Perspectives on living with and self-treating venous leg ulcers: a person's story and a health care perspective

Kapp S, Simpson K & Santamaria N

ABSTRACT

People who live with chronic wounds have many stories to tell and people with venous leg ulcers (VLUs), in particular, have significant stories, as their experiences are typically prolonged and recurrent. The story reported in this paper highlights a range of experiences known to be associated with this condition, including a negative impact on wellbeing and financial expense. This story adds to what is known by illuminating the position of today's health care consumer who seeks more involvement and engagement in their management and care. Optimising self-management was shown in this story to be highly important, in particular the benefits of self-treating the VLU. Having a sense of control, satisfaction from being able to self-care, and the flexibility to do so when and for how long one wishes, are perceived benefits of wound self-treatment. There is little published about self-treatment of chronic wounds and this topic requires further investigation. With an ageing population and increasing numbers of younger Australians living with chronic health conditions, not only is this likely to be a growing preference of wound management consumers, it is also likely in part to be a solution to the growing pressures on health care budgets and expenditure.

Keywords: venous leg ulcer, chronic wound, consumer, self-treatment, self-management.

INTRODUCTION

The aim of this paper is to present a story told by a person who lives with a venous leg ulcer (VLU) and the perspectives of a health care provider on optimising self-management, which was found to be a key element of this person's story.

BACKGROUND

People who live with chronic wounds have many stories — about how the wound started, what they have done to treat it, why it has not healed and their concerns about the future. People with VLUs, in particular, have significant stories, as their experiences are typically prolonged and recurrent. Clinicians who provide care to people with VLUs often hear firsthand how this condition impacts their lives. Many people are forthcoming, because they are perplexed or frustrated by lack of progress, or delighted and hopeful when their wound is healing. Some people are less forthcoming, being stoic in nature or bearing the burden in silence. The stories our clients tell us are important, as they provide insights into living with a chronic wound.

Suzanne Kapp *
BN, PGDip (AdvNsg), MNSci, PhD candidate
The University of Melbourne and Melbourne Health, Royal Melbourne Hospital
Research Fellow, RDNS Institute
31 Alma Road, St Kilda, Vic 3182, Australia
Tel: +61 3 9536 5336
Email: skapp@rdns.com.au

Kim Simpson
Healthcare consumer

Nick Santamaria
RN, BAppSc, MEdSt, Grad Dip Health Ed, PhD
The University of Melbourne and Melbourne Health, Royal Melbourne Hospital, Vic, Australia

*Corresponding author

The interview which generated the story reported in this paper was not part of a research study; rather it is a means for us to reflect on the wishes, desires and needs of a person living with a chronic wound. Human research ethics committee approval was not sought to conduct the interview and there has not been any formal analysis of the interview content. Consent to report the interview verbatim in this paper was provided by the interviewee.

VLUs: A PERSON'S PERSPECTIVE

I can clearly remember when I first sensed there was something wrong, back at the beginning of my leg ulcer story. I was in church at Christmas time and churches often have kneeling pieces of wood that can go up and down, and there were some young little children in the pew with me and they decided they'd play. They were bored, so they picked up the wooden kneeler and then dropped it, catching my shin on its way down. So that's how it started. A dear little child came up with a band-aid for me, so I thought that was cute.

That was three or so years ago, and I still have one from that occasion. It was deep and it had what they call an inset, a lip all the way around the edge. At first I looked after it myself, and I did that for quite a long time because I don't like making a fuss of things much. It put me in control of myself which I quite like. I could do it when I wanted and how I wanted, to a degree, using all the right things. And time, I could spend as much time as I liked soaking them and cleaning them which was very pleasant.

Time progressed and I decided that it was needing more attention. I can't remember exactly, I probably went to a doctor, or I have a very good rheumatoid professor who looks after me and maybe he suggested that the district nurses come in and manage the care. Anyway, there I was one day sitting on my reclining chair doing all this stuff to myself, and it was feeling jolly good, until my hip popped out resulting in a dislocation. I was told after that, that I should not manage the care of my ulcer any more, which came hard for me because I'm a person who's fairly independent, and I sometimes wonder about the district nurses, whether their time could be better used on someone else. But I have to use them, so I've been told I must, so I am, and I'm very thankful for their services.

