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Patient perspectives on the burden and prevention of diabetes-related foot disease

Running head: Perceptions of diabetes-related foot disease

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Abstract

Purpose: The purpose of this study is to understand patient perspectives about the impact and prevention of diabetes-related foot disease (DFD).

Methods: An online survey was distributed to patients with a history of DFD during 2020.

The survey was designed alongside clinical specialists and DFD patients, and utilised the Health Belief Model. It asked about the impact of DFD on health, perceptions on preventative strategies, perceived need for additional support, and patient preferences for telehealth in DFD management. Quantitative data were summarised descriptively and compared between groups. Open-text responses were analysed using conceptual content analysis.

Results: From 80 participants with a history of DFD, foot ulcers were the complication most often experienced, with over two-thirds having been admitted to hospital for a DFD-related issue, and over one-third having a DFD-related amputation. Participants had ranging perceptions on the effect of DFD on health, from minimal to crippling. Those with previous severe DFD complications leading to hospital admission found a lack of mobility and independence the consequences of most concern. Using offloading footwear was perceived as very important for preventing DFD complications though the use of offloading footwear was low, with participants citing issues relating to cost, comfort, appearance, and access to footwear as barriers to better adherence. Perceptions on telehealth were mixed, with many participants not having access to or being comfortable with the use of digital technologies.

Conclusions: Patients with DFD require additional supports for effective prevention, including offloading footwear.

Key words: Amputation, Foot ulcer, Footwear, Hospitalisation, Survey, Telehealth

Diabetes-related foot disease (DFD) encompasses a range of complications secondary to diabetes, peripheral neuropathy, and peripheral artery disease.^{1,2} In Australia, DFD complications such as foot ulcers constitute approximately 2% of annual hospital admissions, and often lead to minor or major amputations, and associated mortality.^{3,4} Current models of care for DFD emphasise treating active complications,² though the high DFD recurrence rate means patients often undergo cycles of hospital re-admission at least once every few years.¹ This can lead to a chronic state of poor health and place a large burden on the patient, their carers,⁵ and the health system.¹ Subsequent issues to recurring DFD include depression, and high rates of major amputations, end-stage renal failure, and mortality.^{4,6}

Improved secondary prevention of DFD therefore represents a cost-effective way of reducing its health and financial burden.^{7,8} Secondary prevention for DFD in current guidelines is complex, and includes a potentially overwhelming number of recommendations for patients, such as changes to diet and other lifestyle factors, wearing offloading footwear, daily foot checks, a high medication load, and appointments with a range of health professionals.⁹⁻¹¹ These recommendations are complicated when patients have had either minor or major amputations, or live in a regional or remote area with a lower socioeconomic status and geographical disparity in access to health services.^{2,12} As effective implementation of these recommendations have not been achieved,¹³ the development and testing of prevention programs are required to evaluate the effectiveness of multiple or complex interventions for a single condition, and their applications to clinical practice.^{14,15} There is currently no secondary prevention program for DFD, representing a

missed opportunity to reduce recurrence rates of DFD complications and improve patients outcomes.

There is an increasing emphasis on the value of patient perceptions for health service development, as they are the eventual end-users, making it useful to understand their needs and requirements and effective methods for health service implementation.¹⁶

Theoretical frameworks such as the Health Belief Model (HBM) which attempt to examine perceptions to understand preventive health-related behaviours are also being relied upon in health service development.¹⁷ Therefore, the aim of this study was to engage with people with DFD to understand their needs and preferences for a secondary prevention program, including how their foot condition is currently managed, and what is missing from current practice. Disparate access to healthcare due to rural and remote locality alongside the burden of DFD suggests that a potential avenue for a prevention program is through remote care.¹⁸ Patient perceptions of telehealth for DFD care were therefore also examined as part of this study.^{19,20}

Methods

Study Design

A cross-sectional online survey was conducted to investigate the experiences of Australians with a history of DFD, and their perceptions of effective current and potential strategies for the optimal secondary prevention of DFD. The survey collected both quantitative and qualitative data, and was administered through Qualtrics from the 15th May to 2nd December 2020. Ethics was granted by the Townsville Hospital and Health Service Human Research Ethic Committee (HREC/QTHS/53880). This study is reported according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guideline.²¹

Participants and Recruitment

Australian adults (aged at least 18 years) with a history of DFD were eligible to participate. A history of DFD was defined as having suffered any of the following secondary to diabetes: a foot ulcer, foot or leg infection, gangrene, loss of blood supply to the lower limbs, or minor or major lower-limb amputation. Participants with carers were encouraged to invite their carer to assist in completing the survey as they contribute to their essential DFD care.

