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Diabetic Foot Care and Lower Limb Preservation

Evolving a Value-Based Healthcare Initiative in Ontario

Issue briefing | July 18, 2024



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This project was conducted by The Conference Board of Canada in collaboration with Diabetes Action Canada and the Program for Health System and Technology Evaluation on behalf of the University Health Network.

Key findings

- Timely and affordable access to skilled healthcare professionals and community-based services remains a major barrier for many Canadians with diabetic foot complications. Not enough preventative care is available to reduce otherwise avoidable ulcerations and limb amputations.
- Foot and wound care for patients with diabetes is unnecessarily costing the healthcare system in Ontario millions of dollars.
- The foot and wound care pathway in Ontario is siloed, with gaps in funding, data collection, and sharing.
- Interprofessional knowledge is lacking in specific clinical and support roles and skills. These roles are fulfilled by foot and wound care teams who support appropriate, safe, and excellent care.
- Systemic inequity is resulting in individuals receiving uneven access to care and delayed treatment. Patients without private insurance coverage and without access to foot specialists in community-based primary care are more likely to develop ulcerations.
- Patients want access to affordable, timely, and culturally responsive care.

Recommendations

- Embed a value-based healthcare approach and fund preventative services to reduce Ontario's rate of lower limb amputations due to diabetic foot ulcerations.
- Increase the use of system-wide and standardized data collection tools and instruments.
- Enable timely data access to support achieving outcomes that matter to patients and a learning health system.



The burden of diabetes to healthcare in Ontario

In Ontario, 1.3 million individuals live with diabetes. This will increase over the next decade as the population ages.¹



The quality of life for patients living with diabetes can be significantly impacted, especially when complications arise because of the disease.

People living with diabetes report significant fear of developing long-term complications because of the disease, with the greatest worry being lower limb amputations (62.1 per cent). Additional concerns include eye/eyesight problems (57.3 per cent) and kidney complications (54.7 per cent).² All of these apprehensions can lead to disability and social isolation.³

Diabetic foot ulcers impact patients' mobility, employment⁴ and quality of life.⁵ They frequently become infected and, if not appropriately managed in a timely manner, can result in amputation. Lower extremity amputations have life-changing physical, mental wellness, and economic impacts.⁶ In some cases, immobility and pain may be prolonged with recurring diabetic foot ulcerations (DFUs) and foot salvage is deemed unlikely, even with ongoing care. However, with adequate supports, patients have reported improved or preserved quality of life post-amputation.^{7,8}

1 Public Health Agency of Canada, *Canadian Chronic Disease Surveillance System*.

2 Kuniss and others, "Expectations and Fear of Diabetes-Related Long-Term Complications."

3 Brinkhues and others, "Socially Isolated Individuals Are More Prone to Have Newly Diagnosed and Prevalent Type 2."

4 Waters and Holloway, "Personal Perceptions of the Impact of Diabetic Foot Disease."

5 Hogg and others, "Measures of Health-Related Quality of Life in Diabetes-Related Foot Disease."

6 Kizilkurt, "Quality of Life After Lower Extremity Amputation."

7 Primadhi and others, "Amputation in Diabetic Foot Ulcer."

8 Lazzarini and others, "Global Trends in the incidence of Hospital Admissions."

At all stages, a patient-centred, shared, decision-making process is critical. An individual's lifestyle and function for their self-determined quality of life must be at the forefront of the pathway of care that the care team and patient are taking.⁹

The cost of care

Currently, there isn't an accurate estimate of the total cost of care for provincial health systems and patients that encompasses public, private, and out-of-pocket expenses associated with diabetic foot management—including wound care and amputation.

In 2011, the total cost associated with diabetic foot ulceration (DFU) was estimated in Canada to be C\$547 million, as shown below.

