

*Descriptive Title:*

The quality of life of people who have chronic wounds and who self-treat.

*Concise Title:*

Chronic wounds and quality of life.

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## **ABSTRACT**

### **Aim**

The aim of this study was to investigate the effect of chronic wounds on the physical, emotional, social, lifestyle and financial domains of quality of life among people who self-treat their wounds.

### **Background**

Patient centered models of care have received increased attention over recent decades because of the potential to contribute positively to the patient's health and well-being. A contemporary understanding of the effect of chronic wounds on quality of life may assist care providers and healthcare systems to respond to patient needs and improve patient outcomes.

### **Method**

A qualitative, exploratory study was conducted in Victoria, Australia.

Participants were aged 18 years or older and had a chronic wound that was currently or previously self-treated. A sample of 25 participants was recruited from the community and in-depth interviews were conducted in participants' homes. A thematic analysis was conducted to identify themes that represented the physical, emotional, social, lifestyle and financial domains of quality of life.

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## **Results**

Study participants (n=25) were 71 years of age (average) and the majority had a leg wound. Participants experienced a negative effect on quality of life. Physical limitations affected activity and compromised the management of other health conditions. Participants felt frustrated with and distrusting of healthcare professionals from whom they received advice and care. Daily lifestyle and workforce participation were disrupted when receiving professional care. Wound treatment and professional care expenses negatively affected personal finances.

## **Conclusion**

Continued effort is required to develop relationships and treatment regimens that are conducive to healing and to optimise well-being. Additionally, healthcare systems should identify and address structural shortcomings of care services to create more patient centered models of wound care in the community setting.

## **KEY WORDS**

Chronic Wound

Interdisciplinary care

Nursing

Patient participation

Quality of life

Self-treatment

Skin care

Skin integrity

Tissue viability

Wound care

## **SUMMARY BOX**

What does this paper contribute to the wider global community?

- Continued attention is required to minimise the negative effects of chronic wounds in the physical, emotional, social, lifestyle and financial domains of quality of life.
- Efforts should be directed toward developing a trusting relationship and mutually agreed goals of care when delivering treatment to individuals who have chronic wounds and who also self-treat.
- Healthcare services should identify system factors that are unacceptable to individuals who have chronic wounds and change service delivery methods so that they are more responsive to consumer preferences.

## **INTRODUCTION**

### **Background**

Chronic wounds are a disruption of the integument associated with protracted healing (Falanga, 2003). Chronic wounds affect 1-2% of the population, this prevalence similar in Australia (Graves & Zheng, 2014), and the United States and the United Kingdom (Graham, Harrison, Nelson, Lorimer, & Fisher, 2003). Chronic wounds cost AU\$3.78 billion in Australia, €4.5 billion in the United Kingdom (Guest et al., 2015) and US\$25 billion in the United States (Sen et al., 2009). The rising prevalence of diseases that cause chronic wounds (such as vascular disease and diabetes) in low middle and high income countries (World Health Organisation, 2015) is likely to cause increased burden associated with chronic wounds in Australia and elsewhere (Kapp & Santamaria, 2015).

There has been increased focus on patient reported outcome measures in wound care over the last decade and, therefore, efforts to understand quality of life among people who have chronic wounds has received increased attention from health care providers and funders (Ousey & Cook, 2011). A contemporary understanding of the effects of chronic wounds on quality of life will assist healthcare providers to provide more holistic care to patients and improve patient outcomes.

This paper reports the findings of a qualitative study that investigated the effect of chronic wounds on quality of life. Qualitative research investigating quality of life among the chronically wounded aligns broadly with physical, emotional, social, lifestyle, and financial quality of life domains, and this literature has been reviewed in the next section of this paper.

The physical effects of chronic wounds include wound pain (Firth, Nelson, Briggs, & Gorecki, 2011; Fox, 2002; Hopkins, Dealey, Bale, Defloor, & Worboys, 2006; Kapp & Annells, 2010; Ribu & Wahl, 2004), changes to body image (Ebbeskog & Ekman, 2001; Foster & Lauver, 2014; Kapp & Annells, 2010), sleep disruption (Foster & Lauver, 2014; Green, Jester, McKinley, & Pooler, 2014) and limitations in physical mobility (Chase, Melloni, & Savage, 1997; Ebbeskog & Ekman, 2001).

