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Patient Perspectives on the Physical, Psycho-Social, and Financial Impacts of Diabetic Foot Ulceration and Amputation

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Abstract

Aims: Diabetic foot ulcers (DFUs) and ulceration are complex and lifelong problems for patients with diabetes which dramatically increase mortality rates. This qualitative study sought to capture detailed personal accounts and insights from patients with a clinical history of DFUs and amputations to better understand patient experiences.

Methods: Fifteen patients from a tertiary referral center that treats diabetic foot problems were approached for participation. Inclusion criteria included having at least one DFU and being of white, Native American, or Hispanic background. Interviews were conducted by telephone by study staff trained in qualitative data gathering and audio recorded.

Results: The main themes that emerged around impacts included the heavy burden of managing care, significant loss of ambulatory function, economic stress due to medical care costs and job loss, and emotional suffering tied to these stressors.

Conclusions: These data illuminate common social and personal impacts of diabetic foot problems across an ethnically and racially diverse and predominantly low-income US sample that

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Author Statement
R.M.C. directed the methodology, conducted interviews and analysis and wrote the results and discussion, K.N.B.P. conducted interviews and analysis and wrote the methods, D.G.M., conducted research, and wrote the conclusion. T.W.T. is the guarantor of this work, directed the conceptualization of this study, recruited patients, conducted analysis, and wrote the introduction.

Conflict of Interest
The authors have no conflict of interest to disclose.

expand our understanding of related declines in well-being. Our results indicate a need for proactive mental health assessment post DFUs diagnosis and the diversification of hospital and community-based support systems.

Keywords

Diabetic foot ulcers; amputations; psycho-social impacts; financial stress; depression; ambulatory decline

1. Introduction

Foot ulceration, which precedes 80% of leg amputations in people with diabetes, is a significant and costly public health problem, accounting for over 20% of the total diabetes related costs in the US.[1–4] It is estimated that one-quarter of the 30 million people with diabetes mellitus in the United States will develop a diabetic foot ulcer (DFU) in their lifetime and people with diabetes are 10 times more likely to undergo amputations than the general public.[1,5,6] Of public health concern, the incidence of DFUs is disproportionately higher in ethnic minorities and in those from disadvantaged socioeconomic backgrounds.[7–10] Patients with suboptimal health insurance and low income have several times higher risk of amputation than their counterparts.[11,12]

A DFU is a complex and lifelong problem for patients with diabetes. Two-thirds of DFUs take more than 12 months to heal, and the recurrence rate is estimated to be 65% at 5 years after healing.[1] Infection and gangrene resulting from DFUs are the leading causes of amputation,[13,14] and taken together, DFUs and amputation dramatically increase mortality rates for patients with diabetes.[6] Moreover, ulcers and amputations have diverse impacts for patients, including impaired physical function, reduced quality of life,[15,16] loss of employment and economic stress,[17] depression and emotional suffering,[18–21] and social isolation.[22,23]

Effective healing of DFUs and secondary prevention of ulcer recurrence compose crucial strategies to lowering such impacts and preventing major amputations in at-risk patients.[1,24] However, there is limited qualitative data on the impacts of DFUs, particularly in diverse, disadvantaged populations. Patient perspectives afford critical lessons for improved quality of care and disease control.[25,26] This article presents outcomes from a qualitative study of people with DFUs and minor or major amputations in a high disparity population in southern Arizona.

2. Subjects, Materials and Methods

This qualitative study sought to capture detailed personal accounts and contextual information from patients with a clinical history of DFUs and amputations to better understand patient experiences with DFUs that could help explain disproportionate rates of major amputations among Hispanics and Native Americans.

2.1 Participants

Patients were selected from a tertiary referral center that treats foot problems in persons with diabetes (Banner University Medical Center Tucson). The multidisciplinary limb salvage team has over 5,000 patient visits annually and more than 40% are Hispanic or Native American patients. Patients with a history of DFU(s) and/or minor amputation (toe, toes, or part of the foot) and/or major amputation (ankle or above) were identified and approached for participation during regularly scheduled clinic appointment or by phone calls. Interested patients provided written informed consent and were scheduled for a telephone interview. This study was approved by the University of Arizona Institutional Review Board in June 2020 (1906749805A002).

