

Our Voices, Our Stories

A Patient Journey Initiative

**Presentations from the
Our Voices, Our Stories Conference 2022**

Edited by:
Idevania Costa, PhD
Darren Levine, EdD



A supplement of



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Executive Summary

The Conference

On June 9 and 10, 2022, the School of Nursing and School of Social Work at Lakehead University, in partnership with Wounds Canada, and with funding from the Social Sciences and Humanities Research Council of Canada, hosted Our Voices, Our Stories, a national person-centred conference, held virtually. This conference was aimed at raising awareness among stakeholders (e.g., researchers, scholars, practitioners, policy makers, community leaders, civil servants, politicians) about the needs, challenges and barriers to health and social care faced by individuals living with complex wounds. This two-day event brought together individuals impacted by complex wounds, researchers and students from Northwestern and Southeastern Ontario, and health and social service providers, clinicians, educators and community leaders from across Canada.

The goals of the conference were to: 1) share individual and family stories of balancing everyday life while living with complex wounds; and 2) advance intersectoral exchanges between academic researchers in the social sciences, humanities and health science disciplines, and with researchers, practitioners and policy makers from the public, private and not-for-profit sectors.

Over the course of two days, 191 participants took part in 17 interactive sessions that involved eight research-based presentations, six patient and patient-advocate stories of lived experience, and four co-creation sessions in which participants worked together to identify emerging themes and opportunities for action. Feedback from participants highlighted that conference sessions were very well received, met their stated learning objectives, engaged the audience in a powerful and meaningful dialogue, were relevant to participants' areas of practice, and enhanced participants' awareness of the patient experience.

This unique knowledge mobilization event held space for the sharing and exploration of patients' and patient-advocates' stories of navigating Canada's health-care system and social life challenges to access wound care services. Together, conference participants listened to and learned from one another while sharing insights into the patient experience, the impact of a wound on one's life, and available opportunities to strengthen wound care. On the last day of the conference, participants were invited to a collective action session focused on co-creating ways to strengthen and improve wound care, and to create a pathway toward a person-centred approach that will help improve outcomes for all Canadians.

When combined, the shared stories, reflections and dialogue converged around several key areas of focus, including: advocacy, change, collaboration, wound specialists, barriers, cultural safety and accessibility. Within these areas of focus, examples of emerging themes included the need for greater:

- Advocacy and awareness surrounding wounds in Canada
- Wound-related education for care providers, patients and patient advocates
- Cultural safety and cultural competence education, practices and policies
- Standardization of wound-related best practices that focus on a person-centred care model
- Collaboration and communication between disciplines, and among care providers, patients and their advocates (e.g., family members)
- Shifts within health care and wound care away from a biomedical model and toward a holistic, person-centred model
- Local community co-production of community-based wound care services
- Easy and timely access to specialized wound care services across jurisdictions

Next Steps

Conference partners are subsequently moving into the next phase of this long-term project by transforming each of the areas of focus identified at the conference into a roadmap for concrete actions, while continuing to collect and promote patient stories. Any proposed actions will consider the ways in which the stories, experiences, research, reflections and insights that were shared

at the conference and gathered afterward can inform efforts for creating a national person-centred wound care strategy. To become involved in, and stay informed about, next steps in this long-term initiative, please visit [Our Voices Our Stories](#).

How to Cite: Costa I, Levine D. Executive summary. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:2–3.



Conference Partners: Wounds Canada and Lakehead University



Established in 1995, Wounds Canada is a charitable organization dedicated to the advancement of wound prevention and management for all Canadians.

Wounds Canada advocates for a population health approach that promotes best practices in support of persons at risk of, or living with, wounds. Our efforts are focused on:

- Education
- Research
- Advocacy and awareness
- Partnerships

The goal of Wounds Canada is to reduce the prevalence and incidence of wounds of all types and their repercussions, including their impact on patients and families and the significant draw on preventable health-care spending.

To achieve this goal, Wounds Canada develops and provides educational programs and resources and supports research, advocacy and awareness to further advance a holistic, risk-based approach to wound prevention and management.

Wounds Canada is a well-established knowledge broker in the field of wound care. We foster relationships with interested individuals and organizations to expand and sustain a robust wound care community in Canada that has mutually beneficial local, national and global connections.



With campuses in Thunder Bay and Orillia, Ontario, Lakehead University serves more than 8,000 students and 300 full-time faculty. The University's vision is "to provide a transformative university experience that is far from ordinary," and its mission is "to be recognized as an innovative comprehensive university that provides an education that is about how to think, not what to think."

Lakehead University's School of Nursing prepares students to become essential members of an interprofessional health-care team. The school's programs and emphasis on Indigenous health and wellness support students to develop the skills necessary to provide high-quality care in a variety of health-care settings.

Lakehead University's School of Social Work focuses on a holistic view of social work practice that blends in-class and field-based learning. The school's programs are fully accredited by The Canadian Association for Social Work Education and support students in developing critical thinking, effective communication, problem solving and interdisciplinary skills applicable to a range of professional practice settings.

Messages from Conference Partners



Mariam Botros

CEO, Wounds Canada

At Wounds Canada, we believe centring the voice of the patient is crucial to enacting change in our health-care systems to deliver the best possible wound care. That is why we're proud to have co-hosted Our Voices, Our Stories.

I want to thank the patients, patient-advocates and care providers who shared their stories. I also want to thank the researchers, scholars and clinicians who discussed their research and best practices, and the many participants who took part in this unique learning and knowledge mobilization event. I invite you to continue to share your stories, experiences and research and to use the hashtags #PatientStories, #PatientAdvocacy and #WoundHealing on social media.



Ide Costa

Lead and Co-founder of Patient Journey Initiative
Assistant Professor, Lakehead University School of Nursing

I am honoured to have been Chair of the first-ever Our Voices, Our Stories conference. The event was organized through an emancipatory framework informed by Paulo Freire, which provided participants the opportunity to engage in reflection and, individually and collectively, begin to consider the actions necessary to shift from a disease-focused to a person-centred approach to wound care in Canada.

This conference had a culture of openness and trust where everyone's voices were heard and listened to. It offered the opportunity to hear the unique, powerful and captivating stories of patients and care partners who have faced struggles and difficulties while navigating social life and Canada's health-care system with a complex wound. As we listened to the stories that were shared, we engaged in self-reflection, shared our insights in the conference discussion forums and posted about our experiences on social media. Participants were also provided a range of downloadable resources.

Every voice mattered, and every story was heard!

Conference Goals

The goals of this virtual conference were to:

1. Share individual and family stories of balancing everyday life while living with complex wounds and the ensuing challenges of navigating health and social service systems
2. Advance intersectoral exchanges between academic researchers in the social sciences, humanities and health science disciplines, and researchers, practitioners and policy makers from the public, private and not-for-profit sectors

The overarching aim of this conference was to honour and share the experiences and stories of individuals living with hard-to-heal wounds by inviting participants to explore: 1) the impact of hard-to-heal wounds on individuals', families' and caregivers' lives; 2) the gaps and synergies in wound care provision uncovered by their stories and 3) the areas in which holistic wound care management is developing and/or can be enhanced.

In doing so, the conference aimed to raise awareness about the struggles and challenges faced by individuals living with complex wounds and highlight the need to address growing inequities in access to care in Canada.

Conference Participation

Over 800 individuals registered to attend Wounds Canada's conferences in 2022, including the Our Voices, Our Stories event. Of these registrants, 191 logged into the Our Voices, Our Stories virtual conference. Over the course of the two-day event, participants had the opportunity to attend 17 sessions that included eight research-based presentations, six patient and patient-advocate stories of lived experience and four co-creation-based sessions in which participants worked together to identify emerging themes and opportunities for individual and collective action. Participants were also provided the opportunity to virtually visit 10 not-for-profit service provider booths. Almost 800 booth visits took place over the course of the conference, and an average of 94 participants viewed each conference session. Participant views ranged from a low of 30 to a high of 261 across conference sessions.

Conference Evaluations

Feedback from participants highlighted that conference sessions were very well received, met their stated learning objectives, were relevant to participants' areas of practice, and enhanced participants' knowledge. Further, participant feedback indicated that session speakers and facilitators created a learning environment that prompted reflection and consideration of areas for individual and collective action. Examples of feedback included the following:

"Thank you to the speakers for sharing your experience! Very powerful and moving!"

"Excellent day! Excellent presentations! Congratulations to Ide and the team!"

"It made me think about how we can create the space and time in busy health care to really listen first, and the importance of listening to stories of others and understanding their perspective."

"We need to help patients and families develop confidence in all aspects of care. It can start by developing a trusting relationship and having open communication."

"As a nurse, I recognize a need for wound care specialists. The very few we have as resources are excellent but we need more!"

"I am not just the wound. Such a powerful statement and a great reminder to us health-care professionals!"

