

Organisational models of care for chronic wound

Evidence check

30 June 2021

Experiential evidence: healthcare consumers and carers

Framing question:

How do healthcare consumers and their carers view and experience the provision of wound care in NSW?

In brief

- Semi-structured virtual individual interviews and focus group discussions were conducted with 10 healthcare consumers and carers to explore their experiences of a chronic wound.
- Consumers with a lived experience of a chronic wound were involved in the development of the interview and focus group guides and facilitation of discussions, analysis and presentation of the findings.
- Data were analysed using thematic analysis and seven themes were identified: lack of continuity and consistency of care, impact on life, mental health impacts, wound-related pain, and lack of consumer information for wound management, morbidities and access to wound care.
- Findings suggest a chronic wound has substantial detrimental impacts on the person's quality of life, as well as the quality life of their carers and families.
- All participants described the psychological distress of living with a chronic wound and indicated there was no support for their mental health. Participants shared how self-conscious they felt and described the daily care for the wound as tedious, embarrassing and relentless.
- Consumers identified significant issues as inadequate pain management, limited consumer information, access to wound care products and a lack of holistic care.

Background

The Chronic Wound Management Project is part of the second set of initiatives of the NSW Ministry of Health's Leading Better Value Care (LBVC) program. Improving the management of people living with chronic wounds is a major challenge for health services across local health districts (LHDs) and in community settings, particularly in Residential Aged Care Facilities and primary care. The LBVC Chronic Wound Management initiative provides opportunities to improve the prevention and holistic management of chronic wounds.

Definition of a chronic wound (NSW Health)

A chronic wound is one that has failed to heal in a timely manner despite receiving standard care. These are wounds that have failed to progress through the expected phases of healing within the predicted time frames. Chronic wounds heal at a much slower rate, heal only partially or often reoccur. Types of chronic wounds include arterial ulcers, venous ulcers, pressure injuries (bed sores), ulcerated and fungating malignant wounds and surgical site infections.

Methods

Semi-structured virtual individual interviews and focus group discussions were conducted with healthcare consumers and carers to explore their views and experiences of chronic wound healthcare provision in NSW. Participants were approached via an electronic invitation and were recruited from a variety of service settings in NSW. Data was analysed using thematic analysis.

Consumer involvement

BR is a consumer with lived experience of life-long chronic illness and chronic wounds who has held consumer representative roles. He is a member of the NSW Chronic Wound Management Taskforce and was involved in the development of the interview and focus group guides. He also co-facilitated discussions, analysis and presentation of the findings. HT has lived experience of caring for a person who has chronic wounds. She has also held consumer representative roles and is a member of the NSW Chronic Wound Management Taskforce. HT was involved in the development of interview and focus group guides and she co-facilitated discussions, analysis and presentation of the findings.

Participants and recruitment

People were made aware of how they could participate in the virtual interview and discussions via a letter of invitation sent through a range of existing organisational networks. A snowballing approach was used where the letter of invitation could be shared to increase reach to a broader and more diverse range of potential participants. Participation was open to consumers who had received care for a chronic wound in the past two years, and a separate letter of invitation was extended to their carers or families. Participants interested in the virtual interviews and discussions contacted the ACI Evidence Generation and Dissemination Manager directly via email or phone for more information and to confirm their participation. All participants received a participant information statement on the initiative and a phone call or email to clarify details, ask questions and confirm their participation.

Sample

A total of eight consumers and two carers participated. Individual interviews were conducted with six participants (five consumers and one carer) and one focus group discussion with four participants (three consumers and one carer). Participants were from metropolitan and rural NSW.

Data collection

Data collection occurred between 12–28 October 2020. The ACI Evidence Generation and Dissemination Manager (TD), the ACI Manager Chronic Care Network (JC) and two consumer leaders (BR and HT) created the interview and discussion guide and facilitated the group discussions. The focus group discussion was video recorded via Skype and JC took field notes. The audio recording of the focus group discussion was transcribed verbatim. TD facilitated individual interviews and made field notes. The individual interviews were not transcribed, however, the field notes were sent to participants so they could check them.

Data analysis

Data were analysed by TD and JC by thematic analysis using Braun and Clarke's six phases of qualitative analysis: familiarisation, coding, generating themes, reviewing themes, defining and naming themes and writing up.⁽⁹⁾ TD and JC reviewed and coded the transcripts, field notes and identified themes and sub-themes. BR and HT reviewed the themes for accuracy and provided feedback on the report. The Co-chair of the Chronic Wound Taskforce (SM) provided revision of the report. The participants also received a draft copy of the report so they could review it and provide feedback.