2.2 Interview Methodology/Data Collection

The interview guide was jointly developed and reviewed by the research team and translated by a native Spanish speaker. Questions related to the topics of interest were asked in a semi-structured format to allow for flexibility and patient-led dialogue. These questions were designed to understand the onset, progression, and impact of diabetic foot ulcers and amputations on patients' lives. Initially planned as a focus group format, the study design was modified to phone interview due to the COVID-19 pandemic.

From June 2020 to February 2021, 50 participants (among 70 patients who meet inclusion criteria) agreed to participate and provided informed consent. Three members of the research team with experience in qualitative data gathering (R.M.C., K.N.B.P., and D.G.M.) completed 15 interviews, five in each of three targeted ethnic populations: Hispanic, European American, and Native American. Interviews were conducted over the phone using the "Tape A Call"[ref] mobile application (www.tapeacall.com) or via the University of Arizona Health Sciences Zoom platform. Patients were interviewed in their preferred language of English or Spanish and were compensated $50 dollars upon completing the interview.

2.3 Data Analysis

Audio files of the interviews were transcribed in the language spoken, and interviewers conducted quality assurance checks of transcriptions. Transcripts were uploaded to Dedoose[ref] (www.dedoose.com) and three members of the research team (R.M.C., K.N.B.P., and T-W.T.) independently coded interview transcripts. Notations of rationale for additional codes and revised codes were discussed for consensus. The research team discussed themes for which data saturation had been established by the data set.

3. Results

All participants had at least one foot ulcer and twelve participants had history of foot infection. Eight underwent minor amputations resulting from these ulcers, primarily toes, knuckles, bone fragments, or part of the foot, and one patient had a major amputation (Table 1.). We summarize the main themes that emerged surrounding the impacts of ulceration and amputation: managing care, loss of mobility, economic impacts, and emotional stress.

3.1 Managing Care

Many participants noted that the complexity of managing care for ulcers and amputations placed a heavy burden on themselves and their family. Elements of ulcer and amputation care in the home included: management of elaborate oral medication protocols, administration of intravenous antibiotics, changing of wound dressing, application of topical ointments, and cleaning and elevation of the wound. One participant explained that healing ulcers depended on: "Keeping [the wound] constantly changed and clean, using the silver solution to debride what was dying off to allow new tissue to grow. Once most of the tissue grew, using moisturizing agents such as Aquaphor to keep the skin moisturized and healthy". Some participants mentioned specific challenges to care regimens. For example, a patient described how she struggled to adapt to using the wound vac, saying: "Sometimes you forget and walk off and pull the cup off and you have to get it redone again".

In addition, participants noted the complexity and burden of coordinating with external care-takers and medical personnel, including arranging transport to and attending follow-up medical appointments, managing home nurse care, and getting fitted for diabetic shoes. Participants mentioned challenges including frequent changes to home care nursing staff, traveling long distances for appointments, and delays in receiving diabetic footwear. A participant lamented that changes to home nursing staff led to confusion and poor provision of care, saying: "That is my frustrating part of it. Like I finally get somebody that does something right and then they send somebody else".

Most participants reported that their family members did the majority of care, primarily spouses and adult children. One participant noted that his adult children had "helped clean me up with hot water, with saltwater, to find a way to keep my feet clean". Participants described their family members assisting them both with direct wound care as well as providing help with daily chores and house maintenance. Another patient remarked: "My wife's like, I say, she's my, she's my home healthcare. She's gotten pretty good at dressings, and we do it, you know, on a daily basis".

While participants described family support as being critical to the healing process, it also presented challenges in shifting the balance of household labor division and inverting care-taking roles. For example, a participant described how his 17-year-old son had had to assume the role of primary caretaker after his amputation. He recalled: "That's a little bit of an adjustment … my doctor said 'stay off your foot as much as possible'…and so [I have to ask] 'hey, Mike, can you grab me something to drink?' And it's like, 'Okay dad,' you know, that sort of thing … I think it's just gonna be an adjustment for him more than anything else, of having to wait on me as opposed to me waiting on him". Another participant described feeling like a burden to his family, saying: "Now I'm depending on somebody to drive me somewhere, I'm depending on somebody to, you know, change the dressing on my feet, and, you know, depending on somebody to grab me something to drink or a cup of coffee … if I did what the doctors wanted me to do, you know, I'd be peeing in a bottle and having somebody else wipe my butt".