Individuals who have chronic wounds may blame themselves for the wound (Beattie, Campbell, & Vedhara, 2014) and feel powerless over their prognosis (Beattie et al., 2014; Chase et al., 1997). Feeling trapped in a burdensome body has been described (Ebbeskog & Ekman, 2001). The receipt of active treatment, for example negative pressure therapy, has been shown to generate hope for healing and symptom control (Moffatt, Mappleback, Murray, & Morgan, 2011).

Avoiding social activities due to concern about wound odor and exudate has been described (Ebbeskog & Ekman, 2001; Gethin, 2011; Ribu & Wahl, 2004). Time spent waiting to receive treatment has restricted the lifestyle of people who receive professional care (Brod, 1998; Hopkins et al., 2006; Ribu & Wahl, 2004; Wellborn & Mocerri, 2014) and employment routines may be hindered by pain and functional impairment (Chase et al., 1997). Environmental modification to accommodate treatment received at home has been described as disruptive (Neil & Munjas, 2000).

The cost of wound dressings and co-payments for professional care has been described as substantial (Firth et al., 2011; Foster & Lauver, 2014; Kapp, Simpson, & Santamaria, 2014) and financial strain, arising from lost or reduced employment associated with chronic wounds, has been reported among people who have foot wounds related to diabetes (Foster & Lauver, 2014).

Research conducted during the late 1900's has provided initial insight about the negative effects of chronic wounds on quality of life. Over recent years, published studies have been fewer and have tended to involve small samples; publications reviewed in this paper have involved interviews with on average 11 participants, minimum 1 participant and maximum 23 participants. This topic requires renewed and increased attention to determine if these negative effects on quality of life remain a problem for the chronically wounded, and in particular for those who self-treat.

Self-care is promoted internationally as an enabler of independence, improved well-being and reduced healthcare costs among people who have chronic wounds (Wounds International, 2016). Self-treatment of chronic wounds however has not been the focus of targeted research. A better understanding of the quality of life of people who have chronic wounds will assist care providers to optimise the care provided to and the outcomes of this patient group. This is particularly important in Australia where healthcare consumers wish to be more active participants in their management and care (Productivity Commission, 2011) and where healthcare providers will be increasingly promoting this approach.

## **METHOD**

### **Aim**

The aim of this study was to investigate the potential effect of living with chronic wounds on the physical, emotional, social, lifestyle and financial domains of quality of life among people who self-treat.

## **Design**

A qualitative, exploratory study was conducted. A paradigm can be described as a way to organise theory and research (Neuman, 2014) and the researcher took a single paradigm stance characterised by a position of pragmatism. Characteristic of this position is an emphasis on problem solving and action orientated enquiry (Green & Hall, 2010). This investigation sought to generate evidence to direct action to reduce the potential negative effects of chronic wounds on quality of life.

## **Sample/participants**

Participants were a sub-group recruited from a larger sample of individuals that had recently completed a survey investigating self-treatment of chronic wounds among people living in the community. General media, professional and consumer networks, and social media were used to advertise the earlier study. Individuals were screened from October 2014 to August 2015.

Individuals were eligible to participate in both studies if they were aged 18 years or older, resided in Victoria Australia, were English speaking, and if they currently or previously had a chronic wound that they had self-treated. Individuals were excluded if they had moderate or severe cognitive impairment or if they were in the terminal stage of illness.

A chronic wound was defined in this study as a break in the skin of any aetiology that took more than four weeks to heal. Self-treatment was defined as the person conducting one or more of the following activities: cleansing the wound, inspecting the wound, applying and removing wound dressings and applying compression bandaging.

The determination of sample size was informed by published expert opinion (Baker & Edwards, 2012) and consideration of the time required to travel to complete the interviews (up to 12 hours return).

## **Data collection**

One in-depth interview of approximately one hour duration was conducted with each participant in his or her home or other agreed location. The interviews were guided by

the intention to explore each of the targeted quality of life domains. All interviews were conducted by the same interviewer (SK) and were audio-recorded and transcribed verbatim.