Targeted and purposive snowball sampling techniques were used to reach potential participants. A target recruitment goal of 100 participants with DFD was chosen as this was expected to result in sufficient quantitative and qualitative data for analysis.

Patients were identified from The Queensland Research Centre for Peripheral Vascular Disease database. An extract was taken for patients in this database who have diabetes and previous history of a foot ulcer, diabetes-related amputation, or osteomyelitis. Patients being treated in both inpatient and outpatient clinics within the Townsville University Hospital were either mailed a copy of the survey or provided a copy in person. Two clinical staff from the Townsville Aboriginal and Islander Health Services brought the survey to the attention of patients who had a history of DFD and asked if they were interested in completing the survey on an iPad. Thirdly, Diabetes Australia was contacted and asked to distribute information about the study to their members, which was done on the 11th September 2020. Finally, the social media and marketing teams of the authors' institutions distributed the study link through their respective web and social media pages. This was an open survey with no password protection.

Online Survey

To ensure relevant and appropriate questions, the survey (see the Supplementary Materials) was developed by the research team in consultation with clinical specialists (including podiatrists, vascular surgeons and endocrinologists) and Aboriginal and Torres Strait Islander peoples and elders piloted by representatives of these groups. These consultations led to improvements in the order and wording of questions. The HBM was also utilised for question design as it is an established theoretical framework that explains perceptions of disease and relevant health-related behaviours through six key elements.¹⁷ These are perceived 1) susceptibility and 2) severity of disease, 3) benefits of and 4) barriers to undertaking health-related behaviours, and 5) cues to action and 6) self-efficacy for these behaviours. Figure 1 illustrates the HBM with examples of each element relevant to DFD. The author team also tested the questionnaire to ensure all questions and logic pathways functioned correctly. An information and consent page preceded the survey questions, detailing their rights as research participants, with consent implied by progression past the consent page. The survey was estimated to take 15-20 minutes to complete, and there were no incentives for participation. Patients first provided information on their geographical location and basic medical history as well as any diabetes-related foot or leg complications they had experienced, including the number of hospital admissions, and how much DFD has impacted on their lives. Questions were presented in a standardised order for all participants.

Participants were then asked if the medical support they were currently provided was sufficient and if not to describe where they felt additional support was needed. They also rated on 5-point ordinal scales and described what preventative measures they perceived as important to protect their feet from DFD, what complications were of greatest concern to

them, and what would increase their adherence to protective footwear. Finally, they were asked how comfortable they were interacting with their health care provider using technology, and what technology was available to them at home for telehealth purposes. Participants could review and change their responses at any time throughout the survey.

Data Analysis

Survey responses with sufficient data for analysis was defined as those in which participants progressed past questions on demographics and providing data on DFD-related complications experienced. The seven-item 2019 Modified Monash Model (MMM) classification system was used to transform geographical data to identify participants as living in metropolitan (1), regional (2-3), rural (4-5), or remote settings (6-7).²² Geographical data was also used with the Australian Bureau of Statistics' Index of Relative Advantage and Disadvantage (IRSAD) scoring system to identify participants' relative socioeconomic status, where a higher score indicates greater relative advantage and a lower score greater relative disadvantage.²³ Data collected in the 5-point ordinal scale questions were scored as 1 to 5 for analyses.

Data were summarised descriptively, and responses between males and females, between non-Indigenous and Aboriginal and Torres Strait Islander peoples, and between those living in different geographical settings were compared using the Mann-Whitney U or Kruskal-Wallis non-parametric tests. Analyses were conducted using SPSS v25 (IBM Corp. Armonk, NY, USA). IP addresses were used to exclude cases of duplicate survey views. Open-ended comments were analysed independently by two authors (BC and AD) using conceptual content analysis,²⁴ to confirm emerging themes that aligned or conflicted with the ordinal scale questions. This involved the identification, coding, and quantification of key concepts

raised by participants relevant to its partner quantitative question. To establish trustworthiness of the data, findings between the two authors were compared and conflicting interpretations resolved through dialogue with a third author (LS). Illustrative quotes that capture the themes identified are reported verbatim to support the findings.