A few participants, however, indicated that their primary sources of support had been in-home nurses or podiatrists rather than family members. This was especially the case for participants who had lost caretakers to death or divorce or who lacked a family support system. One patient lamented that: “My family is not as supportive as I’d like them to be. And mainly it’s just the medical providers [who help]”. Those who noted a lack of in-home support described additional challenges to maintenance of household duties and care regimens. One participant explained: “I’m trying to stay off my foot and everything as best as I can, but I just feel like at the time here at home that my family didn’t really understand what was really going on and they looked at me like, ‘Oh, he’s still mobile, he can still do stuff for himself.’ They relied on me a lot to do a lot of things … And that’s what kept [the ulcer] open all these years”.

3.2 Declines in Ambulatory Function

Most participants reported the impact of physical impairment(s) resulting in significant loss of mobility. Most commonly, participants described reduced movement due to loss of balance, pain, loss of strength, and medical directives to elevate or isolate the affected area. A patient who also suffered from spinal stenosis explained that after his minor amputation: “I was in a boot for three weeks. It pretty much got better but once I got out of the boot, it came back. It was slapping too much. Now, I feel a little unsteady on my feet … I was always afraid I was about to fall over. I actually felt like I was walking drunk”. Another participant who lamented no longer being able to practice Tae Kwon Do said: “My balance is off and … when they put me on antibiotics and put me in the hospital, I got really ill. So, I spent like six months throwing up and lost like twenty pounds. So, my strength has gone”. Several participants were required to utilize assistive devices including a walker or cane.

For participants with multiple ulcerations and amputations or other compounding issues, the loss of mobility was often severe and involved confinement to a wheelchair or bedrest for long periods. One participant described: “It is a huge wheelchair so it can’t get through many of the doors. So what I would have to do was, I would have to stand up … and I have to hold onto something so I don’t lose my balance and fall over. And then somebody would close the chair up and push it through the door. They’d finally open it up again then I’ll sit down. So that’s limiting a lot. That’s why I really don’t go out”. A participant who had undergone three minor amputations in 18 months explained: “I’ve literally been pretty much bedridden. No, no weight bearing on my feet, because of the multiple surgeries … so I my activity level is gone to almost zero. And it’s very painful, because I have other issues that when I just sit around, I get, I mean, extremely sore. I can’t function. So, it’s, it’s been, it’s been hell”.

Several people lamented the slow pace of rehabilitation from ulcers and amputations and described facing setbacks when they tried to resume prior activities. One participant explained how after working to heal from a minor amputation for several months, he reinjured the affected area and had to endure several more months of limited mobility. He said: “I walk a lot better, but I still don’t have no balance. I have to have a walker, no balance”. Several participants cited lasting pain and fatigue that circumscribed their mobility.

3.3 Economic and Employment Impacts

Most study participants cited economic stressors related to ulcerations and amputations, stemming both from medical bills related to foot care as well as loss of income resulting from the inability to perform regular work duties. Medical expenses were varied and differed among participants based on their distance from health centers, insurance coverage, co-payments for medical visits, surgical procedures, and diabetic footwear, length of recovery, and types of medication prescribed. A participant who had three amputations and weekly doctor visits stated: “I mean, it’s a hardship on all the medications that I have to pay for, even though it, you know, we have copays and whatnot. But it all adds up”. Native American participants covered by Indian Health Center programs were the least likely to note financial stressors tied to ulcer care.

Several participants experienced economic stress relating to temporary or long-term loss of or changes to employment. Several men in the sample were forced to leave jobs that had required high levels of physical exertion. One participant explained that the amputation “had a big impact on my work. I’m self-employed so if I’m not working then I don’t get paid. I don’t have [a regular salary], you know what I mean. So that was pretty hard to stay home”. These economic impacts were in some cases amplified by the sudden nature of ulcer onset and progression. Another participant who went into the emergency room the day after noting a strange smell on his sock stated: “I came to work, I put a note on my door that said that I would be opening at 1 o’clock in the afternoon, because I figured that would give me plenty of time [to get back]. And four months later, I came and unlocked the door”.

3.4 Emotional impacts

A very common theme among respondents was the emotional impact of the elaborate care routines, loss of mobility, and financial burdens, as well as body image disturbance. Often, this began at ulcer detection, when participants faced challenges over where to seek care, the best course of treatment to follow, and possible negative outcomes. One participant described his decision-making process on whether or not to amputate his foot. He explained: “With the ulcer on my left, they did tell me I might lose my foot because it really got to the bone and they said it was 50–50. I was in shock, I was scared, I was praying, I was mad. I was so everything with my emotions”. Others mentioned having anticipatory fears over potential future loss of mobility and the possibilities of losing their driver’s license or being confined to walkers or wheelchairs.