### **Ethical Considerations**

The Human Research Ethics Committee of the governing university approved the study and it was conducted in line with the standards and expectations for the conduct of research set by the Australian Code for the Responsible Conduct of Research (National Health & Medical Research Council, 2007a) and the National Statement on Ethical Conduct in Human Research (National Health & Medical Research Council, 2007b).

### **Data Analysis**

A 6 phase thematic analysis was conducted according to methods defined by Braun and Clarke (2006) to identify themes that represented the physical, emotional, social/lifestyle and financial domains of quality of life. Phase 1 involved familiarisation with the data, transcribing, reading and re-reading the transcripts, and noting initial impressions. Phase 2 generated the initial codes by classifying interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. Phase 3: involved searching for themes by collating codes into potential themes, and gathering all data relevant to each potential theme. Phase 4 involved reviewing themes to check if the themes were consistent with the coded extracts and the entire data set. Phase 5 comprised defining and naming the themes, ongoing analysis to refine the specifics of each theme and the overall story of the analysis, and generating clear definitions and names for each theme. Phase 6 produced the report, including selection of vivid, compelling extract examples, the final analysis of selected extracts, and relating these to the analysis and to the research question and literature.

### **Validity and reliability/rigour**

Published criteria informed the techniques employed to ensure trustworthiness in this

study (Lincoln & Guba, 1985). To optimise credibility, the research team undertook regular peer debriefing and data checking which involved discussing some sections of interview data with some participants when there was uncertainty about whether or not the data resonating with their experiences. To optimise reliability, decision-making was documented and appraised by the research team at regular intervals. The characteristics of the setting, study participants and recruitment strategies, have been comprehensively described to enable evaluation of transferability. The researcher stated her philosophical assumptions and stance (single paradigm and position of pragmatism) prior to the commencement of the study thereby accounting for conformability. The authenticity of research can also be appraised (Guba & Lincoln, 1989) and was approached by clearly articulating new understandings and recommendations for action.

## **FINDINGS**

In total 25 eligible individuals participated in the study. Interviews were conducted in-person and in the participant's home (n=23), or an alternate agreed location (n=2). The interview conversations were free flowing, and most participants talked about the quality of life domains without prompting. The interviews were on average 98 minutes (minimum 58, maximum 132 minutes).

Participants were 71 years of age on average, with an equal representation of females (n=13) and males (n=12). All participants had received some professional care at some stage during the wound episode. Care providers included specialist wound clinic practitioners, the local doctor and practice nurse, and domiciliary nurses. The wound and treatment characteristics of the participants are described in Table 1.

The analysis of the interview data is presented as themes that represent the areas that were explored in this study (the physical, emotional, social/lifestyle and financial domains of quality of life) (Figure 1). Data from participants who currently and previously had wounds has been presented together in the results and the reader is referred to Table 1 to identify the status of individual participants.

## **The effect of chronic wounds in the physical domain**

The majority of the study participants (n=22) reported one or more effects in the physical domain. This analysis resulted in 4 themes in this domain.

### **Pain and discomfort**

Participants spoke about their experience of wound pain, although individual experiences varied in timing, characteristics and duration. The following participant described his experiences of wound pain early in the wound episode:

*“... the pain was just totally unbearable. The pain was just absolutely shocking.” (P22).*

Another participant described the constant pain that he experienced:

*“Most of the time, it’s burning pain. Sometimes it’s a lot worse than others. Sometimes I just get excruciating pain like an elephant has sat on it...” (P13).*

Discomfort could be also be unpredictable and the following participant went to painful lengths to alleviate it:

*“Well, last night I was itchy. [I used] a back scratcher. So it was bleeding. The only way I know to calm it down is to spray white vinegar into it. You cannot bear the initial sting of it but it stops the itching.” (P25).*

### **Unwanted physical inactivity**

For many participants, a degree of physical inactivity was required to accommodate the wound or the wound treatment. Inactivity was sometimes in the form of rest that had been prescribed by healthcare professionals or concerned significant others:

*“”Keep it up off the floor and rest it all the time” and things like that, which is useless... I mean, even my daughter says to me, “Mum keep it [leg] on the [foot stool]. I don’t gonna sit there with me leg on that all morning.” (P7).*