"I absolutely agree that there is much more that we can do to educate patients and professionals on all levels to ensure that best practice is the standard of care. Well said!!"

"My dream is to see wound care be taken seriously like other specialties such as cardiovascular disease, cancer, etc."

"The words resonate loud and clear. The frustrating part is we have been on this journey for many, many years and after listening to all of the patients' stories, I'm not sure we have made progress. Are we going to continue doing the same thing over and over or should we change some of our strategies? Fragmented care is a huge problem and that's not getting better with our system."

Conference Agenda



PATIENT JOURNEY CONFERENCE OUR VOICES, OUR STORIES

JUNE 9-10, 2022



Chair: Idevania G. Costa RN, NSWOC, PhD

Chair of Patient Journey Initiative | Assistant Professor, School of Nursing, Lakehead University

Co-Moderators:

Darren Levine, EdD and Marlene Varga, RN, BScN, MSc Wound Healing, IIWCC



DAY ONE - Thursday, June 9, 2022

**9:00–9:25
a.m. EDT**

Welcome and Conference Framework

Presenter: Ide Costa, RN, NSWOC, PhD



9:25–10:25

Opening Panel Discussion The Power of the Patient's Voice and Stories

Presenters: **Pip Hardy**, PhD - Co-founder, Patient Voices Programme, UK
Lana Ray, PhD - Indigenous Research Chair,
Lakehead University, Thunder Bay, ON



10:30–11:15

Matt's Experience of Navigating Social Life with a Diabetic Foot Ulcer

Dialogue with Matt Anderson



11:15–11:30

Break/Meet the Community at Networking Lounge

**11:30–
12:15 p.m.**

Exploring the Social Determinants of Health Through Art-based Approaches

Presenter: **Pilar Camargo-Plazas**, RN, PhD



12:20–1:05

Kathy's Experience of Navigating Social Life with a Malignant Ulcer

Dialogue with Kathy Gillis



1:05–1:50

Lunch/Meet the Community at Networking Lounge

1:50–2:35

Checking In / Emerging Themes

2:40–3:25

Staying with Vulnerability... for a While

Presenter: **Catherine Phillips**, BSW, PhD



3:25–3:40

Break/Meet the Community at Networking Lounge

3:40–4:25

Leslie's Experience of Navigating Social Life with a Skin Tear

Dialogue with Leslie Whitehead



4:30–5:15

Attending to the In-Between of 'Hard-to-Heal' - Learning from Patients and Families

Presenter: **Michelle Spadoni**, RN, MA(N), DNP



5:20– 6:00 p.m. Closing Panel Discussion & Reflection - Emerging Themes and
Discovery from our Patient Stories

Speakers from the day

We acknowledge the funding support of the Social Sciences and Humanities Research Council (SSHRC).



PATIENT JOURNEY CONFERENCE OUR VOICES, OUR STORIES

JUNE 9-10, 2022



Chair: Idevania G. Costa RN, NSWOC, PhD
Chair of Patients' Journey Initiative | Assistant Professor, School of Nursing, Lakehead University

Co-Moderators:

Darren Levine, EdD and Marlene Varga, RN, BScN, MSc Wound Healing, IIWCC



DAY TWO - Friday, June 10, 2022

9:00–9:10 a.m. EDT **Re-cap of Day One**
Presenter: Ide Costa, RN, NSWOC, PhD



9:10–9:55 **Keynote: Bridging the Gaps of Inequities in the Delivery of Wound Care Services Across Canada**
Presenter: Irmajean Bajnok, RN, MScN, PhD



10:00–10:45 **Linda and Kelly's Stories of Advocating to be Heard as Caregivers within Our Health-Care System**
Dialogue with Linda Moss



10:45–11:00 **Break/Meet the Community at Networking Lounge**

11:00–11:45 **PART I: Indigenous Experiences of Navigating Social Life with a Wound: Miriam's and Isabella's Stories**
Dialogue with Miriam Cook & Isabella



11:50–12:35 p.m. **PART II: Indigenous Experience: A Decolonized Approach to Wound Healing**
Presenters: Janet Gordon, COO, Sioux Lookout First Nations Health Authority
Jeremy Caul, R.N. CDE BScN MCISC-WH



12:35–1:20 **Lunch/Meet the Community at Networking Lounge**

1:20–2:05 **Checking In / Emerging Themes**

2:10–2:55 **Debbie's Story of Navigating Social Life with and after a Burn Injury**
Dialogue with Debbie and Andrew Ward



2:55–3:10 **Break/Meet the Community at Networking Lounge**

3:10–3:55 **Taking Control of Your Own Health - Fostering Autonomy and Empowerment**
Presenter: Ide Costa, RN, NSWOC, PhD



4:00–5:00 p.m. **Closing Panel Action-Oriented Discussion - Transforming Our Insights to Actions: Re-designing Our Pathway Forward**
All presenters

We acknowledge the funding support of the Social Sciences and Humanities Research Council (SSHRC).

Acknowledgements

This conference is the result of a collaboration between Lakehead University and Wounds Canada, and it is important to thank those who made this important work possible.

The **patients and patient-advocates**, who shared their powerful stories:

Matt Anderson
Miriam Cook
Isabella Cook
Kathy Gillis
Linda Moss
Andrew Ward
Debbie Ward
Leslie Whitehead

The **conference presenters**, who shared their research and experience:

Irmajean Bajnok
Pilar Camargo-Plazas
Jeremy Caul
Idevania Costa
Janet Gordon
Pip Hardy
Catherine Phillips
Lana Ray
Michelle Spadoni

The **conference co-moderators**, who held the space for dialogue and reflection:

Darren Levine
Marlene Varga

The **Scientific Planning Committee** members, who shared their expertise to inform and shape this initiative:

Kaitlin Adduono
Pilar Camargo-Plazas
Jeremey Caul
Idevania Costa
Robyn Evans
Sheena Fortuna
Chantal Labrecque
Linda Moss
Catherine Phillips
Michelle Spadoni
Marlene Varga

Members of the **Wounds Canada** team, who were critical to the success of this initiative:

Mariam Botros
Laura Clarke
Sasangi Lokugonaduwege
Maureen Rego
Sue Rosenthal
Olena Verhya

Students from Lakehead University's School of Nursing who supported conference preparations:

Yamaan Alsumadi
Malaika Daryanani
Lorraine Flores
Iryna Kyrychenko

The **not-for-profit organizations** that shared about their resources, supports and services:

Canadian Burn Survivors Community
Canadian Lymphedema Framework
Canadian Podiatric Medical Association
Nurses Specialized in Wound, Ostomy and Continence Canada
The Ontario Caregiver Association
Patients for Patient Safety
Registered Nurses' Association of Ontario
Spinal Cord Injury Ontario
Waterloo Wellington Self-Management Program
Wounds Canada

The **research grant** team that prepared an application for funding for this important initiative

Mariam Botros (collaborative partner)
Pilar Camargo-Plazas
Catherine Phillips
Idevania Costa (principal applicant)
Michelle Spadoni

The **Social Science and Humanities Research Council of Canada** (SSHRC), through which funding made this project possible, and in doing so, is helping to improve the patient experience for all Canadians.

Welcome and Conference Framework



Presenter: Idevania Costa

Idevania Costa welcomed participants and set the tone for two days of learning, reflecting and networking. She explained that the conference was created with the purpose of helping families and care partners honour and disseminate their stories of navigating social life with complex wounds and, in doing so, uncover the multiple layers preventing a person-centred approach to wound care (see Figure 1) from being fully implemented in Canada.

She clarified that the conference had been designed based on this framework to guide the speakers and the audience in shifting away from

the current biomedical model of wound care and toward an empowerment and person-centred model of care. She highlighted the importance of understanding patients' contexts, personal factors, social factors and economic factors, and how these work together to influence wound management and healing and affect quality of life. She described how, as clinicians invite patients to share their stories and take time to explore and consider the social determinants of health, they are able to work in partnership with patients to co-create plans of care with them, not for them.

Costa asserted that without considering patients and families in their context and the factors that affect their healing journey, it is unlikely clinicians can provide person-centred care.