Results

Of 119 participants accessing the survey, 80 provided sufficient data for analysis (67% completion rate). Their characteristics are summarised in Table 1. Their mean age was 65.1 years (standard deviation of 13.0 years), two-thirds (61.3%) were male, three-quarters (75.0%) were non-Indigenous, and most (74; 92.5%) lived in Queensland, with two each in New South Wales and Victoria, and one each in Western Australia and Tasmania. Most (60; 75.0%) lived in a regional area, 12 (15.0%) in a rural area and 5% each in metropolitan and remote areas. Two-thirds (50; 62.6%) were either current smokers or ex-smokers. A wide range of IRSAD scores showed that participants came from very disadvantaged (876; 6th percentile) to very advantaged (1081; 89th percentile) regions. There were no significant differences between Aboriginal and Torres Strait Islander participants and non-Indigenous participants according to rurality of residence ($P = .540$) or IRSAD score ($P = .868$).

Previous DFD complications and perceptions of recurrent complications

Foot ulcers were the complication most often (71.3%) previously experienced by participants, with nearly half (47.5%) also having had a foot infection. Over one-third (36.3%) had a diabetes-related lower-limb amputation, and over two-thirds (67.5%) had been admitted to hospital at least once to treat DFD. Non-Indigenous participants were significantly more likely to have reported experiencing foot ulcers (81.7% vs. 40.0%, $P < .001$), and those in rural or remote areas were significantly more likely to have reported having a

diabetes-related lower-limb amputation (64.7% vs. 28.6%, $P=.006$) compared to those in a metropolitan or major regional area. Most (58; 72.5%) participants indicated they had a GP management plan for their DFD, and 65 (81.3%) indicated they receive enough help from health professionals for their DFD, though half (40; 50.0%) had been admitted to hospital more than once for DFD.

Perceptions on the degree that DFD interfered with daily life was varied, with approximately one-third indicating that DFD had no or minimal impact on their life, one-third as some interference, and one-third with a lot of interference. There were no significant differences between sexes, Indigenous status, or rurality. Half of the participants also provided details as to how DFD had interfered with their life, with reduced mobility and the resulting lack of independence most frequently described as affecting daily life.

"I have been wheelchair bound for three years...can't drive, can't walk, can't cook"

(Male, 55 years, Non-Indigenous)

"I like to swim and can't with foot ulcers or infections...not being able to walk great distances like I used to" (Male, 67 years, Non-Indigenous)

"It stopped me from playing games with my kids...I can't walk as far as before"

(Female, 49 years, Aboriginal and Torres Strait Islander)

The amount of time and effort required to have DFD complications treated, including hospitalisations and recovery time, were also described as significantly affecting daily life.

"I have been hospitalised a lot because of this problem. I have had foot ulcers, wounds, and already had two toes amputated" (Male, 56 years, Non-Indigenous)

"Sickness with infection in toe, a five day hospital stay and amputation of a toe last

year, then the recovery time” (Female, 63 years, Non-Indigenous)

Ratings of DFD complications of concern are shown in Table 2, with most participants rating each complication as ‘quite’ or ‘very’ concerning (4 or 5 out of 5). Infection and amputation of the toe or leg were those with the highest ratings for concern, with hospital admission the least concerning to participants. There were no significant differences in these perception ratings between sexes or rurality. Aboriginal and Torres Strait Islander participants were more concerned about the risk of leg amputation compared to non-Indigenous participants ($p=0.034$). The open text comments focused on retaining independence and avoiding complications, such as amputation.

“Having suffered many leg and foot ulcers and hospital visits make me more determined to avoid any problems, and amputations” (Male, 76 years, Aboriginal).

“Don’t want family members waiting on me” (Male, 48 years, Aboriginal).

Perceptions of preventive DFD measures

Participant perceptions on the importance of measures to prevent foot disease are summarised in Table 3. Most preventive measures were largely perceived as ‘quite’ or ‘very’ important (4 or 5 out of 5) by participants, with foot checks by a health professional and regularly taking prescribed medications perceived as the most important (>85% ‘quite’ or ‘very’ important). However, minimising activity on the feet was perceived by less than 40% of participants as ‘quite’ or ‘very’ important. There were no significant differences in these perceptions between sexes, Indigenous status, or rurality. When asked to describe why these preventive actions were considered important, the main reasons described were being able to ensure and maintain general foot health and independence, whilst avoiding complications such as ulcers and amputation.

