Preventing Diabetic Foot Ulcer: Lived Experiences of Patients with Diabetes
Authors

• David Oni  PhD, MSN, RN
• Julie Postma PhD, RN
• Phyllis Eide, PhD, MN, MPH, RN
• Gail Oneal, PhD, MN, RN
• Joshua Neumiller, PharmD, CDE
Purpose

To explore the lived experiences of patients with type 2 diabetes and DFUs regarding their foot self-care practices.
Background

• An estimated 422 million adults are living with diabetes mellitus (DM) globally and Over 30 million in the U.S.

• Diabetic foot ulcers (DFUs) are one of the most significant and devastating complications of diabetes mellitus.

• Each year, nearly 80,000 Americans have DFU-related amputations.
Background

• Preventive foot care practices are recommended by American Diabetes Association’s (ADA) for preventing DFUs.

• Patients do not routinely comply with these foot care recommendations and the reasons for non-adherence are less evident. Few interventions have been successful.

• A gap exists between what healthcare providers recommend versus the actions taken by diabetic patients
Significance of the Problem

- Incidence rates
- Mortality rates
- Re-ulceration rates
- Prolonged hospitalization
- Amputation, and disability
- Quality of Life
- Healthcare system
- Cost of Management and Care
- Cost to Patients and Families
Research Design: Phenomenology

Descriptive phenomenological design

• Edmund Husserl’s Approach

• Bracketing

• Description of the Universal Essence

• Pure and Thick Description of a Phenomena
RECRUITMENT CRITERIA

INCLUSION
- Adults with type 2 diabetes
- Diagnosed with diabetic foot ulcers
- Speak, write, and understand English
- Agree to provide informed consent and be digitally recorded for 45-90 mins.

EXCLUSION
- Unable to read, speak or write English
- Patients with type 2 diabetes who do not have diabetic foot ulcers
RECRUITMENT AND SAMPLE

Recruitment Sites
Podiatric Clinics in the State of Washington

Preliminary telephone interview

Purposive Sampling
Criterion

15 participants (Saturation)
Data Collection

Semi-structured interview

• Informed Consent
• Demographic questionnaire
• 30-90 minutes digitally recorded interview
• Field Notes.

• Interview Questions/

“Can you please describe, in as much detail as possible, how you take care of your feet?”
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (Years)</strong></td>
<td></td>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;60</td>
<td>7 (46%)</td>
<td>≤High School</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>60-69</td>
<td>4 (27%)</td>
<td>Some college</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>&gt;70</td>
<td>4 (27%)</td>
<td>Associate degree</td>
<td>2 (13%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bachelor’s degree</td>
<td>1 (7%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td><strong>Master’s degree</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (46%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8 (54%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Income level</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤19,999</td>
<td>2 (13%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20,000-39,999</td>
<td>5 (33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50,000-69,999</td>
<td>5 (33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70,000-79,000</td>
<td>2 (13%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;100,000</td>
<td>1 (7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>14 (93%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Native American</td>
<td>1 (7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>5 (33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>4 (27%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>6 (40%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of Diabetes Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>3 (20%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>1 (7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-10 years</td>
<td>4 (27%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>10 (66%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>7 (46%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4 (27%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>2 (13%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Windowed</td>
<td>1 (7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of DFU Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>3 (20%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>9 (60%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-10 years</td>
<td>3 (20%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Lack of Initial Awareness and Information on Foot Self-Care

• **Theme cluster:** *Issues with information about foot self-care and DFUs*

• **Theme cluster:** *No advance warning*

• **Theme cluster:** *Foot care is not a perceived priority*
Exhaustive Description: Emergent Theme 1

Research participants, at the time of being diagnosed with type 2 diabetes, lacked awareness about foot self-care or DFUs. Most participants recalled no warnings from their primary care providers about the possibility of developing DFUs nor did participants recognize the importance of preventive foot self-care at the time of their diagnosis with diabetes. This lack of initial warning and/or recognition impacted patients’ perception of the risk of developing DFUs and their prioritization of foot self-care practices.
Exhaustive description for emergent theme 1

This lack of awareness impacted foot self-care practices. Participants did not understand how to inspect their feet, or what they should be watching out for. Thus, most were not paying close attention to their feet, or taking foot self-care seriously. The appearance of DFUs was often sudden and unexpected because most participants missed the early signs and symptoms. This was often due to neuropathy which made it difficult to feel when a DFU was developing.
Summary of quotes for emergent theme 1

- "I don’t think I ever have had anybody tell me what I could expect from my feet and why it’s so important to take care of them" (P6).

- "In the hospital, they – they rarely spoke about taking care of my feet at all. They spoke about what was going on with them and the seriousness of it. But as far as any kind of preventive care or any kind of ongoing care, they never spoke about it at all" (P10).

- “Nobody wants to listen. No doctors [primary care providers]. The doctors just want to try to prescribe something else, but they don’t want to listen to the fact that there’s more than one thing going on in my body. All they want to look at is the diabetes. The diabetes is not me" (P13).