"When a patient comes to a clinic or hospital for treatment, if we jump right to wound management and treatment, it means that we are just

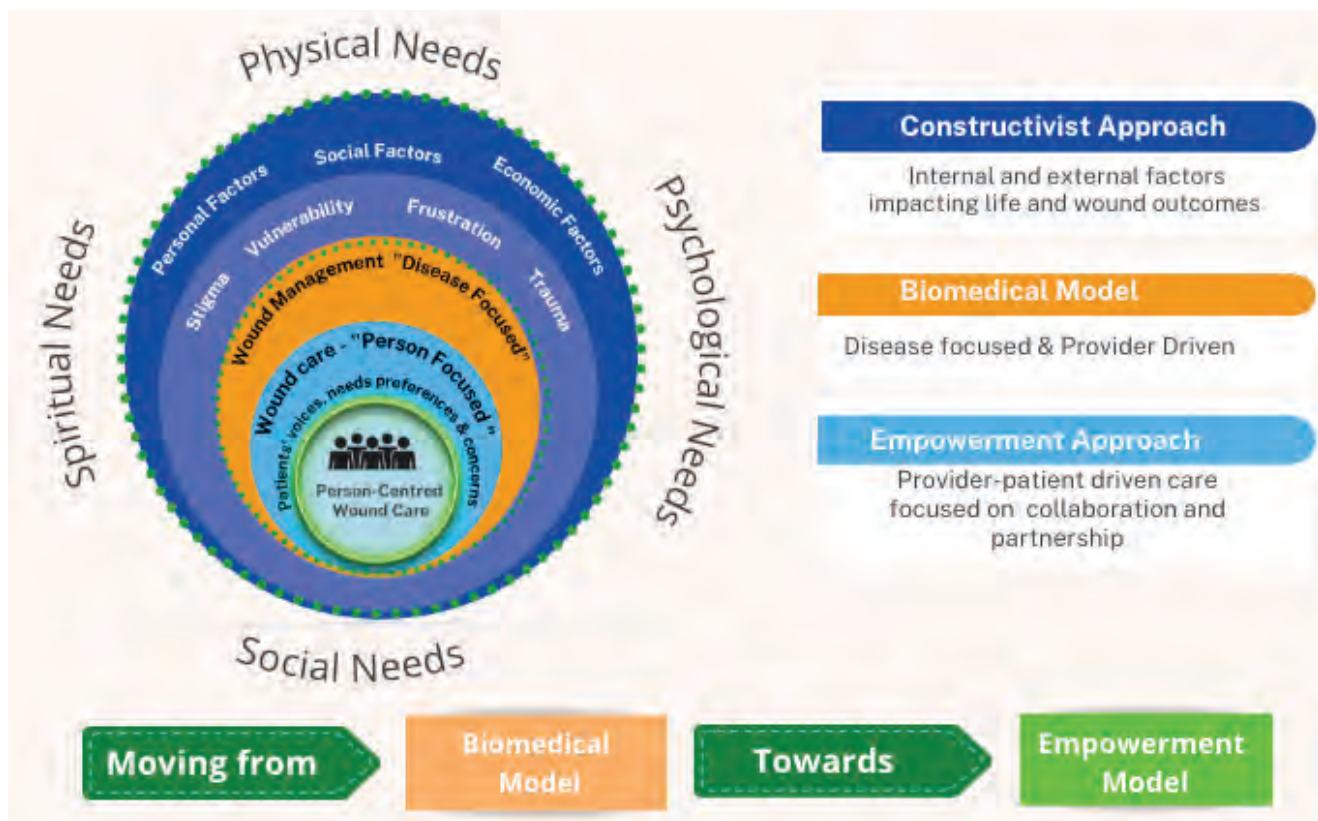


Figure 1: A person-centred wound care perspective framework developed by Idevania Costa.

Representation of the multiple layers to overcome to move from a biomedical model toward an empowerment model developed as a framework for this patient journey initiative.

looking at the disease. Before we can effectively treat the wound, we must consider the patient first and consider their social, physical, spiritual, and psychological needs, as well as how their personal, social and economic situations may be working together to influence their health and wellness and, in turn, how these factors might influence wound healing and recovery.”

Costa challenged conference participants to consider how clinicians, patients and caregivers can work together as partners in care planning, and how each of us—individually and collectively—can be agents of change.

Dr. Idevania Costa is an advanced clinical nurse with expertise in the management of complex wounds. She was educated in Brazil and Canada as a registered nurse and researcher and has over 24 years of clinical, teaching and research experience. She is an Assistant Professor in the School of Nursing at Lakehead University, founder of Advanced Diabetic and Wound Care Consultancy Inc. and a member of national and international wound care societies. She has published articles in peer-reviewed journals, lectured nationally and internationally and has been the recipient of multiple national and international awards in recognition of her work as a wound care nurse and researcher. As a strong advocate for patient empowerment, she strives to improve Canadian health care by including patients’ needs and preferences first.

How to Cite: Costa IG. Welcome and conference framework. In: Costa IG, Levine D (eds.) Our Voices, Our Stories: A patient journey initiative. Wound Care Canada. 2022;20 Suppl:11–12.

Opening Panel Discussion: The Power of the Patient's Voice and Stories



Presenters: Pip Hardy and Lana Ray

This opening panel set the foundation for the conference and highlighted the importance of patients' voices and stories. Pip Hardy explained the importance of clinicians seeing patients as more than just a person with a particular disease or condition, and highlighted that patients care most about being treated with dignity, respect and kindness. Enabling patients to create their own digital stories in their own words allows clinicians to discover what really matters to patients. Hardy's research revealed that, by listening to patients' stories, clinicians become more empathetic and are more likely to adopt a person-centred approach to care. She shared that the **Patient Voices Programme** was established in 2003 and is still the only digital storytelling project in the world focused solely on health care. So far, the project has helped 1,000 storytellers of all ages, races, genders and religions create digital stories which, when released by the storytellers, are all freely available. Hardy explained that "a story conveys values, hopes and aspirations. It reminds all the people who watch it that patients are people first and enables us to walk in somebody else's shoes for a few minutes."

Lana Ray talked about the importance and integral role of stories within Indigenous communities and explained that stories "carry fundamental understandings, insights and attitudes toward life and human conduct. Stories are about roots and relationships, and encourage inward reflection and responsibility and provide the opportunity for people to have their own autonomy." She explained that an Indigenous worldview is a relational process with a community lens. Stories, she explained, are meant to evoke personal reflection and responsibility for action. She cautions however, that for Indigenous people, while telling stories can be empowering, it can also be traumatic

given the history of Indigenous stories frequently being denied in Canada. She explained that we must take steps to understand and honour the context in which people's stories are told and that this begins with understanding that Indigenous people have the right to own and control access to their stories. Ray stressed that we must ensure Indigenous people remain the custodians of their stories and that non-Indigenous settlers take responsibility for their own learning and assessment of their involvement. "There are many stories out there that are accessible that can be a first step to learning and evaluating if it is necessary for the (re)telling of stories. Sometimes asking Indigenous people to tell their story can take away from settlers taking up the work. Maybe they do not need to directly tell you their story but rather draw from their experience to provide direction and advisement."

Dr. Pip Hardy is a Director of Pilgrim Projects Limited, an education consultancy specializing in the development of high-quality open, distance and e-learning programs across a range of sectors, and a co-founder of the Patient Voices Programme, established in 2003 in response to the urgent need for better communication and understanding of all health-care stakeholders' experiences of care. Hardy is considered to be the world's leading practitioner in digital storytelling in health care.

Dr. Lana Ray is an Anishinaabe scholar from Opwaaganasiniing (Red Rock Indian Band). She is Associate Professor in the Department of Indigenous Learning, Lakehead University's inaugural Indigenous Research Chair in Decolonial Futures, and the founding Director of the Anishinaabe Kendaasiwin Institute (AKI). Her experience in public and not-for profit sectors has included serving as Director of Policy and Research at a provincial Indigenous organization. She is a recipient of the Emerging Voices in Indigenous Scholarship/Research Award at the International Conference on Qualitative Inquiry and co-chair of the Global Alliance for Chronic Diseases Cancer Research Programme.

How to Cite: Hardy P, Ray L. Opening panel discussion: The power of the patients' voice and stories. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:13.

Matt's Experience of Navigating Social Life with a Diabetic Foot Ulcer



Presenter: Matt Anderson

Matt Anderson began by sharing his experiences of a foot ulcer that popped suddenly when he was 30 years old. While being treated, the doctor took his sock off and noticed a large ulcer. He explained that he was diagnosed with diabetes when he was 22 and at the time didn't have a care plan, didn't know how to manage his diabetes or how much insulin to take, and did not pay much attention to his condition.

As a result of his diabetes and his foot ulcer Anderson has had to give up his career and has been on disability since 2017. He explained how, in addition to preventing him from working, his diabetic foot ulcer has affected all aspects of his life. "You start to feel like you're not worth anything because you're not making money . . . I used to golf all the time, but I don't play golf anymore. I used to play hockey with the guys on the ice after work, but I can't skate anymore. It affects your entire life. It affects every decision. Where can we

go on a vacation? I can't walk on the beach. I can't get my foot wet."

Anderson explained the importance of a strong, unwavering support network that began with his wife—his number one support—and included his gym and social media network where a community of support began to rally around him. This community began to shift his views about his foot ulcer. "My mentality is no longer about what I can't do, it's now about what I can do."