Emotional distress intensified for many participants as their conditions advanced. Many who had undergone amputations reported feeling depression, frustration, and powerlessness as they worked to heal. One participant shared: “I’ve not been off my couch, you know, or out of my bed very much in the past 18 months. It affected my life and it has affected my…well-being as far as my mental well-being. It’s, it’s affected me tremendously”. Another participant who had been forced to change professions after losing use of one foot said: “Of course it gets you depressed, you know? I mean, for me, it was mainly because I was a welder [using] heavy equipment … It is all in the past … I walked into the hospital, I just never walked out”. Several participants described deep frustration at feeling they could physically tolerate movement but had to follow doctor’s orders to rest.

Loss of mobility also impacted family and social relationships, in some cases causing deep isolation. One participant commented of his recovery period: “Yes, it was a hard time … I just didn’t have nothing to do, like I said. I didn’t talk to nobody”. Others mentioned feeling isolated and alone in their pain. Another participant recalled feeling very hurt by a family member’s response to his toe amputation, saying: “I try not to get angry about it because it has been 20 years. After that [incident], I thought I had to stop talking about this and mentioning it to people. Quite frankly, because I am a private person, most people don’t know”. Others felt frustrated and even powerless at not being able to maintain their parenting or care-taking roles for others.

Lastly, a few participants who had undergone minor amputations described body image disturbances including shame and embarrassment related to the unique experience of limb loss. One participant who lost several toes described feeling that his foot was no longer complete and that he tried to avoid other peoples’ comments or questions. He said: “The only thing is that I feel embarrassed when I take off my shoe or my socks in front of people. Or to swim in a river in front of a lot of people, it makes me feel embarrassed to show my amputated toes”.

However, some participants also stated experiencing positive emotions related to what they had overcome. For example, one took pride in being able to carry out simple tasks such as walking unassisted or pushing a grocery cart, saying: “If I turn around, I am looking at a wheelchair that is folded up, that I am still supposed to be in. Okay? And I took myself out on my birthday, on March 22nd. I said: ‘I’m done with the wheelchair, I am using my walker 100%’ and then a month later, I said I wasn’t using this either”. Several other patients mentioned that recovering from ulceration and amputation had served as a wake-up call, encouraging them to make positive changes in their lives, and a couple mentioned finding encouragement in support or faith-based groups. A participant who had worked long hours for years as a restaurant manager said that his amputation pushed him to find a more family friendly career. He explained: “I have a son and a wife, and I never see them based on my hours … I think the fact that that was already in my head when they said that [I had to switch professions] wasn’t a big shocker to me. If anything, it kind of solidified what I was already thinking … And almost like now it’s not so much I’m thinking to do it, now I have to do it”.

4. Discussion:

The qualitative data presented here illuminate many common social and personal impacts of diabetic foot problems across an ethnically and racially diverse and predominantly low-income US sample. Many of the observations presented in this article extend beyond previously reported outcomes, such as depression and its correlation to post-operative activity restriction.[18,22,27,28] This study advances our understanding of DFU impacts to the more complex variable of well-being, connecting the experiences of burdensome care regimens, post-operative declines in ambulatory function, and economic stress to negative emotional experiences.[20,21] Our data clearly showed a pattern of early emotional distress that worsened as the foot ulcers progressed, with participants describing feeling sadness, fear, frustration, powerlessness[29,30], and embarrassment related to uncertainty about the future, loss of independence,[19] social isolation,[22,23] and body image disturbance.[31]

In addition, this article highlights lesser understood factors that may contribute to heightened stress amongst people with diabetes-related foot problems. One important finding is that slow healing ulcerations, which affect significantly more people than amputations, result in varied and deep impacts to patients, regardless of whether amputation is the end result.[26] This finding extends the temporal nature of amputation-related anxiety, which may begin at the initial point of ulceration at which time patients begin to face fears and concerns over possible future loss of mobility and amputation.[18,32] In addition, patients who suffer from other diabetes-related complications or compounding disease states were more likely to report barriers to healing and well-being post-ulceration,[20] in some cases extending months or even years post-surgery.[22] Moreover, stressors were exacerbated in cases where surgical amputation was sudden and unanticipated.