“Regular observation of my feet is the key to making sure everything is going well.

Early detection of when things are not going well has been the best thing for me”

(Male, 73 years, non-Indigenous)

“Whatever can be done to assist in prevention can only help minimise risks” (Female,

68 years, non-Indigenous)

“Having preventative measures in place to ensure there are no skin tears or breaks

that can turn into an ulcer” (Male, 25 years, Aboriginal)

Use of offloading footwear

Despite the high rate of previous DFD complications experienced by participants, only half of participant ‘usually’ or ‘always’ (4 or 5 out of 5) wore offloading footwear (see Table 4).

There were no significant differences in the reported use of footwear between sexes, Indigenous status, or rurality. The availability of free or low cost footwear was rated as the method most likely to increase the use of footwear, with over 80% ‘agreeing’ or ‘strongly agreeing’ (see Table 4). Convenience in having the footwear fitted close to home, and being able to determine the appearance of footwear were also highly rated. There were no significant differences according to sex or rurality for these ratings. Compared to non-Indigenous participants, Aboriginal and Torres Strait Islander participants were significantly more likely to ‘agree’ or ‘strongly agree’ that determining footwear appearance would improve footwear use ($P=.009$). Cost, comfort and appearance of footwear were similarly raised as issues in the open-ended responses.

“Make recommended footwear realistic for professional people to wear without the

humiliation of publicising their problem” (Female, 55 years, Non-Indigenous).

“Cost to pensioners determines what is worn” (Female, 68 years, Non-Indigenous).

Some participants also detailed issues with accessing shoes based on the slow recovery of foot ulcers or amputations, or physical location.

“Have been fitted for shoes 16 months ago but they wont give them to me because my foot is still bleeding a little” (Male, 58 years, Non-Indigenous)

“Availability to be fitted and obtain proper shoes on Palm Island” (Female, 74 years, Aboriginal)

Supports needed for DFD care

Open-ended responses focused on the support participants receive from podiatrists at hospital and community clinics, such as comprehensive foot checks, receiving footwear and insoles, and other materials such as wound dressings.

“The hospital and [name of community clinic] were very helpful and sympathetic. Everything has been supplied including new shoes with inner soles. They could not have done more” (Male, 65 years, Non-Indigenous)

“They put me on a diabetic care plan, they review and check up on me every three months, they send me to see the podiatrist...everything they provide me is good so far” (Male, 56 years, Non-Indigenous)

“The GP, diabetic specialist, and podiatrist they tell me how I should fix it” (Female, 49 years, Aboriginal and Torres Strait Islander)

As opposed to these positive responses on foot health support, most (63; 78.7%) participants indicated that they needed more help with at least one aspect of care related to their diabetes and general health. This included 29 (36.3%) indicating they need more help

with controlling their blood glucose levels, 19 (23.8%) with cholesterol, 24 (30.0%) with blood pressure, 26 (32.5%) with foot care education, 25 (31.3%) with foot care actions, 12 (15.0%) with smoking cessation, 38 (47.5%) with access to protective footwear, and 37 (46.3%) with increasing physical activity. In addition to these, some participants also described needing mental health/psychological support and advice on nutrition, as well as improved financial support.

“I would have like more (any) psychological help with my foot issues particularly as I moved to and then through an amputation. I have not coped well with this loss”

(Female, 55 years, Non-Indigenous)

“Nutrition mainly, cooking courses, reversing diabetes through food preparation”

(Male, 70 years, Non-Indigenous)

“Travel and monetary assistance to cover expenses to attend appointments” (Male, 70 years, Non-Indigenous)

Technology Access, Use, and Preferences

The final section of the survey on participants' perceptions of the use of technology for foot care received mixed responses. Half (53.9%) of participants thought the use of technology to help in managing foot care believed this approach was 'acceptable' or 'very acceptable' while the other half was less certain (see Table 5). Even fewer participants felt confident in using the required technology for telehealth, with 41% indicating they were 'confident' or 'very confident' and nearly one-third (29.5%) indicating they were 'not at all confident' (Table 5). There were no significant differences according to sex, rurality, or indigenous status. In addition to the abovementioned uncertainty and low confidence with technology, many participants did not have access to technology suitable for telehealth. Eleven

participants (13.8%) indicated they did not have any of the listed devices, and one-third (35.0%) did not have any smart devices capable of audio-visual videoconferencing.