He said the biggest thing for him was to learn to stay positive and learn how to advocate for himself. "I had to come up with the nerve to ask for help. For someone to advocate for themselves, they have to have the confidence to do it."

He added that there are not enough wound clinics and that there is a lack of consistency between clinics. He also stressed that interprofessional collaboration is critical. "If you want to run a wound care clinic and you want to heal wounds, you need to employ every discipline in the same clinic so that you can heal the wound together."

How to Cite: Anderson M. Matt's experience of navigating social life with a diabetic foot ulcer. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:14.



Part I: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=334:matt-anderson-s-story-part-1&files_order=ordering



Part II: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=335:matt-anderson-s-story-part-2&files_order=ordering

Exploring the Social Determinants of Health through Art-based Approaches



Presenter: Pilar Camargo-Plazas

Pilar Camargo-Plazas guided participants through an exploration of patients' context—the personal, social and economic factors that influence health and wound healing (represented by the blue layer in Figure 1). She invited participants to think about the social determinates of health that affect people with wounds and used an art-based approach to highlight issues surrounding access to necessities such as food, clean water and services. She engaged the audience in a dialogue about helpful strategies that could enhance equal

access to health care for all Canadians regardless of where in the country they live and stressed that we must pay attention to marginalization. Equity, according to Camargo-Plazas, means that everyone receives the same standard of individualized care. Equity means that we remove barriers so everyone has the same access to health care and equal opportunity to be healthy. She stressed that we must think about prevention—in our homes and across our communities—and challenged participants to consider how we can create healthy communities and remove health inequities. She further guided participants to consider how factors such as race, gender, ethnicity, income, education and health literacy play a role or pose challenges to wound care, and how these factors

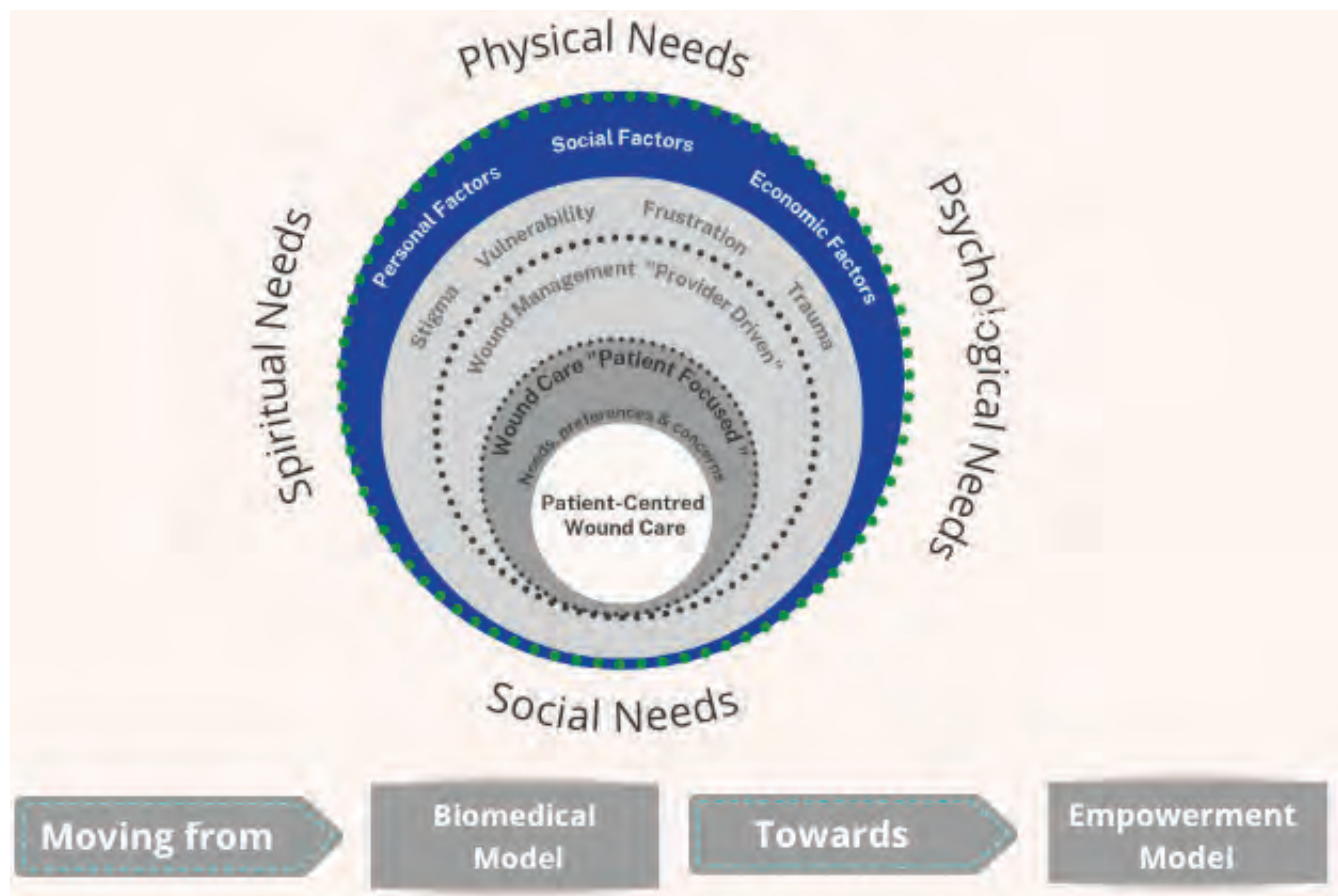


Figure 1: A person-centred wound care perspective framework developed by Idevania Costa. The dark blue layer highlights the topic covered in this section by the speaker.

contribute to people with lower socio-economic status having poorer health outcomes.

To understand how these factors impact health and wellness, Camargo-Plazas asserted that we must “listen to those voices and pay attention to those voices to really create awareness, move forward and take actions to improve access to health care and wound care.”

Regarding the social determinants of health—the conditions in which people are living and working and that have a significant impact on people’s emotional physical, mental and spiritual health and that work together in combination to contribute to Canadians being healthy or unhealthy—Camargo-Plazas invited participants to reflect on the questions: “What have we done? What are we doing? and What will we do? to incorporate a social determinant of a health lens in our practice?”

Dr. Pilar Camargo-Plazas is an Associate Professor in the School of Nursing at Queen’s University. Her research strives to understand the root causes and specific conditions underlying health inequities in vulnerable populations. Recurrent themes in her research to date include the devastating effects of social and health inequities on the health of vulnerable groups. In her view, there is a growing need to explore the complex role that social structures and economic systems play in the health and well-being of vulnerable groups and in nursing practice at local, provincial, national and global levels.

How to Cite: Camargo-Plazas P. Exploring the social determinants of health through art-based approaches. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:15–16.

Kathy's Experience of Navigating Social Life with a Malignant Ulcer



Presenter: Kathy Gillis

Kathy Gillis shared her story about her ultraviolet-related trauma (skin cancer) that started as a small scabby patch on the top of her head and gradually grew into a large tumour. She explained that she had just retired a year before and enjoyed being outside working in her yard. She didn't realize that exposure to the sun may have contributed to her tumour. After receiving surgery to remove the tumour, Gillis explained how she was left with dead skin (necrosis) on the top of her head along with a patch where her hair did not grow back.

She then shared the social impact of this experience. "You want to go to the grocery store or out anywhere, but you have something on your head. People stare."

She explained that the support she received from her husband helped her cope with this experience. She believes that if she had had access

to a family doctor who could have checked the scabby patch on her head earlier while it was small, it might have prevented it from growing into a full tumour and wouldn't have been such a problem.

Gillis shared a call to action with participants. "Be your own soldier. Soldier on. Don't take no for an answer. If you're not sure about something, ask questions. Don't wait. Document and photograph it all."

She thanked the wound care team she had at the clinic she attended for 60 visits and described the nurses as family. She highlighted, however, that more training in home care nursing for serious wounds like hers is needed. "The nurses said, 'well we've never seen a wound like this,' and they didn't know how to dress it and they didn't know how to cover and wrap it." Gillis reminded participants about the importance of covering their heads and wearing sunscreen while in the sun: "This can happen to anyone."

How to Cite: Gillis K. Kathy's experience pf navigating social life with a malignant ulcer. In: Costa IG, Levine D (eds.) Our Voices, Our Stories: A patient journey initiative. Wound Care Canada. 2022;20 Suppl:17.



