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# The Impact of Diabetic Foot Ulcer on Individuals' Lives and Daily Routine

A Qualitative Study Informed by Social Constructivism and Symbolic Interactionism Frameworks

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## ABSTRACT

**PURPOSE:** The purpose of this study was to explore the impact of diabetic foot ulcer (DFU) on individuals' lives and daily routines.

DESIGN: Qualitative design informed by social constructivism and symbolic interactionism frameworks.

**SUBJECTS AND SETTING:** The sample comprised 30 individuals attending a wound care clinic in Southeast Ontario, Canada. Most participants (n = 17) were between the ages of 65 and 92 years, were male (n = 20), married (n = 21), living with their family (n = 23), and had completed high school (n = 26).

**METHODS:** One-to-one semistructured interviews were conducted by the first author until saturation of each emerging theme was achieved. Interviews were audio-recorded and lasted from 45 to 90 minutes. Data collection and analysis occurred simultaneously and included intensive semistructured interviews, field notes, and researcher's journal.

**RESULTS**: Participants with DFUs were found to perceive a "sense of life change," impacting their lives across physical, psychological, and social spheres. They reported 4 key themes indicating that DFUs were (1) limiting their outings; (2) restricting leisure activities; (3) impacting personal and social life; and (4) contributing to emotional fluctuations.

**CONCLUSION:** Sense of life changes resulting from DFUs were associated with participant reporting loss of freedom and enjoyment. These findings underscore the need for holistic support for patients with DFUs that simultaneously address physical, psychological, and social needs and areas of impact.

**KEY WORDS**: Diabetic foot ulcer, Emotional fluctuations, Quality of life, Social impact, Struggles.

## INTRODUCTION

Diabetes mellitus (DM) is a metabolic disorder that is rising in incidence worldwide. In 2019, nearly 463 million adults between the ages of 20 and 79 years were living with diabetes worldwide, a number expected to rise to 700 million by 2045.<sup>1</sup> In Canada, rates of diabetes have been rising across all provinces and territories. In 2015, 3.4 million or 9.3% of the population were living with diabetes. By 2025 however, this prevalence rate is predicted to increase to 5 million or 12.1% of the population,<sup>2</sup> substantially influencing health-related quality of life of many Canadians and resulting in considerable costs to Canada's healthcare system.

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Diabetic foot ulcers (DFUs) are a common complication of diabetes and can negatively affect individuals' physical and psychosocial functioning.<sup>3</sup> A DFU develops in approximately 15% of individuals with diabetes as an open sore commonly located on the bottom of the foot. Having a DFU increases the risk of nontraumatic extremity amputation by 85%, equating to a limb being amputated somewhere in the world every 20 seconds due to diabetes.<sup>4</sup>

In a recent systematic review and meta-analysis about the global epidemiology of DFU, researchers suggested that the highest prevalence (13.0%) of DFU occurred in North America.5 Furthermore, infection, increased risk of recurrence, extended hospitalization stays, and mortality are outcomes of poor management of DFU.<sup>6,7</sup> In addition, individuals with DFU usually experience several compounding health issues that can include peripheral neuropathy, presented by the loss of sensation in the toes and feet, and neuropathic pain described as sharp shooting and burning.<sup>7,8</sup> Development of a DFU has also been associated with an increased risk for all cause and cardiovascular mortality when compared to individuals with DM and no foot ulcerations.9 DFU formation also exerts a negative effect on multiple components of health-related quality of life, including limited physical activity and difficulty walking, social isolation, and reduced work productivity.<sup>10-14</sup> Support from family members and healthcare providers can improve these outcomes, and absence of

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support is associated with impaired quality of life and increased costs.<sup>10</sup>

Treatment of DM and prevention of complications such as DFU should focus on more holistic care than drug therapy and monitoring of serum glucose or glycosylated hemoglobin.<sup>10-13</sup> This expanded care includes psychosocial aspects of living and managing this complex disease and its complications. However, research focusing on patients' voices and perspectives related to the impact of DFU is limited; this study addressed this gap. This study expands previous work examining the journey toward engagement in self-management for people with DFU.<sup>15</sup> The aim of this study was to identify, understand, and explore the impact a DFU has on the lives and daily routine of persons living with DM.