Ethical considerations

This consultation was a quality assurance activity conducted for the primary purpose of improving the service provision within the NSW health system. As a quality assurance activity, an ethical review was not required by the National Health and Medical Research Council, *Ethical Considerations in Quality Assurance and Evaluation Activities* guidance and the NSW Health *Quality Improvement and Ethical Review: A Practice Guide for NSW*. Partnering with consumers in governance, policy and planning is recognised as best practice, and their consultation and co-creation aligned to the *National Safety and Quality Health Services Standards in Australia*.

Limitations

The participant group was self-selected. Although participants had broad-ranging and diverse backgrounds, the group may not be representative of a full range of health care experiences for people with chronic wounds. The consultations were limited to participants who were proficient in English.

Findings

The analysis identified seven main themes: lack of continuity and consistency of care; impact on life; mental health impacts; wound-related pain; lack of consumer information for wound management; comorbidities; and access to wound care.

Lack of continuity and consistency of care

A lack of continuity and consistency of wound care was a major finding; with participants describing a disconnection between the advice offered and treatment given. This included between healthcare professionals and across the healthcare spectrum from the acute in-patient setting to the community. It included general practice, community nursing services and local pharmacies.

“... you leave the surgeon's office and then that's that.”

Most participants described experiencing constant changes in wound dressings and management. Often little explanation was given as to why changes were being made to treatment.

“The wound nearly healed and then the community nurse would change and the treatment would change ... [the nurse would say] we won't do that anymore. Every week there would be a change with little evidence as to why.”

Participants identified a need for, and benefits of, a multidisciplinary approach to wound care. Several participants pointed out the benefits provided by occupational therapists and podiatrists. They said these clinicians improved the participants' understanding of how chronic wounds effect a person's capacity for rehabilitation and quality of life.

When trying to self-manage their chronic wounds, participants reported that their community pharmacist played an important role. Engaging the community pharmacist in care planning helped to review contraindicated medications, assist with pain relief, consider vitamin and supplements to enhance healing and oversee the correct use of wound care products. One participant suggested that having a wound clinic in a community pharmacy setting could be an effective way to ensure the correct use of products.

Participants highlighted the need for better documentation to improve continuity of care. Some participants indicated that photographs of their wounds were taken regularly as part of the documentation process, but this was not a formalised procedure.

“The general practitioner [the third in three years] ... hadn't seen the wound. When I asked, ‘Do you want to have a look?’ she said, ‘No, leave it to the nurses’. She doesn't want to go to the hassle. She said to tell her nurse to take a photo.”

The lack of integration across care settings was highlighted by the frustration that consumers experienced having to repeat their 'story' at each clinical encounter. A need for services to be more trauma-informed by improving the process to capture and record the person's medical history was identified.

"... whatever your health record is, it should travel with you and be available to be picked up, no matter where you are. That's a real bonus, no matter what your illness is. [Regardless of] what's happening, it should all be electronically recorded."

Impacts of daily life

All participants described how a chronic wound effected every part of their day-to-day life. Movement and mobility became increasingly difficult, which impacted on employment, health, relationships and leisure.

"I was a good golfer, but I won't play golf again. I don't walk much now. The paper shop is a six-minute walk and I can't walk there. Now, I watch too much TV and I eat cheese and biscuits. I'm putting weight on. I've never been, and don't want to be obese, but I can't walk."

"... because I had the wound on my foot, I could never do anything like hydrotherapy which would have assisted me to get some exercise, [like] cardiovascular exercise. I could never go to the beach or walk along the sand or anything like that for the 10 years I had [the chronic wound]."

Participants described the burden of managing their chronic wounds, which included multiple dressing changes each week. The strain was significant when participants, particularly those in regional areas, were required to travel long distances for dressings.

"We were still having to have it administered and looked at daily at the [regional] hospital by the community nurses there. That went on for months and months."

Similarly, participants reported challenges scheduling an appointment with a community nurse. To avoid taking time off work this had to be done to coincide with lunch breaks.

"It takes time out of your day. You have to plan for that [and] include it in the things that you're doing each day."

Mental health impacts

All participants described the psychological distress of living with chronic wounds. Participants shared how self-conscious they felt and described the daily care for the wound as tedious, embarrassing and relentless.

"I was actually quite depressed at times because things add up. It's the little things, like you couldn't get into a nice, long shower and enjoy it because I was constantly checking that the dressing was intact and no water was getting in."

While the impact on mental health was significant, all participants indicated they received little support for their mental health. This included some participants with amputations who said that they had received no mental health support.