I have rheumatoid arthritis so I've got tons of medicines. I've tried to drop them back but that is easier said than done. I first discovered I had arthritis when I was about 21 or something, so at 57 now, that's a fairly long time ago. Taking these medications has had a huge impact, and then you don't walk so much because things would be hurting, and then you get fatter and that's not good for you, and your circulation doesn't work as well.

Initially pain was a large factor, you can cry because the ulcer hurt so much. I'm not a person overly given to crying, but these were extremely painful. Never ceases to amaze me that you can have a large joint replaced, as I have, but when you come down to something of a much smaller nature it can give such pain. Seems amazing, but there you go. How do you overcome it, well you've got to think positively really. You've got to look on the bright side and you've got to realise that there are tons of other people far worse off than you, and just try and put your mind in a different place to distract yourself.

I have had a few people involved in the care of my legs, although some of them have dissipated now. I had a hospital wound management clinic, and then some professor of skin disorders and ulcers, the district nurses and the doctor. I also saw a venous professor. I went to the hyperbaric chamber and there were lots of people there who had enormous ulcers. How they get by is beyond me.

We've had tons of different dressings, its cost me a bomb, but I'm lucky I can pay for it. On dressings and products etc, well it's very nice of the girls to come obviously, I pay for that, but the main cost is for the products. They're very expensive for a little piece, 10cm by 10cm, it's $35. We went on our journeys with compression therapy. We had was it 3 or 5 layers, we had some cotton woolly sort of stuff, and then something else goes over the top of that, and there's some more layers and more layers and more layers, and that's rather restrictive, restrictive to comfort and movement. I'm not so much one just for sitting around doing nothing, I quite like to get out and about and it feels weird having all this extra

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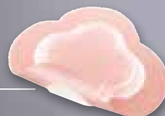

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sort of stuff on the skin. Particularly when it all starts falling down as the day progresses. However, it feels weird if your ulcers are sore, so it is a balancing game.

Other things are also important to the care of one's skin. I am careful. I am a person who likes to be out working in the garden and that is where you can easily get cuts and scratches and that, of course, can be a bit dangerous. I have two little dogs so I have to be careful when they welcome me home jumping up my legs in excitement. Just being mindful, you don't want to not do things because then your quality of life dissipates. About my general health, things like diet and exercise, I could do better.

Health information is really important. I like to ask the nurses who come and some of them speak in words that I perhaps am not familiar with, so I just ask them what they mean. If I hear of something weird and wonderful I'll Google it. And as with most things, you've got to investigate more than one site. So you have to read, ploughing your way through a lot of information, some of which is rubbish. Then we have all different countries that come forward with different aspects, so you absorb some of the good stuff hopefully and you toss out the rest.

Finally, I would like to say that I like going on the same journey you see. I look upon receiving care from the same person regularly to be of a great benefit. If somebody decides that something is good for me then it's nice to continue with that. I'm appreciative of all the people who look after me, they do a good job and we're lucky we live in a country that has these things to offer. It's very good that research is being done into the leg ulcer field, because the more people know about leg ulcers would obviously be for the betterment of everybody's health.

VLUs: A HEALTH CARE PERSPECTIVE

Leg ulcers affect up to 2% of people worldwide and VLUs, in particular, affect up to 3% of older people[1]. Assisting people who have these wounds to heal is a core activity of community nursing services as most people with leg ulcers live at home and receive care in the community. Uncomplicated VLUs typically heal if best practice treatment, compression therapy, is utilised[2]. Just as compression heals venous ulcers, so too it prevents ulcers from recurring[3]. Strategies recommended to people with venous disease also include activity and exercise, attention to diet and diligent skin care. The client, as well as specialist wound clinics, general practice and allied health, complete the interdisciplinary team that is required to achieve the best possible outcomes for this group.

While best practice treatment is well established for VLUs, it is not always realised. Adherence to compression therapy can be a challenge for people with VLUs. Predictors of non-adherence include age, pain intensity, larger wound size and shallower wound depth[4]. Similarly, adherence with the use of compression stockings is less than optimal among people with healed VLUs[3,5]. The capacity of health care providers to complete limb assessments and prescribe and apply compression therapy can influence the appropriateness and use of compression[6]. Similarly the cost of treatment and aesthetic factors may also impact on the person's ability and willingness to utilise this treatment[7]. For many people with venous disease, the strategies required to heal the ulcer and prevent its recurrence are lifelong endeavours. If wearing compression may not be imposing enough, so too may the broader lifestyle changes that optimise skin health. Attention to skin care, activity and exercise and nutrition are beneficial[8]; however, the persistence of these behaviours among people with VLUs has been shown to be variable[9].