Part I: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=328:kathy-gillis-story-part-1&files_order=ordering



Part II: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=329:kathy-gillis-story-part-2&files_order=ordering

Staying with Vulnerability . . . for a While



Presenter: Catherine Phillips

Catherine Phillips guided participants in an exploration of the concepts of vulnerability and participatory care. Together, participants reflected on the questions: What is vulnerability to you? What does it mean to you to be vulnerable? What does vulnerability look like? Phillips focused on the second layer of Idevania Costa's diagram, which includes understanding vulnerability, stigma, frustration and trauma (Figure 1) and provided insights on the ways in which health-care providers could be of support to patients within these areas of focus. She shared

aspects of the history of medicine and highlighted recurring themes surrounding vulnerability, cleanliness, the absence of information and the absence of communication, and explained how these recurring themes continue to impact wound healing today. "Throughout history, cleanliness and care were optimal treatments for wounds. Today, with the patient stories that are the spine of this conference, I've heard many times that there was this feeling that wounds would have been preventable if we had given attention to care and cleanliness."

Drawing on the work of philosopher Judith Butler, Phillips further explained that health care is interdependent, and that vulnerability operates as a result. "We rely on strangers, and I think this is never so true as it is in health care. You're only a nurse or social worker or a physician or an occupa-

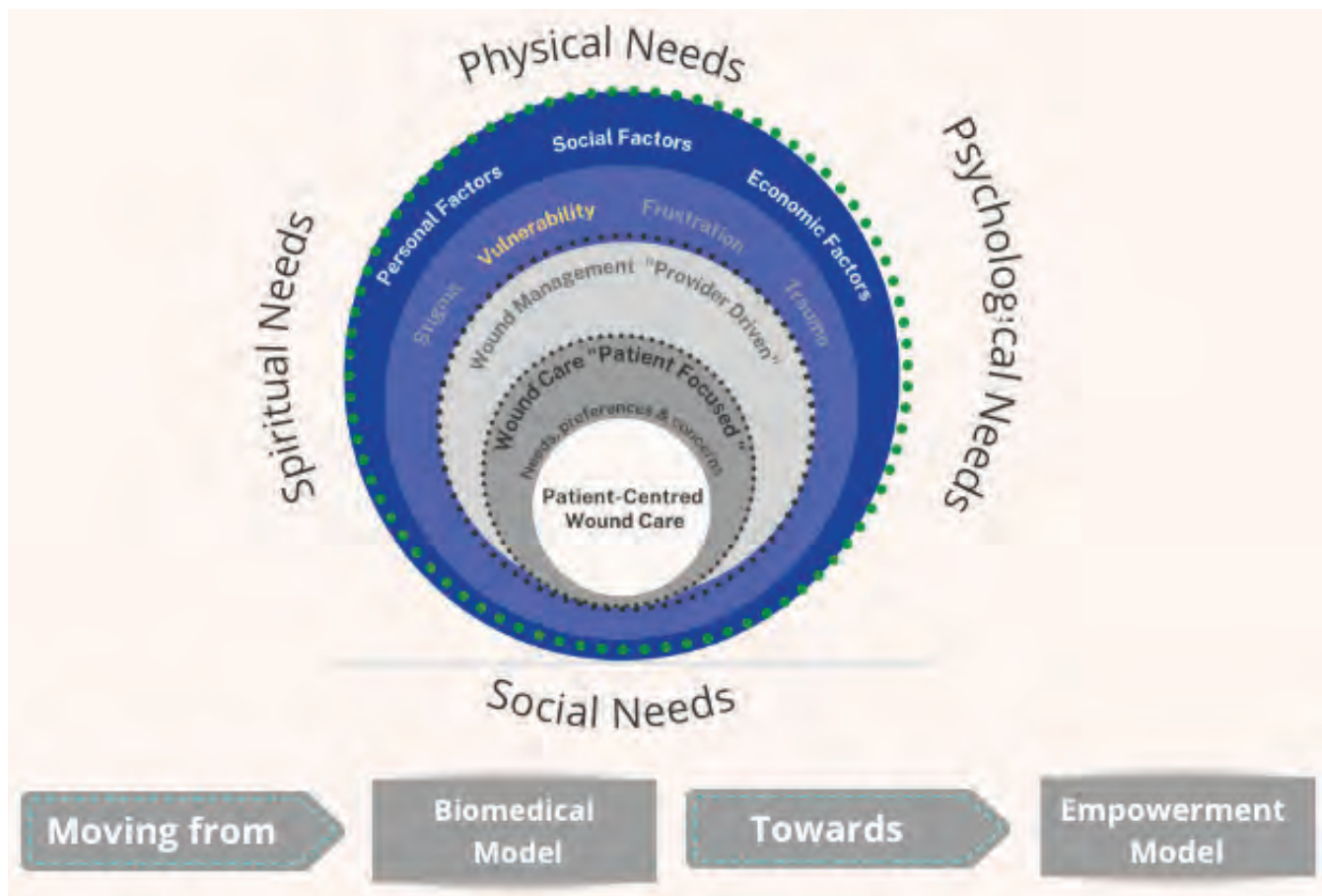


Figure 1: A person-centred wound care perspective framework developed by Idevania Costa. The darker and lighter blue layers highlights the topic covered in this section by the speaker.

tional therapist or physiotherapist because someone is a patient. We do not exist without someone else to care for and this is a moral responsibility and a caring responsibility.” At the same time, Phillips explained that “patients and families are vulnerable because I, as a nurse, am a stranger to them.”

Moments of care, therefore, are co-produced. Phillips emphasized that recognizing the interdependence and vulnerability of care is the foundation of participatory care. She further explained that whether we are a nurse, a caregiver, a physician or a patient, our role is to co-produce care. “If we do not recognize this interdependence of care, this vulnerability, we will miscommunicate. And so, each of us, whoever we are, has a role to play in the recognition of vulnerability.” Phillips then challenged participants to reflect on the question “How do we navigate vulnerability and interdependence in our practice?”

Dr. Catherine Phillips is an Associate Professor in the Faculty of Health and Behavioural Science at Lakehead University. She received her PhD in 2003 from the University of Toronto and was a senior lecturer at the University of Plymouth in England prior to joining Lakehead University. She teaches in the areas of research methodologies and theories of clinical practice. Her research is focused on experiences of health and illness, primarily using arts-based and ethnographic methods. She is widely published in international peer-reviewed journals and has over 12 years of experience as a clinical social worker in emergency and trauma services in Southern and Central Ontario.

How to Cite: Phillips C. Staying with vulnerability . . . for a while. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:18–19.

Leslie's Experience of Navigating Social Life with a Skin Tear



Presenter: Leslie Whitehead

Leslie Whitehead shared her story and experience with a skin tear on her leg. The skin tear occurred while she was gardening, with Whitehead accidentally cutting herself on a three-pronged garden tool. In the hospital, she received 10 stitches. She was concerned about infection because of the dirty garden tools, and was not sure how to care for her wound at home. She asked at the hospital and was sent home with a bandage on her leg, without any other supplies, and was told to wash her wound with soap and water.

"I realized that even though I'm an old nurse I had no current knowledge about what was going on with dealing with wounds or looking after wounds of my kind. I really felt like I needed help of some kind. It's hard to be a patient when you have been a nurse. Even being an old nurse I, in the end, was still an old vulnerable patient."

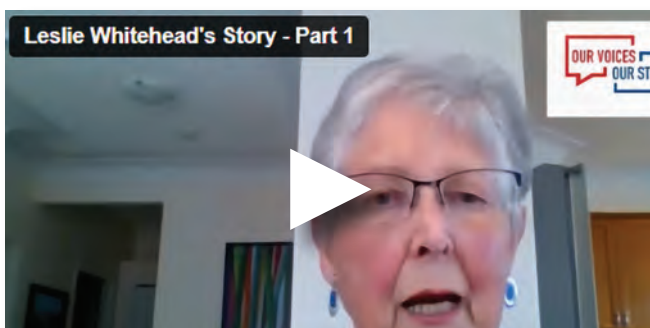
Whitehead explained that she contacted a friend who worked in wound care and was given very

helpful suggestions and information. When visiting her doctor for suture removal she was referred to home care and a wound care clinic. She was told in the hospital that her wound would heal in four weeks; however it took more than 14 weeks until her skin tear finally healed.

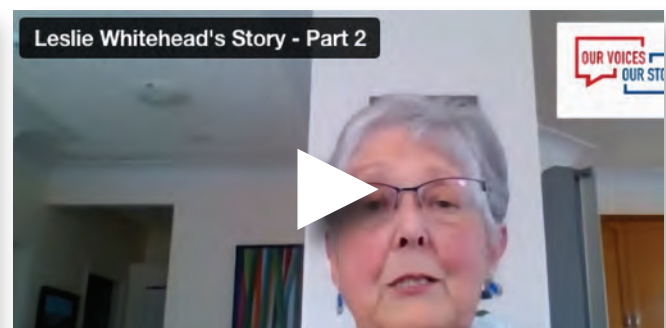
Whitehead shared important lessons that she hopes will help others, including learning to ask questions. "One of the biggest issues is that lots of people are not their own advocates and they're not programmed to question. We have to take some self-responsibility."