This study also addresses the diverse challenges involved in caring for ulcerations and amputations, which are the primary causes of frequent and extended doctors' visits and hospital stays amongst people with diabetes.[6] Our results indicate that foot ulcer patients are deeply dependent on their care-takers, who are not exclusively immediate family members, and that lack of social support adds additional barriers to patient recovery.[33–35] However, dependence on care-takers can also place significant strain on family relationships and produce feelings of loss independence and shifting responsibilities.[20] "Role loss" may result from patients' inability to fulfill prior roles within the family, community, and work, which can increase depression and associated mental health declines.[36]

This article also confirms the prevalence of significant financial stress tied to diabetes-related ulceration and amputation, a topic worthy of greater exploration. Most sample participants cited expenses related to complex care routines and many experienced disruptions to their regular employment. An estimated 35% of people with lower limb amputations do not return to work,[17] a life change that can have profound impact on both perceived well-being and loss of income.[2,27] This study suggests that patients with diabetes who have physically demanding jobs are at higher risk for post-operative occupational stress and job loss due to declines in ambulatory function, suggesting a disproportionate burden on low-income patients.

Lastly, this study confirms a paucity in the literature that minor amputations can be an impetus for positive emotional growth and healthy life changes.[37,38] Study participants cited experiencing pride, empowerment, and inspiration during their recovery periods and noted the importance of positive thinking and adaptability.[20]

4.1 Study Limitations

The COVID-19 pandemic hindered our ability to recruit patients in-person and restricted in-person data collection, which necessitated rapid modification to the study protocol to allow for remote data collection. Although we made efforts to reduce barriers to participation, we encountered a high rate of missed appointments. Several interviews experienced other disruptions such as poor technology and/or connectivity issues. Our small sample size and overrepresentation of male participants limits the possibility of fuller inter-ethnic comparisons, gender breakdown, and overall generalizability. However, the sample demographics represents that of the local clinical population served.

5. Conclusions

The qualitative data gathered from an ethnically diverse and predominantly low-income sample confirm prior findings on high rates of depression and poor ambulatory function related to diabetic foot problems, while also adding greater depth to the complexity of related social and personal impacts. Our results suggest several clinical implications. First, greater emphasis needs to be placed on proactive mental health assessment and support once DFUs are diagnosed. Early screening and treatment of mental health issues is necessary to identify strategies to mitigate the considerable emotional impact of diabetic foot disease to both the patient and their families, especially considering the exacerbating effects that factors including depression, social isolation, and emotional stress can have on DFU patient outcomes.[26,39] Second, it is important to diversify the types of support offered to people with diabetic foot problems in a way that incorporates a varied array of caretakers that extends beyond the formal healthcare system and acknowledges the extensive burden of care. The use of community health workers can provide an effective support system, particularly in the Hispanic and Native American communities that are disproportionately burdened by both diabetes and diabetic foot disease. Lastly, financial stress related to foot disease should be assessed with coordination of ancillary benefits and services when warranted.

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Highlights

- DFUs and amputations carry heavy burden of managing care
- Many patients report economic stress due to medical care costs and job loss
- Heavy burden of emotional suffering tied to care regimens, loss of ambulatory function, and economic stress
- Some patients experience positive emotional growth

Table 1.

Participant Demographic Information

Demographic	**N=15**
Age	54.2 years
Male Gender	10 (66.7%)
Race/Ethnicity	
European American	5
Hispanic	5
Native American	5
Marital Status	
Single	9 (60.0%)
Married	5 (33.3%)
Divorced	1 (6.7%)
Occupation	
Not Employed	10 (66.7%)
Self Employed	2 (13.3%)
Employed	1 (6.7%)
Retired	2 (13.3%)
Primary Insurance	
Commercial	1 (6.7%)
Medicare	3 (20.0%)
Medicaid	8 (53.3%)
Indian Health Program	3 (20.0%)
Urban Residence	11 (73.3%)
Medical Comorbidities	
Neuropathy	14 (93.3%)
Peripheral Artery Disease	5 (33.3%)
Charcot Foot	2 (13.3%)
History of Major Amputation	1 (6.7%)
History of Minor Amputation	8 (53.3%)
History of Diabetic Foot Infection	12 (80.0%)
History of Vascular Procedure	4 (26.7%)

All 5 Native American participants had Indian Health Program as their primary or secondary health insurance coverage.