text passages were coded by the first author (SL) with a focus on the research question. Similar content was labelled with the same codes.
3. Generating themes	The interprofessional research team (SL, MC, JW, RS and EMP) regularly discussed the codes and possible themes based on the interview content.
4. Reviewing themes	The interprofessional research team (SL, MC, JW, RS and EMP) checked whether the themes matched the overall data set. Similarities and differences were identified and discussed.
5. Defining and named themes	The analysis was continued within the interprofessional research team (SL, MC, JW, RS and EMP) and themes clearly identified vis-à-vis the research question. Corbin and Strauss' trajectory model was used as a theoretical frame of reference to systematically present the themes.
6. Reporting of findings	The first author (SL) wrote a first draft of the scientific report and selected quotes to illustrate the themes. The report was presented to the interprofessional research team (MC, JW, RS and EMP) several times for critical evaluation and continuously adapted accordingly.

2.5 | Quality Criteria

The trustworthiness of the reported research are supported by a comprehensive description of the study protocol, a purposive sample covering a variety of perspectives, the use of direct quotes from study participants (within the Section 3) and the research team's regular reflection on and discussion of the data collected and analysed within the triangulation process [36].

3 | Results

3.1 | Sample

We interviewed eight men and four women ($n = 12$) aged 32–80 years (mean: 61 and median: 67). The 12 interviews lasted an average of 63 (range 39–91) min, with data saturation achieved in all cases. Nine participants reported DM-associated comorbidities. In four, their current DFU had existed for less than 6 months; in one, their current DFU was their first and in five, DFS had led to amputations on the affected foot. Details of the participants' socio-demographic and health-related data are summarised in Table 2.

With scores ranging from 3 to 45 points, the sample had a medium to high disease-specific health-related quality of life (mean: 21 and median: 22) and 'rather adequate' to 'adequate' foot-related self-care (range: 33–61, mean: 49 and median: 51).

3.2 | Illness Trajectory of People With DFS

We identified six phases in the illness trajectory of people with DFS: (1) pre-trajectory phase: silent or non-apparent DM; (2) trajectory onset: occurrence of the first wound: present DFS; (3) acute phase: needing inpatient treatment; (4) crisis: from a mosquito emerges an elephant; (5) stable phase: being in outpatient treatment and experiencing wound-free periods and (6) unstable phase: the occurrence of recurrences.

Exploring these topics revealed various sub-topics. 'Dependency' was also explained in more detail (Figure 1).

Pre-Trajectory Phase: Silent or Non-Apparent DM

In this phase study participants either learned about their DM for the first time when they were diagnosed with DFUs or knew about the underlying disease but were unaware of the importance of preventive measures.

One-third of the study participants did not know that they had DM before the onset of diabetic foot ulceration. They only learned of the diagnosis when they visited healthcare institutions because of their ulcers.

> P2: "Just then I was… in this surgery department and … then I was diagnosed with diabetes, which I didn't know before."

Two-thirds of participants had already been diagnosed with DM before the appearance of their first DFU. This occurred

TABLE 2 | Characteristics of the final sample ($n = 12$).

	Number	Percentage (%)
Gender		
Female	4	33
Male	8	67
Age		
< 40	2	17
40–65	3	25
> 65	7	58
DM type		
Type I	2	17
Type II	10	83
Comorbidities		
DM associated (e.g., cardiac diseases, renal insufficiency, polyneuropathy and diabetic retinopathy)	9	75
Other (e.g., rheumatism, arthrosis, psoriasis and spinal stenosis)	3	25
Duration of wound problems		
< 2 months	3	25
2–6 months	1	8
> 6 months	8	67
Recurrences		
Yes	11	92
No	1	8
Amputation (only minor)		
Yes	5	42
No	7	58
Nationality		
Swiss	11	92
Abroad	1	8
Living situation		
Living alone	5	42
Not living alone	5	42
Nursing home	2	16
Support requirement		
Yes	6	50
No	6	50

(Continues)

TABLE 2 | (Continued)

	Number	Percentage (%)
Employment		
Employed	2	17
Retired	8	66
Unemployed	2	17

on average 21 years after diagnosis. However, many were not particularly concerned about this development, partly because, considering their comorbidities, they did not see DM as a priority. Until the first wound appeared, some were not even aware of what DM entails or of the importance of self-management regarding the prevention of secondary and concomitant diseases.