She also wonders why there is not a standard wound care protocol across health-care settings. "I know there's lots of processes and protocols in many areas of medicine and nursing but there doesn't seem to be a standard wound care protocol that everybody knows. I know health care is an expensive process; however, without a healthy population we're nowhere. I think, overall, there needs to be a country-wide wound care protocol."

How to Cite: Whitehead L. Leslie's experience of navigating social life with a skin tear. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:20.



Part I: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=332:leslie-whitehead-s-story-part-1&files_order=ordering



Part II: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=333:leslie-whitehead-s-story-part-2&files_order=ordering

Attending to the In-Between of “Hard-to-Heal”: Learning from Patients and Families



Presenter: Michelle Spadoni

Michelle Spadoni explained that patients and families who tell their stories of illness or suffering often do it because they feel a responsibility to share what they’ve learned about navigating through or struggling with the management of hard-to-heal wounds. She commented that this may involve how they learned to advocate for themselves, or how they figured out the workings of the health-care system. She shared with the participants that hearing or telling these stories may help patients to not feel as alone, afraid or uncertain.

Listening to stories may also help practitioners discover ways they can invite patients and families to become part of the discussion in meaningful ways. Reflecting on her own nursing experience, Spadoni stated that “there are times when I listen to the stories of others and I begin to see moments in my own care where I may not have been as present. We become vulnerable when we listen to stories, because sometimes it can really hit home about our ability, and our capacity, and perhaps identify areas where we need to improve.”

When listening to a patient’s or their family members’ stories, Spadoni invited clinicians to consider: How is the story impacting them? What is drawing their attention? What’s making them pause and reconsider what they thought they knew? According to Spadoni, to think about why a person’s story has impacted us is an opportunity to look for action. She shared that her appreciation of patients’ stories grew through her study of Arthur Frank and his ideas around wounded story-

tellers, particularly the idea that we never know when, where or how we might become a “wounded storyteller.”

Spadoni explained that “attending to the in-between” is about learning to listen, staying curious to what might be revealed, not jumping to conclusions, not trying to end a story and letting go of being a knower. “Sometimes as practitioners when we listen when people talk it takes us back to the moment where we shut down a patient conversation. Maybe we discouraged them from coming back to a clinic with the way we approached them or what we said, or how we saw them as a medical condition, not as a fully formed human being living a fully formed human life.” She advised participants to always remember that stories can make people feel less alone and widen the circle of understanding related to the impact of hard to heal wounds.

Dr. Michelle Spadoni is a Professor in the School of Nursing at Lakehead University. She began her nursing practice in oncology and, after 20 years, shifted to community nursing, where she recognized the complexity of practising in the patient’s and family’s world(s). As a researcher, her interests lie in finding meaning in peoples’ lived experiences and showing how these understandings can better help practitioners provide responsive care. She blends hermeneutic/phenomenology, critical theory and critical power analysis with anti-colonial, post-structural perspectives, and art-based inquiry. Working with learners, she embraces experiential ways of knowing and art-based pedagogy to support learners to understand their emerging experiences of being and becoming practitioners.

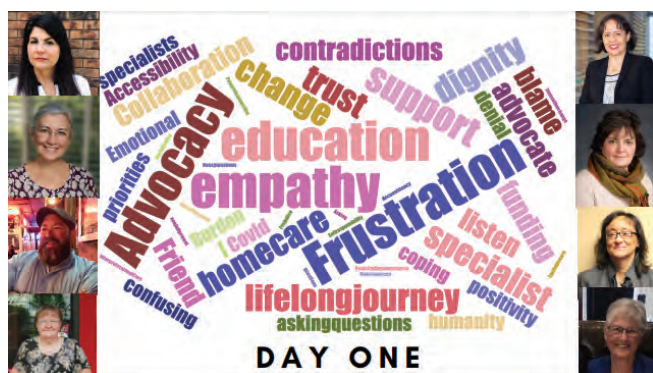
How to Cite: Spadoni M. Attending to the in-between of “hard-to-heal”: Learning from patients and families. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:21.

Closing Panel Discussion and Reflection: Emerging Themes and Discovery from Our Patient Stories



Moderators: Darren Levine and Marlene Varga

At the end of Day 1, event moderators Darren Levine and Marlene Varga invited all speakers and participants to reflect on the stories and presentations shared over the course of the day. This was an opportunity for participants to come together and reflect on what they had heard, and to share what resonated with them, what connected with them, what surprised them, and what moved and inspired them.



To help guide this reflection, a word cloud was formed based on the words that were repeated over the course of the presentations and stories. Words that appear larger indicate those repeated more often, such as: *frustration*, *education*, *empathy*, and *advocacy*.

While discussing the implication of these key words, participants also raised important questions and shared valuable insights. Examples included:

"As much as we should be proud of the care we give, we can do more. What are we going to try to change? How are we going to go about it?"

"Are we going to continue doing the same thing over and over or should we change some of our strategies? We need to be advocates."

"How can we improve our communication? How can technology improve communication between teams, disciplines, and between clinicians and patients?"

"Staff education is a priority." "There is a lack of wound care specialists."

"There is a critical need for home care standardization."

"There is a need for comprehensive, holistic teams beyond just the medical team."

"There is a need for better collaboration and communication between disciplines. The burden for care planning should not fall to the patient."

"There is a need for accessible standardized best practice wound care guidelines."

"We need to involve patients. Real engagement and empowerment of patients is critical. We must give them a voice. It's about listening to their stories and recognizing the importance of the relationship."

"It's the initial engagement they have with us that can stop them from trusting us and coming back through our doors and health-care facilities. The stigmatization that they experience trying to access care from health-care providers must be addressed."

How to Cite: Levine D, Varga M. Closing panel discussion and reflection: Emerging themes and discovery from our patients' stories. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:22.

Keynote: Bridging the Gap of Inequities in the Delivery of Wound Care Services Across Canada



Presenter: Irmajean Bajnok

Irmajean Bajnok started by asking participants to consider how we can remove inequities in the delivery of wound care across Canada. She went on to review the social determinants of health, their implications for wounds, and the factors that contribute to inequities in health care in Canada. She reinforced that “we know there are conditions in which people are born, grow, live, work and age that have an impact on their health. Social determinants of health interact with the biology of the individual and can determine health outcomes. They do impact wound healing. When you are not sure where your next meal is coming from, when your nutrition is poor; of course, all these factors are going to impact your wound healing.”

She asked participants to consider the second burden of wounds—to look beyond the wound and think about the burden to patients’ quality of life. She then challenged participants to think about how much they strengthen, support and cheer patients’ self-advocacy. She stressed the importance of staying focused on what patients really want: to be partners in planning their care.

“Wounds are a rapidly growing health issue in Canada, and one that is not well understood,” Bajnok suggested. She believes that, with an aging population, Canada needs a serious focus on wounds, with wound specialist teams, and

evidence-based interprofessional wound care protocols. She asserted that “we all need to take action in addressing the urgent wound care issue in Canada. We also need to talk about co-creating plans with patients, listening to patients, asking for their feedback, and giving them a voice.”

Bajnok then shared with participants the importance of starting a social movement to draw local, provincial and national attention to the importance of, and critical need for, a co-ordinated focus on wound care.

Dr. Irmajean Bajnok is an international health-care consultant specializing in change management, leadership, and implementation science, and is currently a Senior Policy Analyst at the Registered Nurses’ Association of Ontario (RNAO). She has held various positions at the RNAO since 2000, most recently as Director of RNAO’s International Affairs and Best Practice Guidelines Centre, where she led strategic development and enhancement of the program pillars of guideline development, implementation science and evaluation. Over the course of her career she has held executive positions in home care and acute care and was founding Executive Director of the Canadian government-funded women’s health program in Pakistan. Her career has also spanned administrative and professorial roles in academic settings including serving as Director of Toronto Metropolitan University School of Nursing.

How to Cite: Bajnok, I. Bridging the gap of inequities in the delivery of wound care services across Canada. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:23.

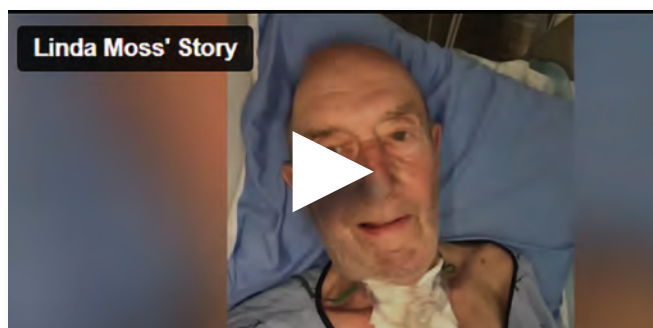
Linda's Story of Advocating to be Heard as Caregivers within Our Health-Care System



Presenter: Linda Moss

Linda Moss shared the story of her father, who was in hospital recovering from a head injury sustained in a fall. After several months he was transferred to another hospital where the doctors discovered a devastating unstageable pressure injury (bedsore) had developed. The family had been unaware of the bedsore, and the focus now shifted from their father's head injury to his pressure injury.