# **METHODS**

Qualitative data were collected via semistructured interviews; a social constructivist approach and symbolic interactionism perspective were employed to guide the research design.<sup>15</sup> In symbolic interactionism, research participants are seen as active subjects and social actors engaged in daily activities to and constructors of the world in which they live and interact.<sup>16</sup> Social constructivism is the framework used as a foundation for the constructivist-grounded theory developed by Charmaz.<sup>17</sup> This framework indicates that individuals are active contributors in the creation of their own knowledge and social reality. It also suggests that the understanding an individual develops about any aspect of his or her life is shaped through social interaction between both subjective and environmental factors that occurs over period of time.<sup>18</sup> The combination of both symbolic interactionism and social constructivism allowed us to uncover, understand, and explain the impact of DFU on individuals' lives and daily/activities.

Purposive and theoretical sampling techniques were used to recruit potential participants. Purposive sampling was used to recruit participants who met the following inclusion criteria: (1) confirmed medical diagnosis of a DFU for at least 2 months, which ensured enough experience to reflect living with a DFU; (2) age 18 years or older; (3) able to speak and read in English comfortably and articulate their experience of having a DFU; and (4) willing to engage in active self-reflection and self-disclosure about their experience of living with and managing a DFU. Theoretical sampling was used to achieve saturation of each emerging category and concept. Study procedures were reviewed and approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (TRAQ IRB#6020520).

#### Study Procedures

Data collection procedures included intensive semistructured interviews, field notes, and researcher journaling. Study authors codesigned the first 20-question interview guide. The first author (I.G.C.) then tested the interview guide with 5 participants; this procedure enables us to develop insight into the types of interview questions best suited to uncover and explore the process of self-management of DFU within the participant sample. We then worked together to codesign a second iteration of the interview guide comprising 32 questions based on the insights gathered during testing. All interviews were conducted by the first author, transcribed by a professional transcriptionist, and entered into data analysis research software (N-Vivo, version 11.4.1; QSR International, Burlington, Massachusetts). Interviews varied in length from 36 minutes and 41 seconds to 1 hour and 42 minutes.

### **Data Analysis**

To ensure the usefulness and quality of this social constructivist study, we implemented the 5 trustworthiness criteria suggested by Charmaz<sup>17</sup>: (1) credibility in order to ensure a transparent internal and external audit of the analytical methods, (2) originality via the analytical insights that were grounded in data to uncover meaning and experiences, (3) confirmability/ validity via follow-up with each participant to confirm whether the summary of findings' was an adequate understanding of their experience, (4) resonance to ensure that data analysis included what is meaningful about the substantive area and described the fullness of participants' perception about the impact of DFU on their lives, and (5) usefulness identified as key messages drawn from participants' experiences in that are useful to clinical practice and policy.

Data analysis was conducted in a cyclic research process that began with initial coding and proceeded to focused coding. Data were collected and coded by the first author (I.G.C.), and confirmability of the data was certified through an audit of the transcripts and codes by the second author (P.C.P.) and by an external researcher. The external researcher conducted cross-coding to evaluate accuracy and the extent to which the findings, interpretations, and conclusions were supported by the data.<sup>19</sup>

Stage 1 of the data-coding processes involved idea-by-idea coding, generating 529 codes identified by action or in vivo words as recommended by Charmaz.<sup>17</sup> Stage 2 involved focused coding used to explain more substantial segments of data. During this stage, some redundant codes were collapsed into categories. In total, 250 codes were ultimately clustered to form categories and its related concepts (Table 1). The results of this coding process coupled with successive levels of abstraction through comparative analysis and memo-writing (Memo-writing no. 1) led to the inductive generation of the substantive categories. Saturation and redundancy of each category occurred after 30 participants had been interviewed 2 to 3 times and subsequent data did not alter the concepts that had been discovered.