CHRONIC WOUNDS: A SELF-MANAGEMENT APPROACH

The story presented in this paper illuminates many experiences that would likely resonate with other people who have VLUs, and other stories heard by clinicians. VLUs have a broad impact on health and wellbeing, including physical, emotional and financial costs. There is, however, another message that is particularly important in this story and it is reflective of the position of today's health care consumer who seeks more involvement and engagement in their management and care. Optimising self-management has been shown in this story to be highly important, in particular the benefits of self-treating the VLU. Having a sense of control, satisfaction from being able to self-care, and the flexibility to do so when and for how long as one wishes, are perceived benefits of wound self-treatment. The impact of the loss of control, when self-treatment could not be continued, is evident in the story.

To improve the capacity of people to successfully self-manage their chronic health conditions requires action in five areas: building the consumers' capacity, building the capacity of health professionals to support them, building collaboration in self-management, embedding the approach in the health care system, and building an evidence base for this approach[10]. If there was ever a time in wound management to move this approach forward, it is now. With an ageing population, and increasing numbers of younger Australians living with chronic health conditions, not only is this likely to be a growing preference of wound management consumers, it is also likely in part to be a solution to the growing pressures on health care budgets and expenditure. The Australian Government Productivity Commission Report, Caring for Older Australians[11], states that older Australians want to be active recipients of services and to make choices about the care they receive. Essentially Australians want to be independent as they age, a desire clearly evident in the story told in this paper.

What is known about self-treatment of wounds

There is little published about self-treatment of wounds and what is known is largely about wounds that are not chronic in nature. Traumatic or accidental wounds, which are common across age groups, are not typically treated by health care professionals[12], although who does treat them is not reported. Australian research has shown variable results in studies considering the capacity of people to self-assess surgical wound infection, an earlier study finding under-diagnosis and a latter study finding over-diagnosis when compared to assessments by health care professionals[13,14]. Malignant wounds are reported to be self-treated in many instances, and up to 10% of people experiencing cancer are suggested to have this type of wound[15]. A range of reasons such as exudate, malodour and embarrassment may contribute to a preference to self-treat malignant wounds[16].

Certain groups of people have been reported to self-treat skin injuries, including people who self-injure[17,18], people who experience intimate partner violence[19] and injecting drug users[20]. Over recent decades, understanding of the extent of self-treatment among people who receive tattoos and piercings (which are associated with a high risk of infection) has increased[21,22]. One large study has shown that 46% of family caregivers undertake some medical or nursing tasks for a person they care for, with wound care conducted by more than one-third[23]. In 2009 2.6 million Australians (12% of the population) identified as an informal caregiver[24]. While this involves wound treatment of another person, this group is similarly a non-professional group attending to this health care task.

DISCUSSION

It is well established that chronic wounds such as VLUs are challenging to live with and the impact of this condition extends far beyond the treatment. This is evident in the story told in this paper. This story adds to what is known about people with leg ulcers by introducing the concept of the individual's preference for self-treatment among people with chronic wounds. The story shows the benefit that self-treatment can have on a person's sense of control over their health and wellbeing.

The literature suggests that the types of wounds that are commonly self-treated are not chronic wounds. It also shows that the particular groups of people who tend to self-treat do not experience chronic wounds. The involvement of informal carers in conducting wound treatment is also of interest.

There is much more to be learned about the extent of self-treatment, the characteristics of people who self-treat and the impact of self-treatment among people who have chronic wounds who live in the community. Research exploring this phenomenon will provide some impetus to address those action areas required to improve the capacity of people to self-treat chronic wounds.

CONCLUSION

The stories told by people who live with VLUs are highly valuable as they provide rich descriptions and have the potential to illuminate less known perspectives of living with this chronic condition. Taking the time to talk should be part of the care provided to every person living with a chronic wound. The story reported in this paper suggests that VLU self-treatment can be more acceptable and convenient to the person and this is an approach worthy of further attention, given its alignment to the consumer-driven care model that is guiding health care service delivery in Australia.

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