- “And I had no advanced warning for the first toe. I had like a hard lump that started and it hadn’t even busted or anything” (P1).
Summary of Quotes for emergent theme 1

“Eight or nine months ago – maybe eight months ago, I had gotten out of the shower and I looked down at my foot, and I noticed it was black on the end of it. And that toenail was always black anyway. And so I reached down and kinda flicked it, and a chunk of my toe came off. The end of it” (P14).

But, um, I just never really paid attention to it ‘cause I never had any problem with ‘em up until about four years ago” (P14).

“Before I got the one [DFU] on my toe. So I was pretty lax, not checking my feet at that point” (P5)
Emergent Theme 2: DFU and Its Consequences Is a Wake-up Call to Adapt to a New Reality

• **Theme cluster:** DFU and its consequences is a wake-up call

• **Theme cluster:** Developing awareness and recognition about DFU conditions, treatments, and foot self-care

• **Theme cluster:** Foot self-care is evolving

• **Theme cluster:** Adapting and adjusting to a new reality

• **Theme cluster:** Foot self-care behaviors and practices
Exhaustive description for emergent theme 2

DFUs and their consequences became a wake-up call to adapt to a new reality of being vigilant about foot self-care. Participant foot self-care practices continued to evolve based on their new reality. Participants reported that they were taking more preventive actions, developing awareness about DFUs and foot self-care, and taking more responsibility to care for their feet. Most participants admitted being “poor at it [foot self-care] before” but were now being more proactive about foot self-care by paying more attention to their feet and finding new strategies to inspect and protect their feet.
Exhaustive description for emergent theme 2

Many participants were developing new habits, and positive emotions about foot self-care. For example, when they felt an ulcer developing, participants sought immediate medical intervention. However, some participants disregarded foot care recommendations and sought solutions through unhealthy foot self-care practices in a quest to make their feet comfortable and continue with their preferred lifestyle. Participants wanted more emphasis on foot care as part of diabetes education at hospitals and clinics.
Summary of Quotes for emergent theme 2

“I’m aware of now, it [diabetes] does affect your feet a lot” (P6).

“And since then, I was, you know, very much, um, aware that I have an issue with that I can’t let a blister go too long" (P12).

“I didn’t really worry about my feet a lot until I got diabetes and started realizing that even little things like an ingrown toenail wouldn’t heal... you need to bring that and say this is just as serious as anything else" (P10).
Summary of Quotes for emergent theme 2

“Well, I was poor at it before I got the sore... I was ignoring that. I was pretty much in denial, I guess. ‘Cause I wasn’t checking my feet until I got that diabetic ulcer.... Then I have been more vigilant” (P5).”

"I keep ‘em clean. Keep ‘em, um, protected. Most of the time, I wear shoes. I always wear shoes and keep the sugar levels under control" (P2).

"And so that experience, you know, I’m just always on the lookout for foot care, you know? I just need to have it" (P12).

“I want to do the best I can to take care of myself" (P12).

“Because I really should not be going around the house, I should not be going barefoot. I should have something on my feet... if I drop a glass or if my wife happens to drop a plate and we’ve got something broken, I will stay out of that area” (P14).
"I still love to mow the grass without any shoes on, though. But that’s I guess that’s how I’m doing it" (P3).

"And I go barefooted a lot of times, which I shouldn’t be doing, and I bump into things...I hurt it really bad and almost lost one of my toes" ...When I’m around the house, I don’t wear shoes or slippers...And it’s an easy fix. I just don’t like wearing shoes" (P6).

“I like to go to buffets. I eat all I want to eat... I drink what I want to drink. You know, and that’s what my problem is... it just depends on how much you want to make it work. I haven’t wanted to make it work" (P8)
Emergent Theme 3: “It is ongoing: Challenges “across the spectrum [life dimensions]”

- **Theme cluster:** Treatments and care are continuing challenge

- **Theme cluster:** “It is ongoing: It [DFU] never gets better”…”It’s been a battle”

- **Theme cluster:** Other negative emotions and feelings

- **Theme cluster:** DFU is creating life challenges outside of foot care

- **Theme cluster:** Foot self-care is overwhelming and a continuing challenge
Exhaustive Description for Emergent Theme 3

The sudden onset of DFUs, followed by the rapid foot infection, and the unexpected loss of toes, resulted in diverse challenges which impacted participants’ lives across the spectrum. Treatment of DFUs was a continuing challenge. DFU treatments created additional problems because treatment was difficult, time-consuming, and financially burdensome. Moreover, DFU treatments were not working as expected by participants. To many participants it seemed that there was no cure for DFUs, irrespective of what was done. The ongoing nature of DFUs made people feel helpless, defeated, and hopeless.
Exhaustive description for emergent theme 3

Participants experienced a range of other negative emotions such as feeling disabled, angry, scared, regretful, devastated, irritated, horrible, frustrated, and skeptical. They also felt inadequate, embarrassed, tired, and depressed. Most participants experienced limitations to everyday life which adversely impacted their lives. Participants described their experience with DFUs as a daily ‘up and down battle’ which has no end in view. Many participants described foot self-care as overwhelming, and a continuing challenge. Feet were difficult to inspect due to physical limitations that constrained visualization and feeling; this impeded adequate wound care and foot monitoring. Participants reported foot self-care as time-consuming, tiring, a nuisance and inconvenient.
Summary of Quotes for emergent theme 3

"But obviously, they [DFUs] don’t stop. They keep comin’…I’ve had ‘em come back like eight, nine times, in a matter of four years” (P2).