Some participants described how they did not engage in physical activities because of their risk of skin injury:

*“But I’m different. My skin is different. It’s perished, who knows, for whatever reason. But a lot of guys my age will be fine. They’ll be running down the street and going to a gym and all that sort of stuff, but I won’t be doing that. That’s for sure. I’ve had it.” (P5).*

While gesturing with his hands during his interview, the skin on the hand of the following participant was noted to crack and bleed. He described the experience as a type of ‘attack’ on his skin:

*“But when I get physical, and stuff like repairing things or working hands-on, if there’s a slightest bit of resistance [on the skin], be careful. Because that resistance is gonna end up flying off and biting you.” (P21).*

#### Exacerbation of other health problems

Some participants found that being unable to undertake usual physical activities had an adverse effect on other chronic health conditions:

*“They told me, “No way. You’re not going to the pool for a couple of months until it’s healed.” Well, it had a flow on effect because it increased all the pain [related to another condition] because I couldn’t do what I used to do to manage that.” (P24).*

This same constraint was found to have an effect on the mental health of the following participant:

*“... I can’t swim, although I did speak to [domiciliary nurse] about that and she said, really, if I asked the Professors they’ll say no because of infection, but – yeah. I gotta balance the quality of life.” (P12).*

## **The effect of chronic wounds in the emotional domain**

All study participants (n=25) reported one or more effects in the emotional domain. This analysis resulted in 4 themes in this domain.

### **Frustration with the healthcare system**

Many participants experienced frustration when interacting with the healthcare system for professional wound treatment and advice. Sometimes this occurred when they believed they were not being heard:

*“I kept on saying there is something in the bandages or in the treatment or in both that I'm allergic to. Nobody believed anything. And then eventually, the second last time that I saw her [wound nurse specialist], she said, “Oh. I got another patient with the same type of [reaction]” (P17).*

When the treatment goals of the participant and healthcare practitioner were not aligned this led to frustration because the participant's priorities were not being met:

*“... Every time you go to the doctor – it's ‘getting better’ and this and that. To me, it's still the same, still weeping, still sore, still doing the same thing.” (P21).*

### **Distrust of healthcare professionals**

Distrust of healthcare professionals was a concern for some participants and this sometimes left them wondering if their best interests were being served. For one participant, his distrust arose from believing that his doctor was manipulating the healthcare system by billing for full consultations that he had not received:

*“I mean half the time, the doctor looks at it and says, “Nurse, go and take it over.” Why didn't I go and see her in the first place instead of you looking at it and going “Yeh we know what it is.”... Because otherwise they don't get paid do they? (P11).*

The following participant believed that his specialist had a vested interest in certain skin care products:

*“I went to see a [dermatologist] and I wasn’t happy with him... pushing products for one particular company. “Ah this will do. But if that doesn’t work you can try this product, or if that doesn’t here’s another product. And I came home and I called up [searched] the product [on the Web]. They were all made by the same company. This guy’s just laundering stuff through his pocket.” (P25).*

Worry about wound infection

Worry about wound infection was not uncommon. Past experiences led participants to worry that they may develop another infection and a range of more serious consequences:

*“... a lot of things pass through your mind - like gangrene, and had that infection golden staph and all that sort of stuff... I’ve had cellulitis, must have a few bouts of that ...“ (P5).*

Many participants shared the concern that exposure of their wounds would put them at risk of developing a wound infection:

*“Look, it just seems so wrong. You’ve taken the dressing off, and you’re leaving me now. Last time I had to wait three quarters of an hour with it exposed before the specialist came and had a look.” (P22).*

Feeling disheartened about treatment and progress

The perceived quality of treatment received from healthcare professionals was found to be variable, and at times this caused participants to feel disheartened about their care:

*“Some of them [practice nurses] are really good, very clever, very switched on, and the others don’t have much of an idea on your particular problem. Sometimes I go there and I come home, bouncing. Other times I come home and the dressing’s already falling off...” (P6).*

Desperation set in for some participants, particularly when healthcare professionals had tried ‘everything’ in terms of wound dressings and other treatments:

*“... and I mean we just tried everything: stockings, compression, everything. I wanted the thing to go away, and I wanted to see a result that it was healing and not looking like the way it was (P19).*

The pharmacological treatments that were required for wound healing had side effects that were a source of sadness for some participants. The following participant describes the effect of a drug treatment for wound pain on his sexual function:

*“I mean I could honestly say that when I was on all the pain killers combined with the immune suppressants, to put it quite simply, one couldn't even function as a man! - and that was really depressing for a while.” (P22).*

### **The effect of chronic wounds in the social/lifestyle domain**

Less than half of participants (n=11) reported one or more effects in the social/lifestyle domain. This analysis resulted in 2 themes in this domain.