> P8: "I thought it was all good and this little bit of diabetes, in God's name and that's it…"

Even after experiencing DFUs for months or years, some participants persistently failed to grasp the disease's danger. During their initial diagnoses, several recalled receiving information not only on DFS's pathophysiology and long-term consequences but also on diabetes management; however, they could no longer explain either in detail. Some reported hearing that good foot care is important for DM.

Trajectory Onset: Occurrence of the First Wound: Present DFS

In this phase, participants usually discovered their first wounds by chance and initially treated them according to their experience until this reached its limits.

Most people discovered their first wound by chance when they noticed wound fluid. In most cases, though, they were unable to determine the wound's origin.

> P12: "Then my wife said… you're bleeding somewhere on your foot… and then we realised that the big toe on the right foot had burst open… I thought maybe it was from the safety shoes or something."

In some cases, the initial wounds were discovered by a podiatrist. Some participants who noted a decline in their general condition visited their general practitioner or hospital. There, ulceration was detected and identified as the cause of their deterioration. Other DFUs were precipitated by accidents caused by walking barefoot (e.g., stepping on a piece of broken glass) or arose from other medical conditions and procedures (haematoma evacuation as part of a coagulation disorder and infection of osteosynthesis material).

Most of the participants initially treated their wounds themselves, only consulting medical professionals weeks or months later, when they noticed signs of inflammation or felt fever and

