

Patients' Voices, Stories and Journeys of Navigating Social Life while Having and Managing Complex Wounds:

A Knowledge Mobilization Project

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Wounds Canada is thrilled to announce the launch of the "Patients' Voices, Stories and Journeys" project, which aligns with the research program and previous work related to patients' empowerment and engagement in everyday self-management of diabetic foot ulcer (DFU) of Idevania Costa (principal investigator).¹⁻³ A central aspect of the project will be the gathering and disseminating of individuals' and families' video stories about balancing everyday life while living with complex wounds. This project is particularly relevant because:

- Health-care professionals have noted a rapid rise in the unmet needs (e.g., physiological, emotional and spiritual) of people with complex wounds in all parts of the country
- Not everyone is aware that living with a complex wound is challenging and affects many aspects of individuals' lives
- Health-care providers need to understand the social determinants of health (SDH) that may be

preventing these individuals from successfully navigating through their journeys

Why Listening to Patients' Voices, Stories and Journeys Matters

Nationally, health-care professionals have noted a rapid rise in hard-to-heal wounds that require life-long management and affect patients' physical, psychosocial and spiritual lives, particularly for low-income, marginalized and/or vulnerable people. The cost to Canadians of treating complex wounds is estimated at \$3.9 billion per year. The indirect costs to individuals is more significant, and include stigmatization, social isolation, economic hardship and psychological issues such as depression, stress and anxiety.⁴ Unfortunately, many health-care providers and social service practitioners do not have a widespread understanding of such indirect costs. Frequently, individuals are blamed or judged for not being "compliant" or "adherent" to a plan of care "designed

for them” but “without them.” In these cases, the plan of care is often not inclusive of their unique needs or lifestyle. The extent to which these plans consider social context, needs, concerns and preferences can vary significantly.

This project will provide an opportunity to listen to and disseminate individuals’ and families’ stories and:

- Capture the impact of hard-to-heal wounds on their lives
- Identify the gaps and synergies in wound care provision uncovered by their stories
- Identify areas in which holistic wound management is developing and/or can be enhanced

Throughout the project, the research team and participants will create an online library of resources to help individuals living in similar situations find new pathways and support to address the impact of wounds on individuals and families. The multiple knowledge translation materials generated from this project will be distributed widely to the media along with events hosted on Wounds Canada’s website.

Implications

Our aim is to have this project generate new knowledge and learning that will address a gap in current thinking and evidence about people with wounds who live on a low income, have limited access to specialized wound care or who are marginalized and/or vulnerable. Our study will inform policy makers, government bodies, non-specialized wound care providers and those new to the field on the realities of living with a complex wound. The desired result is that health-care providers and authorities in the position to improve care and access to services and resources for this population will have more resources to help them visualize what lies beyond the ragged edges of a wound and appreciate how aspects like the SDH intersect with an individual’s overall health and well-being.

Listening to patient and family stories potentially may uncover social realities that perpetuate health and social inequities and social injustice.


Our goal is to influence health policy and clinical practices and shift the current paternalistic paradigm that places individuals and families as passive recipients of information and care and does not consider the effects of the SDH. Our proposed work goes beyond the disease/wound or dressing management and moves toward understanding the reality and uniqueness of individuals living with wounds in the Canadian context.

Ultimately, this work will emphasize the process of rethinking and revising the delivery of wound prevention and care programs and lead to placing individuals at the centre of care and engaging them as more active participants in their own care and decision making.

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