Discussion

This online survey examined the perceptions of people with DFD, including how it has impacted their health, current management strategies including offloading footwear, and their needs for further support. Examining perceptions on these issues is expected to inform on the development of an effective secondary prevention program for people who have experienced DFD. Aligning with previous research on DFD, these patients can suffer recurring foot ulcers leading to debilitating consequences including multiple hospital admissions and amputations.^{1,3,4} Podiatrists were seen as a critical source of DFD care and prevention, with preventative measures perceived as very important for foot health, though offloading footwear was infrequently used by half of participants.¹³ In addition to the need for further support in foot care education and access to offloading footwear, support with other risk factors relating to diabetes and psychological support were also raised, similar to previous qualitative studies on DFD patients.²⁵⁻²⁷ There were few instances where perceptions varied between participant demographics, indicating that a secondary prevention program with a uniform approach may suit the needs of most people with DFD.

When examining the results through the lens of the HBM, it appears that most people who have had DFD complications are aware of their susceptibility to subsequent complications and the potential severity of these complications.²⁵ However, not all participants had the same concerns on their susceptibility to further DFD complications, and preventive behaviours did not align with their concerns, such as poor use of offloading footwear.

Amputations leading to reduced mobility and lack of independence were the consequences

of most concern, particularly for the Aboriginal and Torres Strait Islander participants, possibly due to their higher rates of DFD-related amputations in Australia compared to non-Indigenous people.²⁸ Therefore, a secondary prevention program for DFD requires patient education as a key component in its design, as it is a recommendation in current DFD guidelines,²⁹ and ensures that patients are aware of the recurring nature of DFD as well as the severity to which it can impact on their health. Increasing awareness of susceptibility and severity of DFD complications increases the conduct of positive health-related behaviours.¹⁷

Previous research has also highlighted several barriers to prevention strategies such as offloading footwear,¹³ with footwear cost, appearance, and convenience raised by participants in this study. Other barriers relating to self-efficacy in caring for feet were also raised in this study and elsewhere,^{25,26} with the psychological toll of caring for feet daily and suffering complications such as lower-limb amputation raised as being unmet in current care. An effective secondary prevention program needs to overcome these barriers where possible, facilitating people with DFD to care for their feet. Half of the participants had been admitted to hospital more than once due to DFD, and also cited the critical care provided by podiatrists. Due to the complexities in diabetes care and DFD care, a secondary prevention program should be holistic in its approach, and support patients in managing all aspects of their health related to diabetes and their feet. These recommendations are similar to current clinical DFD guidelines, though have not been successfully implemented in practice.^{9,29}

Telehealth as a medium for promoting secondary DFD prevention has been tested previously, though the effectiveness of this approach is not clear.³⁰ Participants in this study

often did not own the required technology for telehealth, or were not confident in using technologies they possessed, such as smartphones. However, others were more confident and open to using telehealth to manage their DFD, with previous research indicating that both patients and health professionals see the potential benefits of telehealth for DFD care.³⁰

Strengths and limitations

There are strengths and limitations of this research of note. The survey tool used in this study was developed by the author team who come from a range of health-related backgrounds, in addition to consultations with other relevant health professionals and representative patients. While the number of participants recruited was less than the initial target, the number of participants was sufficient to identify key themes in the quantitative and qualitative data collected. Also, the survey was successful in recruiting a large proportion of Aboriginal and Torres Strait Islander participants, ensuring that their voice is heard regarding the impact of DFD on their health, their needs for a prevention program, and preferences for using telehealth. While most participants lived in a single Australian state (Queensland), they resided across all MMM rurality categories with a wide range of IRSAD scores meaning they are more likely to represent the needs of the diverse Australian population. Finally, people who participate in research may not have views comparable to those who do not participate.

Conclusions

Mechanisms for the improved secondary prevention of DFD is needed within the community to prevent complications and hospital admissions. Despite the perceptions of participants indicating their concern on a range of DFD-related complications, preventative

behaviours do not reflect these perceptions. A secondary prevention program with the capacity for telehealth offers an opportunity to support people with DFD in more effectively monitoring and managing their foot health and reduce related complications.

Declarations of interest

None.

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