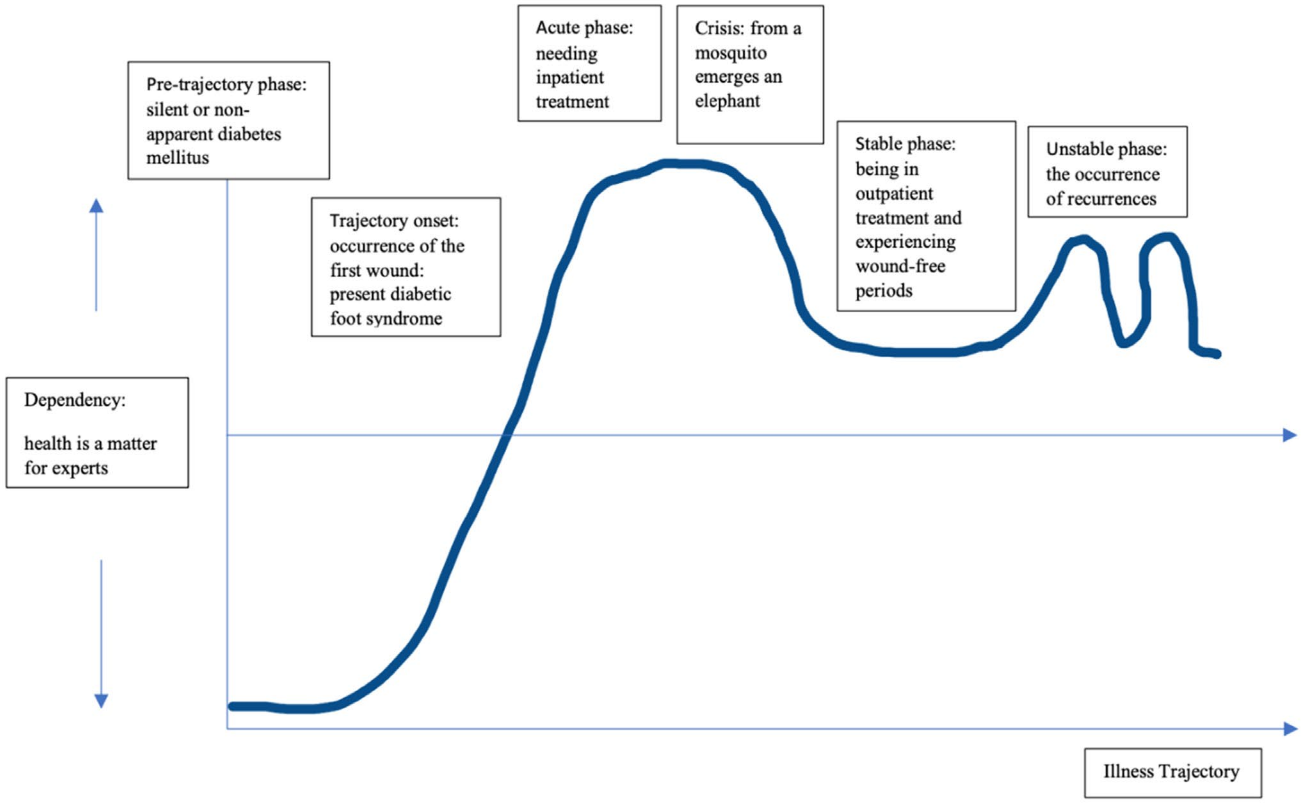

FIGURE 1 | Themes within the illness trajectory of people with diabetic foot syndrome.

chills. Participants followed their judgement until they reached their personal boundaries.

> P9: "No, I didn't go to the doctor. I went through everything… and then there were difficulties and it got to the point where I lost a piece of toe."

In some cases, even after people sought clinical help, their medical specialists, including nurses, podiatrists or general practitioners, found that the problem was beyond their expertise and referred patients to experts in hospitals or wound clinics.

Acute Phase: Needing Inpatient Treatment

After long delays before seeking clinical care, participants' first meetings with foot ulceration specialists, the deterioration of their wounds typically led directly to inpatient treatment. This usually involved prolonged bed rest, often accompanied by surgical interventions (debridement or amputation) as well as intravenous antibiotics and offloading through bed rest.

Because participants did not understand the need for offloading, they found the bed rest difficult to accept.

> P5: "I didn't see the point or benefit because I was lying here most of the time and couldn't do anything."

All study participants reported improvement in their wounds following hospitalisation and surgery, with several even reporting full wound healing. Inpatient treatment was usually followed by outpatient wound care.

Crisis: From a Mosquito Emerges an Elephant

Even as participants repeatedly described their wound as 'bagatelle', they had begun to grasp their effects and the threats she carried of amputations and long-term restrictions. Maintaining their quality of life was now a central goal.

> P1: "Yes, actually if you look at it like that, you can say it's almost a bagatelle, but it's not."

Participants confronted with the need for amputations were in shock. Most knew from relatives with the same condition that amputations could occur in DM. Nevertheless, none fully transferred that possibility to their own situation.

> P8: "Of course, I never thought that they would ever take off my toes and stuff… they said it as a matter of course, yes, now we have to take off the toe… and then I thought, no, that can't be right now."

DFUs led to long-term restrictions for all participants. The necessary wound care was experienced as very time-consuming, whilst the therapeutically necessary offloading impeded activities of daily life. With one exception, all study participants still working were on sick leave of between 50% and 100%. For most, then, this meant financial losses and was perceived—especially by the younger ones—as a major burden. Two lost their jobs during the course of their illness.

> P2: "The longer it takes, the more I realise that it has an impact both professionally and privately."

Sometimes, to live normally and maintain their quality of life, participants disobeyed therapeutic recommendations. All negotiated workable levels of adherence to their therapeutic regimens with their healthcare professionals.

> P7: "Sometimes I listen and then I think, yes, I'll take out what I think is right for me."

Stable Phase: Being in Outpatient Treatment and Experiencing Wound-Free Periods

Participants reported stability when undergoing outpatient treatment. They came to terms with the longer-term treatment and the protracted healing of the DFUs and were satisfied as long as the wound did not show any acute deterioration.

All study participants reported notable periods during which they regularly consulted the outpatient wound clinic. They appreciated the outpatient wound care service as it enabled them to fulfil their daily routines. Although they found attending appointments at the outpatient wound clinic time-consuming, they grew accustomed to the dressing changes, which usually had to be carried out daily, with wearing a relief shoe and with the need to schedule and attend regular appointments.

> P2: "Yes, it was a real adjustment at first, but it's really become a routine for me now. You know you have to. You have to do it."

Many participants emphasised that, during their outpatient treatment, they had received important information on foot care activities they could do for themselves.

Participants' dread of sudden deterioration was as present amongst the study participants as their desire for healing. This explains why many were satisfied with slow or stalled wound healing.

> P1: "Yes, that's everyone's wish, being healthy…, but if it stays like this now or doesn't get worse, I'm happy too."