# RESULTS

The sample comprised 30 participants with active DFU who attended a wound care clinic in Ontario, Canada, between April 2017 and August 2017. Most participants (n = 17) were between the ages of 65 and 92 years, were male (n = 20), married (n = 21), living with their family (n = 23), and had completed high school (n = 26). Twelve participants had completed post-secondary education. Fifteen participants were retired and 7 were actively employed outside the home. Those who were unemployed were dependent on financial assistance from either family or government income support (Table 2).

Participants with DFUs were found to perceive a "sense of life change," impacting their lives across physical, psychological, and social spheres. Analysis of participant responses revealed 4 key themes highlighting that DFUs contribute to (1) limiting their outings; (2) restricting leisure activities; (3) impacting personal and social life; and (4) contributing to emotional fluctuations. Perception of DFU seriousness was associated with the extent of reported impact across these 4 themes, replicating prior research findings examining the impact of DFU on health-related quality of life.<sup>10,11,13,14</sup>

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TABLE 1.

Categories	Themes/Concepts	Supporting Quotes
Perceiving a sense of life change	Limiting their outings	I'm having so much trouble to ambulate I'd really like to walk more in our pretty little town When I got this ulcer on my foot, that grounded me because every step I took hurt It's just limited some of the things that I can do that I'd like to do
	Restricting leisure activities	It limits me in what I can do. I can't walk as far as I would like Even when I walk the dog, I can only go so far before it bothers me enough I can't go in the pool now, I can't walk on concrete, can't go to the beach Yeah. It's, uh, it really impacts your life
	Impacting personal and social life	The fact of the wound interferes with job, interferes with travel It interferes with a whole bunch of things. It kept me home. It grounded me I didn't want to go visit people because I didn't want to take my shoes off in their house
	Contributing to emotional fluctuations	At times I get really depressed Oh God. I'm up and down Well, it kind of gets you down emotionally cause you don't want to lose your toe or leg That's scary

# Summary of the Core Category "Perceiving a Sense of Life Change," Its Related Themes/Concepts, and Supporting Quotations

#### Theme 1: Limiting Their Outings

Nearly all participants described their DFU as interfering with their mobility and sense of freedom. Mobility limitations varied from difficulties standing for long period of time or walking long distances to not being able to engage in exercise and leisure activities such as swimming, biking, hiking, golfing, and dancing. Respondents also reported that these physical limitations were due to pain, the need to avoid pressure on the ulcer, not being able to get the ulcer wet, and isolating at home due to shame associated with smell from the ulcer. For example, a female participant explained that the pain increased with walking and hence prevented exercise and leisure activities. "I'm having so much trouble to ambulate ... I'd really like to walk more in our pretty little town and keep in touch with my neighbours ... when I got this ulcer on my foot, that grounded me because every step I took hurt."

Respondents further explained that the need to prevent pain from the DFU was slowly taking away their freedom to enjoy daily life activities, including exercise, an important part of managing diabetes and DFUs. For example, 1 participant stated, "It's [DFU related pain] just limited some of the things that I can do that I'd like to do. When I went on vacation, it limited me from swimming. It makes weight loss harder, because I can't do all the exercising, I would like to do because of this. It's limiting, that's about it."

#### **Theme 2: Restricting Leisure Activities**

Approximately half of the participants reported that DFUs led them to restrict engagement in hobbies and recreational activities, which negatively affected socialization. For example, 1 participant stated that his DFU prevented him from doing things he enjoys such as walking the dog, driving, swimming, and wearing his favorite shoes. He stated, "It limits me in what I can do. I can't walk as far as I would like. Even when I walk the dog, I can only go so far before it bothers me enough that we have to turn around; if I'm driving long distances, just the pressure on the gas pedal. I'm always aware of it. Swimming, I wear water shoes because I keep it wrapped underneath. I love wearing Crocs, they're the most comfortable thing I have, but I can't wear them with this thing." Another participant stated that the inability to get his DFU wet impaired leisure activities such as going to the beach and to the pool. He explained that, "You know, I can't go in the pool now, I can't walk on concrete, can't go to the beach. Yeah. It's, uh, it really impacts your life. No, I can't get it wet. I can't go in the sand, can't go in the pool, can't go in the hot tub. What the hell's the point of going, you know?" Participants further explained that the requirement to wear ill-fitting shoes instead of offloading devices contributed to their pain and, in turn, their inability to engage in regular physical activities.