- C\$358.6 million in acute care institutional costs
- C\$125.4 million in home care costs
- C\$63.1 million in long-term care costs¹⁰

A 2017 systematic review estimated that the per-case cost of amputation in developed countries, depending on the type of amputation, is between C\$ 35,000 and C\$ 45,000.¹¹

For those individuals who do require an acute care institute admission for a DFU in Ontario, the net lifetime cost-of-illness, compared with an individual without a DFU, was estimated in 2018 to be C\$619,300.¹²



9 Ong and others, "Decision-Making Processes for Non-Emergency Diabetes-Related Lower Extremity Amputations."

10 Hopkins and others, "Economic Burden of Illness Associated With Diabetic Foot Ulcers."

11 Petrakis and others, "Losing a Foot Versus Losing a Dollar."

12 Chan and others, "Lifetime Cost of Chronic Ulcers Requiring Hospitalization."

Value-based healthcare

A multidisciplinary approach toward comprehensive wound care for DFUs has been recommended for many years. However, wound care in Ontario functions in silos, without a consistently coordinated approach to ensure continuity of care across the various sectors of the health and care ecosystem.¹³

Value-based healthcare (VBHC) has emerged as a leading approach to improving the organization of healthcare to transform health outcomes.¹⁴ VBHC links funding spent on healthcare programs or services provided over a patient's journey of care to the outcomes that matter most to them.

This is in contrast to conventional funding that focuses on direct costs of services, processes, or products. VBHC acknowledges that outcomes—and how they are achieved—vary considerably in different contexts. It also aims to demonstrate how value can grow as total costs of achieving the same or better outcomes can effectively decrease.¹⁵

13 Lysy, "Prevention of Diabetic Foot Ulcers"; Hussain and others, "A Call for Integrated Foot Care and Amputation Prevention Pathways for Patients with Diabetes and Peripheral Arterial Disease Across Canada;" Weisz, "Some Assembly Required."

14 Slovinec D'Angelo, Moroz, Smith, and Barrett, *Value-Based Healthcare in Canada*.

15 Canadian Foundation for Healthcare Improvement, *Value-Based Healthcare Toolkit*; Slovinec D'Angelo, Moroz, Smith, and Barrett, *Value-Based Healthcare in Canada*.



A value-based approach in Ontario

Over the past few years, three clinical sites in Ontario have developed and implemented initiatives to address the needs of patients at risk of developing or living with diabetic foot ulcers. In early 2020, each of the three sites convened to implement a value-based approach to evaluating the strengths and challenges of these programs. Since March 2020, delivering care to this population has been impacted by the COVID-19 pandemic.

This issue briefing explores current issues and opportunities associated with the ongoing implementation of foot and wound care pathways in Ontario. We partnered with the Programs for Health System and Technology Evaluation at the University Health Network, and with Diabetes Action Canada, to undertake a mixed-methods study that provides perspectives from Patient Partners as well as stakeholders from Ontario’s healthcare system.

Patient Partner and clinical site forums

“I am seeing myself slip through the cracksyou’ve got to fight for your feet.”

Patient Partner

In October 2022 and July 2023, the Program for Health System and Technology Evaluation supported by Diabetes Action Canada hosted two Patient Partner forums. These forums gave patient stakeholders a chance to offer their perspectives and experiences as individuals living with diabetes. The forum participants were asked to share views on what they “value the most” when thinking about an integrated approach to receiving care—rather than a siloed care pathway. Importantly, our aim was to identify specific outcomes that patients hoped would come to realization.

Our participants included patients from a range of cultural and socioeconomic backgrounds, residing in urban, rural, or remote communities. They expressed frustration at the lack of information, resources, funding, and access to timely care. Patients also expressed hopefulness that change is possible, but emphasized a need for more capacity to prevent rather than just treat foot ulceration. Additionally, patients stressed that healthcare providers need to have the skills to know when patients were at risk of developing a foot ulcer. This includes the knowledge to assess and implement specific interventions in a timely manner to prevent or avoid ulcer development.

“I think there’s a lot of interest in doing this better and we all have seen too many people who’ve lost their legs that perhaps could have been avoided. So, I think there’s also a lot of room for optimism ... some of the solutions don’t require huge investment.”

Clinical site forum participant

In March 2023, The Conference Board of Canada hosted a virtual clinical site forum where representatives from three hospital-based Ontario foot care clinics discussed their unique care pathways. They described current processes for patient referral, clinical staff roles and skills, data collection, and how their sites were funded and resourced.