Wound-free phases lasting between 4 months and 9 years were also reported. During this time, participants appreciated being able to carry on with their normal life activities.

Unstable Phase: The Occurrence of Recurrences

Wound recurrences or worsening wound conditions were frequently reported as setbacks on the path to a DFU-free life.

Participants described their illness trajectory as a series of unpredictable 'ups and downs', during which powerlessness and uncertainty were their constant companions.

Most participants had experienced wound recurrences. They were repeatedly confronted with new wound diagnoses, often feeling depressed as a result. This explains their perception of the illness trajectory being an 'up and down'.

> P5: "Yes, there are always ups and downs. When things get better again, then you're happy again. And then that thing comes again, that crack. It hasn't always been easy, it's not always easy now either."

Due to the changing condition and the protracted nature of the illness, those affected repeatedly found themselves at the limits of what they and their care teams could do. This engendered not only a sense of powerlessness and insecurity but a tendency to question their own actions.

> P5: "You also ask yourself from time to time, 'What am I doing wrong?' or 'What is not good?'"

Dependency: Health is a Matter for Experts

Participants showed a relatively high level of dependence both on medical professionals and on relatives throughout the illness trajectory and generally believed they were doing everything they could. Interruptions in care occurred only when participants paused it or when podological treatment was discontinued, for example, due to retirement or pregnancy from podiatrists.

Participants received considerable support from specialists and relatives throughout their illness trajectory. Managing their ulceration meant dealing with 5–10 stakeholders (median: 7), for example, podiatrists, wound experts, doctors, nurses and medical supply stores. In addition, up to 11 other stakeholders (median: 3 and range 0–11) were involved in their DM management, endocrinology and diabetes counselling, and other comorbidity treatments. The participants acted as 'care coordinator' for all these stakeholders, for example, by coordinating appointments and ensuring the flow of necessary information between the stakeholders.

Due to physically limiting comorbidities, relatives or medical professionals often took over the foot inspections and changing of dressings. Some participants stated that they ensured regular foot inspections via regular check-ups at the outpatient wound clinic and podiatrist consultations.

Participants stated self-management abilities. Regarding DM management, all reported taking either oral antidiabetic drugs or insulin. Some also reported restricting their diets and exercising regularly, as well as scheduling regular HbA1c check-ups with their general practitioner or endocrinology department.

Methods of regular blood glucose level measurement varied. Regarding wound management, only younger or more flexible participants could generally change dressings without assistance. Most participants regularly attended appointments at the outpatient wound clinic for ulcer treatment. Although all participants wore orthopaedic aids for offloading, some admitted to not wearing the therapeutic shoe regularly and walking barefoot often. All but two had shoes custom-made in an orthopaedic shop. All but one visited a podiatrist regularly. Whilst their accounts of foot self-care activities were imprecise, several reported inspecting their feet and applying foot cream rather irregularly, if at all.

Podiatry was considered essential: podiatrists both safely remove calluses and provide regular, high-quality foot care and foot inspections. All participants knew that the feet should only be treated by a medical podiatrist. However, where participants' podiatric care was interrupted (e.g., due to the podiatrist's retirement and pregnancy) or they failed to attend their outpatient wound consultations, their DFUs worsened.

4 | Discussion

The aim of this research project was to evaluate how people with DFS experience the illness trajectory. To achieve that aim, the current study presents the first systematic description of the illness trajectory of people with DFS. Apart from the participants' predominantly Swiss nationality and, in comparison with other studies, rather positive ratings for health-related QoL and foot-related self-care, their heterogeneity produced a broad spectrum of experiences and perspectives [16, 37].

The participants' experiences showed that people with DFS experience six phases in their illness trajectory. A stable phase is repeatedly replaced by an acute or unstable phase, leading to a sense of powerlessness and uncertainty. Those affected are unsettled. This manifests itself strongly in how they view the future and the possibility of recovery but above all in how they believe they should deal with their illness [13].

Major characteristics of the DFS disease trajectory echo those seen in other disease populations. For example, the fluctuation between unstable and stable phases is also seen in the trajectory model of people with mental illness—a population who, like our DFU sample, live with high recurrence rates [8, 38]. Similarly, our group's insecurity also belongs to the illness trajectory of those with metastatic breast cancer and HIV/AIDS [25, 26]. During the stable phase in the illness trajectory of people with DFS, it came sometimes to a regression of symptoms (remission), which was also observed in the illness trajectory of people with cancer [39]. However, unlike the trajectory models for life-limiting conditions such as metastatic cancer or multiple sclerosis, in which Corbin and Strauss identified specific declining and dying phases [40], we observed no such phases affecting our DFS group.