While sharing her father's story, Moss explained the critical importance and need for family members to advocate for their loved ones. "I think when most families walk into that big bright and busy hospital it becomes very intimidating. Family



www.woundscanada.ca/patient-or-caregiver/patient-stories/item?id=331:linda-moss-caregiver-story&files_order=ordering

members really want to help, they just don't know how or what to do. One of the things I tell a lot of families is to document everything, become educated on the issue and ask questions, including about potential further complications."

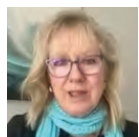
Moss described the "Cs" that are critical to advocating for patients: communication, comfort, companionship and champion. "You are their advocate," she explained, "You have every right to ask a question when it comes to your loved ones, and the medical teams should appreciate the question because that means you're involved and you care."

Moss further shared her insights surrounding the need for consistency in wound care and management across health-care institutions and the important role technology may play. "There was a different care plan at each hospital. What's really important is that policy, procedures and protocols need to be consistent at every health-care facility. New technology can not only help to monitor the wound and help it get better, but also prevent it from getting worse."

Moss asserts, however, that the best prevention is communication and alignment among family members and clinicians. "One of the things I talk about is not only pressure injury prevention, but also how we can align. Families need to be integrated into the care plan because we are essential together. Prevention starts with a collaborative and communicated care plan from the start."

How to Cite: Moss L. Linda's story of advocating to be heard as caregivers within our health-care system. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:24.

Kelly's Story of Advocating to be Heard as Caregivers within Our Health-Care System



Presenter: Kelly O'Leary

Kelly O'Leary shared her story about her father who, at 87, fell and broke his hip. Following surgery, he was discharged from hospital to recover at home. Several weeks later he was readmitted to hospital to have his medication regulated to help manage dementia.

While in hospital his mobility was limited and, as a result, he developed a deep pressure injury. By the time the family was notified of the wound, it had become severe and infected and, due to a series of subsequent complications, her father's health began to decline.

O'Leary shared her reflections and insights about the importance of family members advocating for their loved ones. "I feel that as a family we let

him down because we were so trusting, and you think that the experts are doing what they should be doing. We didn't know any better. We let him down. Had we known, he would probably still be with us."

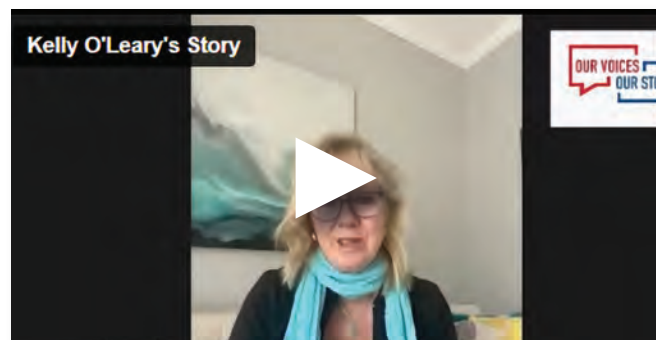
She highlighted the need to improve communication between clinicians and family members.

"Why did the hospital not tell us he needed to be repositioned every two hours? And why did they wait so long to tell us about the wound?"

O'Leary stressed the critical need for family members to overcome their fear of asking questions and becoming involved in the provision of care. "One of the biggest things I think that I had was fear to speak up. I was so afraid to speak up and ruffle feathers as I thought his care would get even worse, so I was afraid to approach anybody. I think I would now ask better questions . . . this is the type of information that should have been provided to us; we could have participated in the care."

She further called on care teams to educate patients on how they can be a valuable support and resource to clinicians. "We didn't know what our role was or what our role could have been as a family. What I would tell a family now is when your loved one is in the hospital, and they're going to have an extended stay, have a family meeting right at the beginning. Don't wait until three months, when you know the patient has declined so much that they're never going home. Be very proactive from the very beginning."

How to Cite: O'Leary K. Kelly's story of advocating to be heard as caregivers within our health-care system. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:25.



www.woundscanada.ca/patient-or-caregiver/patient-stories/item?id=330:kelly-o-leary-story&files_order=ordering

PART I: Indigenous Experiences of Navigating Social Life with a Wound: Miriam's and Isabella's Stories



Presenters: Miriam Cook and Isabella

Miriam Cook shared the story of her mother Isabella's experience with the health-care system after falling at home and suffering a hip fracture. While in hospital, Cook learned that Isabella developed a pressure injury on her right heel. Cook explained that communication between Isabella and her care team was an area of difficulty, as English was not Isabella's first language. "There are some times when she just doesn't understand. She would call me to ask to contact her nurse if she didn't understand something. I would do that a lot for her because I wasn't able to visit."

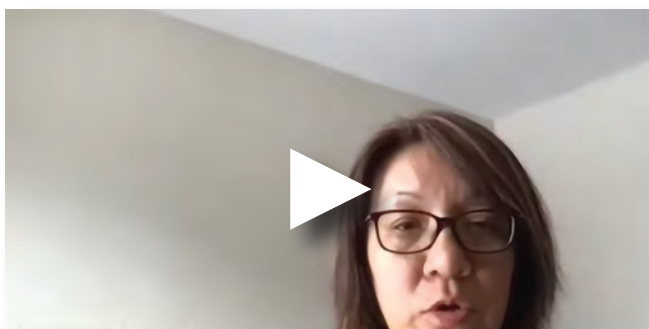
She explained that although she was given instruction on how to change Isabella's dressings, once Isabella was released from hospital there was no follow-up. Unfortunately, the wound did not heal and became infected. By the time Isabella saw a specialist, she was told that amputation below the knee would be required due to the severe infection.

Through her mother's story, Cook shared the importance of respect and support for elders.

"Elders don't have an advocate by their side. It's very difficult for them to navigate the system on their own. Elders should not have to absorb the care plan on their own. They should have an advocate listen in on a call and help translate if they can't physically be there. They need to speak up for their loved one."

She also emphasized the importance of individualizing care for each community and for each patient. She explained that this begins with inviting patients and their caregivers to be part of their care team, and inviting the local Indigenous community to be part of the health-care planning team within the community. "Everybody's different. Everybody's family dynamics are different and their backgrounds are different. The Indigenous community people need to be part of health teams at the community level and hospitals so they can be advocates and be able to assess and make sure the community is heard. Especially in the First Nations, it's never one person making a decision. When a loved one is in the hospital, a lot of people come together because that's just how we were raised."

How to Cite: Cook M, I. PART I: Indigenous experiences of navigating social life with a wound: Miriam's and Isabella's stories. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:26.



Part I: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=336:miriam-cooks-story-part-1&files_order=ordering



Part II: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=337:miriam-cook-s-story-part-2&files_order=ordering

PART II: Indigenous Experience: A Decolonized Approach to Wound Healing



Presenters: Jeremy Caul and Janet Gordon

Jeremy Caul and Janet Gordon engaged participants in an exploration of strategies to support the empowerment and engagement of Indigenous patients, many of whom experience the ramifications of intergenerational trauma that stems from colonization and the systems imposed on them and their communities.

Caul and Gordon highlighted the importance of developing local approaches to health care hand-in-hand with Indigenous communities, and the critical need to build systems collaboratively. “Engage with your communities. Learn from them. Understand their differences and their worldviews. When we understand a person’s worldview, we can better communicate with them,” suggested Gordon.

Caul and Gordon also explained that patients from Indigenous backgrounds and communities don’t always advocate for themselves. According to Caul: “We need to look at things like access to basic necessities and how they impact skin health. Something like access to clean water. There are communities in our catchment who’ve experienced a boil water advisory for nearly 30 years. Skin hygiene, wound cleansing and preventing skin breakdown is almost impossible due to the lack of even the most basic necessities of life. Because of all this, patients from Indigenous backgrounds don’t always advocate for themselves through learned helplessness and a loss of self-determination.”

They noted the dangers of adopting a “one-size-fits-all” approach and recommended working together with local Indigenous communities. Caul pointed out that “Individuality refers to the unique

nature of our communities. Now go ahead and provide the same service to each community in the same way—it does not work. You have to take the community’s lead and partner hand-in-hand with respect for the uniqueness of each community.”

Caul and Gordon then stressed the importance of investing in relationships. “Take the time and be prepared to build those relationships and establish a truly therapeutic relationship”, said Gordon. “It’s going to take time. People need to feel safe. If they feel safe, they come to their appointments, they dialogue, and they’re more likely to follow through with their goals and with their treatment plans.”