Representatives from several levels of Ontario’s healthcare system participated in discussing critical areas for improvement in how the care pathway is structured. We were informed about the need for greater awareness of footcare for persons living with diabetes and the necessity for their caregivers. The forum also provided international examples of leading models of care.

A framework for understanding the issues

Macro, meso, and micro levels of diabetic footcare



Patients want a healthcare system that provides “culturally responsive, accessible, and affordable footcare.”¹⁶

Diabetic footcare is complex, and a broader framework is required to effectively navigate patients across different levels of the care pathway. Patient perspectives tend to get lost when considering larger systemic challenges like integration of care, or the ways in which organizations can or cannot access reliable, up-to-date patient data.

This issue briefing explores core themes from our participants that we outline below through a framework that considers patient and expert-participant perspectives into macro, meso, and micro levels. Our approach categorizes the complexity of the care pathway for diabetic foot care and treatment. This framework includes a systemic (macro) or healthcare system level; an organizational (meso) or care centre/regional community and acute care network level; and an individual (micro) or point-of-care clinic-based patient and doctor/nurse and allied health provider level.

Macro – system level

Lack of access to primary care and chiropodists and podiatrists (foot and ankle specialists): A major barrier to adequate care and prevention impacts all individuals living with diabetes, and overwhelmingly impacts marginalized community members.

¹⁶ Comment from a Patient Partner.

Access to primary care is required for referrals to specialized services to access treatments needed to minimize the impact of diabetic foot ulcers. An exception is chiropodists/podiatrists, who are overwhelmingly in private practice and require direct out-of-pocket payment. The role of chiropodists and podiatrists is of critical importance to an interprofessional practice model—whether community- or hospital-based.

“At one time many hospitals across Ontario had staff chiropodists. That has now become a rare position, even as the need has exponentially increased. Since they [chiropodists] were non-union staff, they were easy to cut when hospital budgets were tightened. A classic case of knowing the cost, but not the value, of the services provided.”

Patient Partner forum participant

Lack of awareness: From a societal perspective, there needs to be a much greater understanding of the connection between foot and wound care and diabetes.

A gap in providing preventative care for ulceration: Stakeholders were clear:

“It’s been demonstrated elsewhere that prevention ... is an overall cost savings to the system”

Clinical site forum participant

And, as another asserted,

“We are very good at taking care of problems, but not so much at preventing them.”

Site forum participant

Funding: Uncertainty remains when it comes to paying for wound treatment and footwear. The care pathway needs to be evaluated from this standpoint. There is a pay inequity for specialists—community health care cannot compete with private sector and hospital wages.

“It’s all about pulling the pieces together and it’s been done everywhere. Canada is ... behind the 8-ball on this one.”

Site forum participant

Resources are needed to create an integrated clinical care pathway: Even to healthcare providers, there is a lack of knowledge about which limited resources are available.

Systemic inequities in care: One participating site reports that five to eight per cent of patients undergoing leg amputations are homeless.

“There is a huge gap in care, and unfortunately those who are most marginalized are the ones likely to end up with limbs lost.”

Site forum participant

Lack of oversight in the sale of footwear: Orthotics are not prescribed. Anyone can sell them. There should be a standardized system for vendors to obtain accreditation. Additionally, the insurance industry has an opportunity to play a leading role in supporting excellent practice. A chiropodist creates custom-made prescription functional orthotics, designed to change how the foot and ensuing kinetic chain works and/or changes the pressure patterns on the foot during normal ambulation. This enhances safety and supports healthy foot care. Off-the-shelf or minimally altered orthotics lack this customization and assurance. Patient Partners expressed a lack of confidence in knowing where to go for appropriate footwear.

“It is the wild west out there regarding footcare.”

Patient Partner

Discrimination and racism: Better cultural awareness, sensitivity, and training for healthcare professionals could begin to reduce the ongoing effects of systemic discrimination. Indigenous patients with diabetes face unique challenges in the care pathway due to systemic racism.

“And again, for those populations of patients who are marginalized, who are vulnerable ... they’re being taken advantage of because it’s a field that is so unregulated. And there’s no oversight from any kind of professional organization.”