Knowledge deficits and a lack of understanding of the overall condition, as well as experiencing significant limitations in daily activities, posed an ongoing challenge for participants in implementing preventive and therapeutic measures.

Some respondents stated that they were not particularly concerned about their DFS, as they saw the management of other comorbidities as more important. The Health Belief Model assumes that individual beliefs and perceptions are major determiners of health behaviour—an idea that would explain why people do or do not take preventive health measures [41]. If a person believes that their illness is serious and threatening, they are more likely to adhere to treatment recommendations than if they consider it less of a threat [42]. The fact that our study participants considered the treatment of their comorbidities to be more important could be related to their health beliefs and in turn explain their behaviour. This is why it is important for health professionals to get to know the health beliefs of patients with DFS so that they can provide information that is personally relevant to the patients or explore with the patients the possibility of lifestyle changes or treatment. It is also possible that DFS's lack of discernible symptoms, until the onset of ulceration, may lead those affected to perceive it as less of a threat. Such an underestimation might also explain their failure to implement self-management activities, whilst prioritising more noticeable comorbidities. In addition several studies confirm that the gradual, 'silent' onset of diabetes gives those affected little reason to take action [6]. It is possible that the disease remains undetected in some people for the same reason. According to the International Diabetes Federation, one in two adults were unaware of their diabetes in 2021 [43]. To improve the prevention and management of DFUs, healthcare professionals will need to understand DM and all its facets and get to know the individual situation of the patients to support them person-centred. And hopefully, promoting professionals' understanding of the situations of people with DM (with or without ulceration) will prevent many from simply stigmatising people with DFUs as 'non-compliant'. It is also an excellent basis for a respectful and trusting interpersonal relationship, which is essential for person-centred care [22].

In our sample, then, wounds were mostly discovered by chance, with the causes being unclear. Unaware of the need to seek immediate medical care, most initially attempted to treat themselves before finally consulting with a physician. This situation is common [13]: Ma et al.'s meta-synthesis confirms that, as many patients do not associate foot wounds with DM, they do not immediately seek medical advice. In some cases, however, even those who do recognise the connection delay seeking treatment—most commonly via hospitals, wound clinics or general practitioners [13]. Delays can have severe consequences. An estimated 40%–60% of amputations occur due to late reporting by patients [44].

In addition to increasing the risk of ulcer formation, diabetic neuropathy can distort people's attitudes towards the affected body parts. Risse notes that when a person loses sensation in their extremities, they may develop 'body island atrophy', that is, a sense that the numb parts—in this case, their feet—are environmental islands separate from their body [45].

Once people with DFS are receiving regular care, Zhu et al. [44] note a tendency towards passivity regarding their care teams' actions; however, our participants played active roles in their care. In addition to self-management regarding their DM, DFS and DFUs, all acted as their own 'care coordinator', coordinating consultations and disseminating relevant information as necessary. Their only non-adherence to behavioural recommendations was linked either to knowledge deficits or to a desire to be as 'normal' and as independent as possible from the healthcare system.

The majority of our participants seemed resilient and determined, facing setbacks but maintained hope and engaged actively in their care. This was congruent with Ma et al.'s conclusion that people prone to DFUs do their best and maintain hope for the future despite the challenges [13]. However, as all of our participants suffered from comorbidities, which also demanded attention [23], silent diabetes and the DFUs were often afforded low priority.

Current guidelines recommend educating patients and relatives regarding DFS and DFU [46, 47]. This promotes both the prevention and early detection of ulcers via daily foot inspections. In the context of person-centred care, this strategy first anticipates and prepares patients for the possibility of DFS-related health needs, then responds to those needs if they arise by supporting them to participate in their own care. The six illness trajectory phases identified above can help medical professionals and family caregivers to better understand and meet DFS-related needs and perceptions and to meet them with empathy [22].