Jeremy Caul is a registered nurse from Northwestern Ontario. He has dedicated his career to advocating for Indigenous populations in his region, where Ontario sees its highest rates of diabetes and amputation. He currently supervises a team of allied health professionals working in a mobile primary care team in Sioux Lookout, including 33 remote First Nations communities, most of which are fly-in. He has education from Lakehead University and Western University as well as many CMEs from various institutions for wound healing, foot care and diabetes.

Janet Gordon is originally from Kasabonika Lake First Nation but recently became a member of Lac Seul First Nation. She has worked in the health-care system for over 30 years. She began her career as a staff nurse at the Sioux Lookout Zone Hospital before working as a community health nurse in First Nations communities in Northwestern Ontario. She has been with Sioux Lookout First Nations Health Authority for over 25 years, where she currently holds the position of chief operating officer.

How to Cite: Caul J, Gordon J. PART II: Indigenous experience: A decolonized approach to wound healing. Wound Care Canada. 2022;20 Suppl:27.

Debbie's Story of Navigating Social Life with and after a Burn Injury



Presenter: Debbie Ward

Debbie Ward shared her journey of overcoming an accident as a young child that left her with severe burns. In addition to the pain of her wounds, Ward explained that she also had to overcome the difficult responses from others in her community. "A lot of times the parents could be as cruel as children because parents, not knowing what happened, thought I had a disease and would tell their kids to stay away from me. I basically spent my childhood alone."

Ward talked further about the social impact of her wounds. "I wanted friends, but I couldn't participate in childhood games because I couldn't keep up. Growing up, it was difficult to get a boyfriend. I would make excuses if there was a bunch of people getting together for a swimming party, for example. Twelve to 20 were my hardest years because I was not accepted. I always felt unaccepted and unwanted."

She explained how it wasn't until she was in her 40s that she met other burn survivors and that this offered her a powerful sense of community. "It was a shock to my system. I learned I wasn't the only one, that there are other people. I thought I was the only burn person in the world. I remember being in a group of 10 to 12 adults crying our hearts out because we finally found somebody that knew what we were going through. I realized that I am not a victim, I am a survivor."

Ward shared with participants the importance of treating the whole person, not just the wound, and highlighted the importance of faith and purpose in helping her on her journey.

"You know, as we're treating the body, we also need to remember that we're treating the mind as well. We have to remember; I'm still a person with a beating heart inside and a brain that turns. Don't tell me what I can't do, I will prove you wrong. I don't care what religion you are or who you pray to, but you have to have something to believe in. That's what got me through."

How to Cite: Ward D. Debbie's story of navigating social life with and after a burn injury. In: Costa IG, Levine D (eds.) Our Voices, Our Stories: A patient journey initiative. Wound Care Canada. 2022;20 Suppl:28.



Part I: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=326:debbie-ward-story-part-1&files_order=ordering



Part II: www.woundscanada.ca/patient-or-care-giver/patient-stories/item?id=327:debbie-ward-story-part-2&files_order=ordering

Taking Control of Your Own Health – Fostering Autonomy and Empowerment



Presenter: Idevania Costa

Idevania Costa guided participants through the journey of shifting from a biomedical model to a person-centred model. She challenged participants to consider how, through their practice, they can help patients take control of their own health. Costa invited participants to reflect on what patients need to know about their condition to take control of their journey, and how practitioners can help patients navigate their journey.

She highlighted the need to move away from a paternalistic and prescriptive model of care in which patients are told what to do, and instead move toward an approach to health care that is based on patient-provider collaboration.

She stressed that patients have the right to participate in their care and that patient autonomy, advocacy, engagement and empowerment must be key areas of focus for all clinicians. “How much control should patients have over their own health? The answer is as much control as possible. We must create a safe environment for patients to ask questions without fear. We must provide information at the right time and in the appropriate language—a language the patient can understand. It is important that we provide patients the freedom to direct their own health.”

Costa then highlighted the importance of patient self-advocacy and explained that, for someone to advocate for themselves, they must

have the competence and confidence to do it. Clinicians, according to Costa, have an important role to play in preparing patients to advocate for themselves and take control of their health-care journey. “Patients, don’t wait for someone to say you are allowed to speak. Speak up and stand up for yourself. Ask questions. Have your say. For patients, self-advocacy provides an opportunity to voice your concerns and get your needs met.”

Clinicians have a responsibility to listen, provide patients with the information they need and create a safe environment within which patients can make their own decisions and take control of their health-care journey.

Dr. Idevania Costa is an advanced clinical nurse with expertise in the management of complex wounds. She was educated in Brazil and Canada as a registered nurse and researcher and has over 24 years of clinical, teaching and research experience. She is an Assistant Professor in the School of Nursing at Lakehead University, founder of Advanced Diabetic and Wound Care Consultancy Inc. and a member of national and international wound care societies. She has published articles in peer-reviewed journals, lectured nationally and internationally and has been the recipient of multiple national and international awards in recognition of her work as a wound care nurse and researcher. As a strong advocate for patient empowerment, she strives to improve Canadian health care by including patients’ needs and preferences first.

How to Cite: Costa IG. Taking control of your health – Fostering autonomy and empowerment. In: Costa IG, Levine D (eds.) *Our Voices, Our Stories: A patient journey initiative*. Wound Care Canada. 2022;20 Suppl:29.

Closing Panel Action-Oriented Discussion: Transforming Our Insights to Actions and Redesigning Our Pathway Forward



Moderators: Darren Levine and Marlene Varga

At the end of Day 2, event moderators Darren Levine and Marlene Varga invited all speakers and participants to reflect on the stories and presentations shared over the course of the day and begin to co-create areas of focus for action.



To help guide this reflection and co-creation, a word cloud was formed based on keywords that were repeated over the course of the presentations and stories.

Together, speakers and participants identified a broad range of areas of focus that will act as a

springboard for co-ordinated action. Examples included:

- Formation of a unified voice and action plan that includes clinicians, researchers, scholars, patients and their families, and community members focused on improving wound care in Canada.
- Blending of patient voices and stories with quantitative research data to create a national awareness campaign to make the case for change away from the biomedical model and toward a patient-centric model.
- Widely sharing patient stories to raise public awareness and, with schools of nursing, medicine and social work, highlighting the importance of listening to, and empowering, patients, as well as the critical importance of interprofessional collaboration and communication. This includes creating a website and online library to host patient videos and stories.
- Examination of how existing, new and emerging technologies can improve access to wound care and support care teams in the provision of wound care, including the identification of pressure injuries, interprofessional collaboration and communication between health-care providers and families.

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Summary: Our Voices, Our Stories: Journeying Together in Community



Over the course of two days, the Our Voices, Our Stories Conference held the space for the sharing and exploration of patients' and patient-advocates' stories of lived experience navigating Canada's health-care systems and receiving wound care services. Together, conference participants—patients, patient-advocates, researchers, scholars, clinicians and students—listened to and learned from one another while sharing insights and opportunities to strengthen wound care and improve patient experiences and outcomes.

When combined, the stories, reflections and dialogue shared converged around several key areas of focus, illustrated in the word cloud above. These recurring areas of focus included: advocacy, change, collaboration, wound specialists, barriers, cultural safety and accessibility.

Within these areas of focus, examples of emerging themes included the need for greater:

- Advocacy and awareness surrounding the wound epidemic in Canada
- Wound care education for care providers, patients, and their advocates
- Cultural safety and cultural competence education, practices and policies
- Standardization of wound care best practices that focus on a person-centred care model
- Collaboration and communication between disciplines, and between care providers, patients and their advocates (e.g., family members)
- Shifts within health care and wound care away from a biomedical model and toward a holistic person-centred model
- Local community co-production of wound care services
- Easy and timely access to specialized wound care services across jurisdictions

The opportunity before us is to transform each of these areas of focus into concrete actions for the months and years ahead, and to consider the ways in which the stories, experiences, research, reflections and insights that were shared can inform efforts in the creation of a roadmap for a national person-centred wound care strategy.

While the 2022 Our Voices, Our Stories Conference has concluded, our work as a wound care community continues. To become involved in, and stay informed about, next steps, please visit [Our Voice Our Stories](#).

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Not-for-Profit Agencies

Canadian Burn Survivors Community
<https://www.canadianburnsurvivors.ca/>



Canadian Lymphedema Framework
<https://canadalymph.ca/>



Canadian Podiatric Medical Association
<https://www.podiatrycanada.org/>



Nurses Specialized in Wound, Ostomy and
Continence Canada (NSWOCC)
<https://www.nswoc.ca/>



The Ontario Caregiver Association
<https://ontariocaregiver.ca/>



Patients for Patient Safety
<https://www.patientsafetyinstitute.ca/en/Pages/default.aspx>



Registered Nurses' Association of Ontario
<https://rnao.ca/>



Spinal Cord Injury Ontario
<https://sciontario.org/>



Waterloo Wellington Self-Management Program
<https://www.wwselfmanagement.ca/>



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