The first author (I.G.C.) summarized the emerging insights in a memo that pointed out limitations related to respondents' ability to perform simple tasks such as going to an appointment, traveling, fishing, or swimming. They described being afraid of having hypoglycemia while doing leisure activities or hurting their feet when walking long distances and not being able to find help when away from home. Some participants stated that they would not go too long walking alone. Others said that they would always look around to see whether there was a seat around in case they feel weak and need to sit for a while. For many of them, having a DFU was perceived by themselves as homebound and isolated from social life.

#### Theme 3: Impacting Personal and Social Life

Participants reported that DFUs had a negative impact on their socialization. One participant explained that having mobility restrictions due to his DFU prevented him from working and traveling. He stated, "That's how I would look at that. It's the fact that they're there you become dependent on. The fact of the wound interferes with job, interferes with travel, interferes with driving because of this boot. It interferes with a whole bunch of things. It kept me home. It grounded me" This participant further explained that he used to be very independent but his DFU has negatively affected his employment, vacations, and even driving within his community. Another participant described how her DFUs prevented her from going out dancing with her partner, "It bothers me because I like male companionship like talking and going out but I can't go dancing. You know what I mean?"

A male participant described how a DFU foul smell restricted his social life and embarrassed him when he was near

TABLE 2.	
Demograp	hic and Pertinent Clinical Characteristics of
Participant	S

Sociodemographic Characteristics	Frequency (N = 30)	Percentage
Sex Male Female	20 10	67 33
Age, y <65 ≥65	12 18	40 60
Marital status Married Nonmarried	22 8	73 27
Living situation Alone With family	7 23	77 23
Level of education Primary school Secondary school Post–secondary school	6 12 12	20 40 40
Employment status Employed Retired Government income support	7 15 8	23 50 27
Diabetes type Type 1 Type 2	7 23	23 77
Diabetes duration, y <5  y $\ge 5 \text{ y}$	12 18	40 60
Ulcer duration, mo 2-7 8-12 >12	16 6 8	53 20 27
Amputation Yes No	6 24	20 80

others. He explained, "...it really stunk at one point so that's kind of disgusting ... I didn't want to go visit people because I didn't want to take my shoes off in their house.... My son also tried to avoid getting close to me (sad face).

#### **Theme 4: Contributing to Emotional Fluctuations**

Participants described how their emotions fluctuated based on their perception of the seriousness of their DFU. They described mood swings, feeling depressed and hopeless as a result of physical limitations, social isolation, and fear of amputation. As 1 female participant noted, "At times I get really depressed.... To feel depressed is a really dark place sort of thing. You're sitting in the chair and you have to get up and, frankly, it's like, 'Why bother?' That sort of thing. And the idea of my foot's not going to get better, it's going to take forever and nobody wants to take it off anyways, it's really depressing thinking about stuff like that. I try to flip myself and think happily." Another noted "Oh God. I'm up and down, I'm all over the place, but just ... I deal with it. It is what it is. I still have my leg, and that's how I deal with it. It could be a lot worse." A male participant described how his emotions are influenced by the possibility of amputation. "It don't ... Well, it kind of gets you down emotionally

'cause you don't want to lose your toe.... When it's open like that then it gets infected and the infection just keeps going, just keeps spreading and you end up losing your leg at the knee. I don't want that. Definitely not. That's scary."

# DISCUSSION

Findings from this study provide insights about the impact of DFUs on daily life. Mobility restrictions regulated daily life and ability to participate in leisure activities such as vacations, hobbies, and recreational pastimes. Furthermore, in line with the findings of Costa and colleagues,<sup>14</sup> participants' perceptions of DFU seriousness were reported to be positively associated with greater mobility restrictions.