Patient Partner forum participant

Meso – organizational level

Coordination of care: Participants in the site forum expressed an overarching theme within the meso framework—the need to establish a vision for the coordination of care. This was supported by a data-sharing model that provides consistent patient information across participating healthcare sites.

Funding: Footcare funding depends on clinics’ individual organizational capacity. That makes it challenging to plan over the long term or for variations in population needs and growth.

“The lack of sustained future funding is a big concern and I’m sure that is [true] for everybody. We don’t have a model beyond, you know, ‘we’ve got some funds for now.’ But what’s going to happen in five years time, etcetera?”

Site forum participant

Data collection: There is no standard tool for collection and sharing of patient data, particularly across care settings or electronic medical record systems. This makes it difficult for specialists to access patient health information collaborative care plans and outcomes of care—a significant barrier to enabling a learning care system.

Patient care pathways: Footcare clinics have unique care pathways that provide uneven inpatient and outpatient care, patient monitoring, and wound/dressing follow-up. Depending on where patients live, or where they may be admitted, the variation in treatment could vastly affect outcomes.

Specialization and skills: No ideal foot care clinic exists where patients can receive comprehensive and timely access to diagnosis or treatment. Care is dependent on the capacity, resources, and referral process of each clinic.

“A true podiatry training program, based on the United Kingdom and Australian models, is long overdue. The current chiropody program, despite the excellence of some of their graduates and the work they do, is simply insufficient.”

Patient forum participant

Understanding the needs of the community: Being able to adequately support and respond to a clinic’s referral base can be difficult without resources and timely access to interoperable data.

Micro – individual level

Patient advocacy: Patients identified the need to self-advocate when it comes to diabetic foot care. There are too many gaps in skills and in the care pathway, and patients should be able to have their voices heard.

Patient quality of life: Diabetes can have an overwhelmingly negative impact on a patient’s quality of life. The possibility of enduring ulceration or amputation—long before it is necessary—is, as one patient put it, “horrific.” The ongoing mental health and emotional stress is significant.

Relationship between doctors and patients: Patient Partners want to be more involved in their footcare and want to feel respected by professionals who are making decisions on their behalf. They also want to see a better rapport between themselves and healthcare professionals and truly experience a shared decision-making relationship with their care team.

Patient and doctor education about foot and wound care: When we asked patients what they wanted to see in the future of footcare, education was a primary concern. Patients described feeling helpless and unsupported when seeking information about diabetic footcare. Conversely, they want doctors and nurses to also have the skills and knowledge to prevent ulceration and to advance patients along the pathway of care. While there is a community of clinicians who specialize in diabetes wound and foot care, patients described the need to establish a medical specialty in this area.

Lack of empathy among healthcare professionals: The emotional toll of living with diabetes needs to be acknowledged by healthcare workers. Patients feel that a lack of empathy, respect, and understanding remains a pervasive concern for them.

Stigmatization: Living with diabetes comes with a range of challenges beyond the treatment patients receive. Patients described the stigma of the disease, and its effect on their social and emotional well-being. Specifically, ulcer treatment is commonly visible, such as when using a total contact cast (TCC). As well, sometimes the ulcers can have a strong odour, adding to stigma.

“Diabetes often has a larger ‘lifestyle’ component than actual medical care ... that’s a giant void in resources.”

Patient Partner participant



Key recommendations

- Embed a value-based healthcare approach to diabetic foot care to ensure patient perspectives are at the centre of care.
- Fund preventative services to begin decreasing patients presenting with a diabetic foot ulceration. This will reduce Ontario's rate of lower limb amputations due to DFUs.
- Increase the use of system-wide and standardized data collection tools and instruments to monitor wound care processes and outcomes.
- Enable timely data access to support a learning health system across primary, community, and hospital settings.
- Patients diagnosed with diabetes should have a foot examination immediately. Preventative, ongoing footcare should not be an afterthought.



Appendix A

Methodology

Research questions

The primary objective of this study is to understand the contextual specifics of the diabetes foot care and limb preservation (DFCLP) pathway components, providers, and care settings involved, and the patient populations they serve.

There are three secondary objectives. They are to:

- Examine current data collection, pathway implementation, and outcome measurement strategies for each site, and how these changed due to the COVID-19 pandemic.
- Identify how DFCLP pathway implementation is funded at each site.
- Understand patients' perspectives with respect to values, care coverage, and out-of-pocket expenses related to foot care for those individuals living with diabetes.