"In the short time [between] being rushed up to the ward and having body parts removed, I had to fight to even get assessed. I would think if [you are] losing body parts, you could automatically speak to someone."

Participants highlighted the need for health professionals to acknowledge the grief associated with a wound, for example, the change in body image and the lifestyle that is lost. As well, the trauma associated with the breakdown in healing and duration of the wound.

"One of the doctors said to me at one stage, 'Nobody has a wound forever.' I was thinking, well 10 years, it sure felt like it was forever."

The mental health impacts for partners, carers and family members were also identified. Some partners were very active in their support with wound care and this contrasted with others who avoided or ignored it.

“It was really hard on her too, because she's watching me and she can't really help ... she went through it worse than I did, I think ... her mental health was pushed as well.”

“He's the sort of person who would faint when he'd see blood ... he got quite frustrated and then one day he just burst out and said, ‘I'm sick of doing this!’ ... It really hurt my feelings because I thought, well, I can't do it. I know it did have a bad impact on him.”

Wound-related pain

Some participants described the pain they experienced with a chronic wound, including nerve pain, the discomfort and inconvenience of wound care, dressings, padding and compression. They also spoke about how this impacted their employment, mobility and shopping.

“I can't do my shoes up because I can't bend that far. And the nurse tells me off for wearing boots that slip around. Even when she does my wounds, if she ties my shoes up, I can't take them off.”

“Amputation is not an equal option for good, wound treatment. Better wound care and pain relief could improve wound care and overall quality of life.”

Lack of consumer information for wound management

Most participants indicated they did not receive information or resources to help them understand the wound. This included the evidence, healing processes and different options for treatment. Participants suggested that a lack of information impacted on their expectations, including the time it takes to heal.

“Where would we get the information from, do you think? Does the doctor tell us, the surgeon tells us? Does the anaesthetist tell us? Does the mate down the road tell us? I don't know. Where do we get the information?”

A lack of information to guide self-management in a holistic way, such as improving nutrition to promote healing, was highlighted.

Some participants had minimal information in preparation for an amputation:

“The surgeon said, ‘If we find any infection in the bone, blah blah, we might take it off below the knee’. I swore and said, ‘No way! I can't make that decision’. That frightened me when they said that, and it came out of the blue. It's just another job! She was so blasé about it.”

Several participants reported that they had done their own research to identify other treatments options to discuss with health professionals when their wound was not healing.

Participants also identified the benefit of peer support; sharing information with other people in a group to access information on wound care and other health topics.

“We meet every Friday down at the club and we chit chat ... about depression, wounds, weight. I look for information to share with the group. If you don't look and research, you won't learn. It's difficult to get information.”

Comorbidities

All participants identified the impact of comorbidities; several had developed wounds because of conditions such as diabetes. Venous leg ulcers were a common wound type described by participants.

“I can’t get my hips done until I get my leg [wounds] done.”

Participants described a need for health professionals to better understand the challenging intercurrent conditions faced by people who have a chronic wound. Participants expressed concern that there was a lack of holistic understanding from health professionals about other things happening in a person’s life.

“It’s really important for the health professionals involved to understand that it’s not just about the wound. Sometimes it’s that I don’t have somebody to support me or I’m not feeling good. So [we need] that more holistic approach, not just, ‘Where’s your leg, let’s look at that’. [Ask] what else might be happening for that person?”

Access to wound care

Challenges of living in a rural or regional area

Locating appropriate health care services to manage a chronic wound was found to be more difficult for people in rural and regional areas. Wound clinics were identified as valuable in metropolitan areas, however, participants highlighted a need to provide outreach to rural areas with nurse practitioners trained in wound care.

Some participants were concerned that community nurses in rural settings had limited clinical skills in wound assessment and care. One participant described travelling two hours for debridement, and the associated impacts of travel time and costs.

For participants in rural areas, the burden of traveling for wound care was significant.

“I go into town, a 70km round trip, three times a week for treatment. This week, I drive into town to see the high care wound specialist. This is a 350km round trip. I’ve been going there each week for the last five weeks.”

Some participants reported that the use of telehealth was a promising development in wound management.

Products

All participants indicated that consistency in the use of quality products was important. However, access and cost were identified as barriers.

At times it was difficult to find appropriate or recommended products. Participants in rural areas described the lack of availability of products in rural pharmacies and how they undertook trips to the hospital to access products. Participants were also worried about the waste of wound products in hospital settings caused by the incorrect application or not using the entire product.

The cost of dressings was identified as an issue for all participants, with half of the participants required to self-fund their wound products.

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