Participants reported the loss of independence to navigate their daily life and usual routines, contributing to depression, mood fluctuations, feelings of hopelessness, and social isolation. Furthermore, participants reported that the need to avoid pain, weight-bearing activities, and specific footwear (eg, offloading boots) dictated the type of shoes, the amount of walking, and the leisure activities could partake in. Findings from previous studies suggest that DFUs interfere with multiple activities of daily living, creating emotional fluctuations and psychosocial responses such as feelings of being a burden to others or living a restricted life.<sup>20</sup> Our findings also align with results from previous research indicating that impaired ambulation is the most commonly reported functional impact of DFU on individuals' lives.<sup>21</sup> Respondents also reported that inability to exercise was a direct result of having a DFU, as this creates additional challenges in controlling their diabetes. Research also indicated that lack of physical activity is associated with an increased risk for experiencing complications.<sup>22,23</sup>

The use of therapeutic footwear and exercise improve DFU outcomes. However, they are not always accessible to patients in need of these products.<sup>22-25</sup> Management of DFU also includes recommendations to avoid (1) weight-bearing movements; (2) shoes not appropriate for DFUs (eg, high heels, flip-flops, san-dals), (3) wetting the wound dressing, and (4) standing for long periods of time; and includes wearing offloading boots to redistribute pressure and immobilize the affected foot. In this study, the participants reported that wearing offloading boots or total contact cast hindered their ability to drive, increased their dependence on others, and leisure activities.

Researchers have documented that the smell associated with DFU infection contributes to personal and social issues.<sup>6,26</sup> Diabetic foot ulcer infections lead to pain and malodorous exudate, resulting in patients taking steps to distance themselves from others. In this study, 3 participants mentioned DFU odor and appearance as contributing to social isolation. These respondents went on to describe that the malodor of an infected DFU acted as a barrier to social and family engagement.

Our study findings replicate and build on the findings of Kinmond and colleagues<sup>20</sup> and Firth and coinvestigators,<sup>14</sup> who described that participants with DFU reported restrictions on their freedom to perform daily routines, live well, and enjoy life. Our research raises awareness about the impact mobility difficulties have on the daily life, leisure, and social activities of individuals with DFU, resulting in multiple psychosocial challenges.

#### Implications for Practice and Policy

Our findings challenge clinicians, researchers, and practitioner-scholars to look beyond DFUs as a wound and consider

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the full impact on patient lives. As highlighted by participants, DFUs have the potential to negatively influence physiological, social, and well-being aspects of individuals' lives. As such, a holistic approach is needed that focuses simultaneously on both the physical care of a foot ulceration and the individuals' mental health and ability to continue to engage in social, leisure, and recreational activities while managing their foot ulceration. Our study findings demonstrate that assessing participants' past and current engagement in exercise and their ability to keep active while receiving DFU treatment is an essential point of consideration that should be included in all DFU care planning and delivery. In addition, the current research further highlights the need for care teams to work collaboratively with patients during treatment planning to facilitate continued mobility, social inclusion, and engagement in daily physical and leisure activities to the greatest extent possible to maintain a sense of independence among patients throughout DFU treatment.

#### Limitations

Participants in this study were drawn from 1 wound care clinic in the province of Ontario, Canada; a great selection of sites from other locations may have produced additional or different results. Another potential limitation is that participants in this study had access to specialized wound care services, which facilitated their journey toward engagement in self-care management. They had the advantage of accessing an essential resource that other patients may not have. The last limitation was undertaking this study as a novice researcher. To mitigate that, the principal investigator (I.C.G.) reviewed and carefully followed the steps of social constructivism and symbolic interactionism frameworks informed by Charmaz<sup>16</sup> as closely as possible and consulted with supervisors as needed.

# CONCLUSION

Our study examined the experience of individuals with DFUs. Participants described a "sense of life change" as a result of their DFU, negatively impacting their lives across physical, psychological, and social spheres including limiting their outings; restricting leisure activities; impacting personal and social life; and contributing to emotional fluctuations. These findings underscore the need to listen to patients in order to enhance our understanding of their struggles, frustration, and other negative emotions they experience related to their DFU. We also assert the need for implementing multidisciplinary holistic care and treatment for patients with DFU to meet their physical, psychological, and social needs while advancing their ability to independently navigate their social world.

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