This mixed-methods research study comprises two components. The first involved two focus group sessions of Patient Partners of Diabetes Action Canada. The second involved representatives supporting the current diabetes foot and wound care pathways at three academic teaching hospitals in Ontario. The study was fulfilled through the administration of a clinical site questionnaire and a clinical site forum.

Participation was as follows:

The first Patient Partner focus group was conducted in October 2022, with five participants and four observers; and the second on July 2023, with nine participants and four observers.

The clinical site forum was conducted in March 2023. A total of 15 participants from three hospital sites took part. A total of five others attended, including researchers from the project team, support staff, and the facilitator.

During the Patient Partner focus groups, participants were invited to discuss values and priorities for care needs, experience with foot and wound care pathways, and benefits and challenges associated with care received. Topics also included barriers and facilitators for care, and out-of-pocket expenses and impact on treatment.

During the clinical site forums, the areas discussed included the:

- wound assessment parameters (pathway categories);
- documentation methods for diabetes foot care (i.e., clinical notes, and electronic health record (EHR);
- data entry and digital wound capture tools and applications;
- billing and reimbursement (e.g., ICD codes; dressing costs; human resources etc.);
- evaluation of outcome measures, including how and to whom are data–related to DFCLP pathways–reported;
- impact of COVID-19 related adaptations to care pathway;
- question of what values does each of the three sites bring to the development of the DFCLP.

Patient Partner forums

The two focus groups consisted of facilitated sessions. The October 2022 session was conducted in-person in Toronto, and the July 2023 session virtually on MTeams. These sessions lasted approximately one and half hours to two hours in duration. The discussions involved:

- forums for a robust dialogue around patient values and priorities for care needs;
- experience with foot and wound care pathways;
- benefits and challenges associate with care received;
- barriers and facilitators for care and out-of -pocket expenses;
- impact on treatment.

Transcripts were anonymized and analyzed thematically by the research team. A total of four hours of Patient Partner focus groups resulted in 40 pages of transcript with 21, 218 words of text.

Clinical site forum and questionnaire

A clinical site questionnaire was sent to each of the three participating hospitals prior to conducting the clinical site forum. Each clinical site team was asked to complete a survey of current practices. Additionally, each team was requested to designate a responsible party to collate team data, complete the survey, and return one copy to the researchers by the date outlined in the invitation. The results from the questionnaire were used to guide the discussion in the Clinical Site Forum, which involved representatives (site leads) from each of the hospitals. Each site self-selected the team members to present. It should be noted that one site was unable to return the survey questionnaire.

Participants for the Patient Partner focus groups were recruited from Patient Partner members of Diabetes Action Canada (DAC). All individuals provided consent to receive an email for such purposes. A written study information sheet and consent form were provided via email to the Patient Partners as a part of this initial communication. Interested participants responded directly to Diabetes Action Canada to express their willingness to participate. All scheduling was done by DAC to ensure DAC remained the primary contact.

For the clinical site forum, various stakeholders were approached to participate. These individuals were representatives of the participating care organizations and patients, including:

- chiropody,
- nursing,
- vascular surgery,
- family medicine,
- internal medicine,
- endocrinology,
- infectious disease,
- physiotherapy,
- occupational therapy,
- social work,
- nutrition,
- senior leadership,
- decision support.

An invitation letter to attend the clinical site forum was sent to site leads for distribution to staff, clinicians, and others whose work intersects with the DFCLP team (e.g., referring agencies, allied health professionals, administration and policy decision-makers).

Since generalization beyond the selected sites is not an aim of this project, a representative sample was not required. Registration to attend the clinical site forum was considered as consent by participants for the proceedings to be recorded and transcribed. At the time of registration, participants were advised that information shared at the event may also be used to inform upcoming research projects.

The site forum was coded and analyzed in NVivo by the research team. A total of two hours of the clinical site forum resulted in 40 pages of transcript and 17,531 words of text.

The study was reviewed and approved by the University of Toronto Research Ethics Board Protocol # 00042321.

Appendix B

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