Gethin et al. observe that person-centred care in the treatment of chronic wounds has improved outcomes regarding patient knowledge, satisfaction and quality of life [48]. This requires a comprehensive person-centred anamnesis and specific assessments at the start of treatment to form an overall view not simply of the illness, but of the situation and needs of the person in question. Some study participants had reasons why they deliberately did not implement recommended preventative or therapeutic measures, for example, because recommendations restricted everyday life too much. In this case, healthcare professionals should either find ways with the patients in which they can maintain their everyday lives as much as possible or they can try to motivate patients to change their behaviour by applying models like the behaviour change wheel or the transtheoretical model and behaviour modification techniques such as motivational interviewing, to help to minimise risky behaviour [46, 47, 49]. Based on the available evidence, it is also recommended that professionals clearly communicate to patients who is responsible for which tasks in the treatment process, as this can improve patients' foot-related self-care [50].

In this study, participants reported that, throughout the illness trajectory, they had contact with a wide range of specialists. Considering the complexity of the underlying disease, current guidelines recommend a multi-professional approach to the treatment and prevention of DFUs [51, 52]. An advanced practice nurse (APN) could make an important contribution to a DFS care team within a multi-professional approach. APNs' extended evidence-based medical and nursing knowledge enables them to comprehensively assess a patient's situation and plan appropriate care. They can also support and promote the development of patients, their relatives, other care providers and treatment teams. With a comprehensive understanding of the entire treatment process, APNs are trained both to coordinate diverse interdisciplinary or interprofessional roles and to advocate for patients and their relatives [53]. To relieve each affected person's burden as a 'care coordinator', healthcare professionals should try to better coordinate interprofessional and interdisciplinary interfaces, for example, via interprofessional and interdisciplinary progress documentation, which can avoid duplication, omission and loss of information. APN's could also take on coordinating tasks here and ensure continuity in the treatment process.

For this study's participants, podiatry was a 'fixed star'. The correlation between interruptions in podiatric and setbacks in progress suggests that it factored importantly in our participants' relatively good scores for foot-related self-care. However, there is a shortage of trained podiatrists in Switzerland [54], which may explain the longer interruptions in care in this context in our study.

Whilst current guidelines recommend regular foot care for persons with DM [51, 52], the current shortage of podiatrists often means not only that they receive no preventive treatment, but that they often arrive at wound clinics weeks or months after the appearance of ulcers. To correct this problem, we recommend that policymakers launch targeted measures to ensure an adequate supply of podiatrists. In the Swiss context, this would mean both training new podiatrists and recruiting experienced ones from elsewhere. Until the current supply–demand gap is bridged, healthcare institutions should consider offering telemedical foot consultations by trained healthcare professionals. After all, as we saw during the Covid-19 pandemic, telemedicine showed high value as an alternative to face-to-face treatment [55].

5 | Strengths and Limitations

This study's main strength is that, for the first time, it systematically describes the illness trajectory of people with DFS, thereby providing valuable insights for prevention and management. Additionally, its results' validity was increased by the research team's regular discussion of the data. Still, we cannot rule out selection bias: Our sample was comprised entirely of patients from one university hospital, most of whom were receiving treatment for critical wound conditions, but none of whom were subject to poor quality of life or inadequate foot care. Also, because of language barriers, we had to exclude typical patients with migration backgrounds. Therefore, the transferability of our results to other settings is limited.

6 | Conclusion

This study shows that, even before people with diabetic foot ulceration are treated in an outpatient wound clinic, they normally have a long DM-related journey behind them.

Regarding our sample's DFS illness trajectory, each of the six phases identified above involves a set of coping tasks. However, as any comorbidities have their own demands, we found that these commonly take priority over 'silent diabetes'. To ensure that persons who develop DFS both receive the necessary assistance and practice good self-management practices, we recommend that their care team members follow the principles of person-centred care. In relation to the results of our study, person-centered care means that people with DFS are approached without prejudice, knowing their care and disease progression, and that needs-oriented support depending on the phase is offered to them and their relatives—similarly, Healthcare professionals should be empowered to provide this support.

Finally, regarding recommendations for future research, each of our illness trajectory phases should be verified and developed in other settings and samples.

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Ethics Statement

The study was approved by the Ethics Committee of Northwestern and Central Switzerland (Project ID 2021-01494). Study participants were informed verbally and in writing about the study and informed consent was obtained from all of them.

Consent

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts 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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