“Just keep goin’, and it [DFU] will never get better. It’s an ongoing, all the time” (P1)

"There’s no cure. It’s going to get worse and worse and worse" (P9).

"It makes me feel helpless, I guess would be a word” (P7)

"A little angry. I mean, it cost me two toes. You know, could that have been prevented?” (P13).

"It makes me scared afraid because there’s no end" (P9).

“I should’ve listened. I should’ve taken better care of myself. It wouldn’t kill me to miss a few buffets" (P8). “It makes you feel real disabled” (P2).
Summary of Quotes for emergent theme 3

"And I just got some surgery done or I had another amputation done... It’s depressing " (P12).

“I’m embarrassed because that was preventable” (P14).

"It makes me feel like I wasn’t heard. You know, what I wanted, what my feet wanted" (P7).
"It’s a day-to-day challenge whether I could get up and walk around or not. You know, it’s kinda – you’re stuck in bed" (P11).

“Well, to save time so I can get back to work, let’s just cut her [toe] off. So that’s what we did was cut her off at that point because it wasn’t healing real quick." (P3)

"Financial challenges...there’s some physical challenges... lack of energy...concerns about work. Um, I have people filling in for me while I’m taking it easy. I’m not supposed to be on my feet that much " (P12)
"And I had never been this heavy before...I gained so much weight. So that’s the main reason I can’t reach my feet. I’ve lost a lot of weight, but it’s still difficult" (P6).

"Um, when I’m on the road, you know, it’s not like I’ve got a bathroom I can walk into to wash my feet or do anything...I take a shower about once a week." (P8).

“But it’s just a real nuisance. I have to get up a half-hour earlier just to make sure I have time to check everything out and re-wrap stuff and make sure things are ready to go... it’s a disincentive for doing a good job...And you get tired of doing it every day” (P15).

"Just challenging to understand everything you need to know to take care of yourself " (P13)

“I was always trying to get something very comfortable... I didn’t care what they looked like. I just wanted something comfortable" (P7).

"I mean, I smoke (marijuana) some occasionally. Well, you have to. I mean, it helps take the pains away...I can’t get no medicine from anybody. Even I’m trying to go through pain management" (P9).

"Oh, before I had that, I used to massage my feet a couple times a week and then not really much otherwise" (P4)
Participants with type 2 diabetes in this study were passive about foot self-care because they did not perceive it as a priority when there was no immediate threat to their feet. This perception was impacted by a lack of awareness about the connection between foot self-care and DFUs. However, the sudden onset of these ulcers, followed by foot infection and loss of toes, was a wake-up call to adapt to a new reality. This adaptation included taking responsibility to perform foot self-care, being vigilant about monitoring the feet, developing awareness about DFUs and taking actions to prevent DFUs. Based on this new reality, participants’ foot self-care practices continued to develop. However, DFU-related challenges continued to adversely impact many areas of participants’ lives. Participants said treatments and care of ulcers were a recurring challenge. The ongoing ulcer treatments were difficult and not always effective. Participants continued to experience limitations to everyday life and described foot self-care as an overwhelming and continuing ordeal.
Implications for nursing practice

• Primary care providers

• Changing future educational intervention and management

  Foot care education (Consistency, literacy level, follow-up, and family)

  Reviewing care coordination protocol
Implications for nursing research

• Exploring perceptions of primary care providers

• Management of patients with diabetes in primary care

• Identifying the best methods of delivering educational intervention

• Evaluating gaps in care coordination and referral protocol
Implications for nursing Education

• Need to educate nurses to improve foot screening, education, and care

• Promoting nursing education to respond to the need for chronic care management of diabetes.
  Integration of the standards of care guidelines and DSME education
STRENGTHS of the study

• A descriptive phenomenological approach. Resolving the researcher’s preconceived biases through bracketing, performed to minimize researcher influence on the findings.

• First qualitative study exploring the phenomenon of foot self care practices as experienced by patients with diabetes in the U.S.

• Collaboration with different podiatric clinics
Limitation of the study

• Limited to Washington State

• Potential researcher’s bias (Bracketing by reflexive journaling)

• Mean age 62 (Limits the insight into the lived experiences of patients of other age groups.

• Sample (Perspectives of other minority groups were underrepresented)

• Recruitment sites: podiatric office (transferability of the findings)
Thank You