#### Time required receiving professional treatment

Participants described how being available at home, or attending appointments for care, had a negative effect on their lifestyle. The following participant described a full day lost:

*“... but I hate like when - the [domiciliary] nurses coming to your house - because you have to sit there all day and wait for them ‘cause they don't sort of get there at a specific time or whatever.” (P13).*

The need to frequently visit the general practitioner interfered with the following participants recreational activities:

*“Going to the doctor every second or third day, it breaks up your week and nothing you can do for yourself. We haven't been up there [show picture of holiday house] six, seven months now.” (P21).*

Difficulties working in paid employment

Some participants described difficulties when trying to work in paid employment. The following participant described the challenges of finding work that did not aggravate the wound, and then feeling the need to hide the wound from the manager:

*“Tried to get myself re-employed somehow, but that didn’t work because even just working in a [type of] shop was bad enough – just from cleaning up and general activities.... I was wrapping gaffer tape around my leg, to disguise it from the boss.” (P5).*

The following participant struggled to get work and had not worked in his trade since he commenced wearing the offloading air boot:

*“... I wanted to work and it’s so hard to get a job because people look at you and go, “I’m not hiring you.” I mean they used to take me on – with one artificial leg there was no problem...[I] haven’t done any [of previous type of work] since this [wound] has happened basically.” (P11).*

Another participant found the pain associated with the wound treatment to be so overwhelming that it directly contributed to the need to cease paid work all together:

*“It [not working] is, a bit [related to the wound]... it had just got twice as bad, so the pain then became worse... And it was just too much with this and the stress of the [job] and I just had to resign.” (P12).*

### **The effect of chronic wounds in the financial domain**

More than two thirds of participants (n=18) reported one or more effects in the financial domain. This analysis resulted in 2 themes in this domain.

Wound treatment, adjunct therapies and professional care was costly

Wound dressings were a major contributor to expense, as described by the following participant who was facing a cost that was equivalent to 25% of his future disposable income:

*“I’m not sure what might happen from here on... But if I go on the pension, I’m spending \$90 [of it] on dressings a week.” (P25).*

The expense associated with adjunct therapies including medications (analgesics and antibiotics) and alternative therapies (homeopathy, naturopathy and Chinese medicine) increased the overall cost of wound treatment:

*“Well, I’ve stopped going to the naturopath. She’s not happy, but it was costing me \$560 to \$600 a fortnight. I only work three days, and I kept saying to her it wasn’t sustainable... \$72 a visit plus the rest was supplements and the testing.” (P16).*

The cost of receiving professional care was an expense for participants who were making co-payments for post-acute, general practice and domiciliary nursing care:

*“Well, it was costing me a heap of money ‘cause I had to pay every time. Each time I went there [general practice], it was five dollars plus the dressing. I’m only on a pension.” (P6).*

Wound treatment caused financial stress and stressful life events

Participants described how their wound treatment expenses affected their disposable income, their current and future financial stability, and how this was stressful for them:

*“I haven’t kept track of it [money spent on wound dressings] ‘cause I don’t want to. It’s pretty distressing. Finances are shocking. I don’t think I’ve got enough money to get through to the end of life, but that’s what I’m looking at now. And – yes – it’s going and spending 50 bucks in a chemist’s shop or more. Even going through the one you mentioned, [not-for-profit wound product supplier] we’re talking hundreds of dollars, whenever I place an order with them.” (P5).*

Another participant described financial stress that resulted in her needing to sell her family home:

*“Financially, we’ve probably spent about 15 to 20,000 dollars on these legs. It’s the products. I mean – Let’s put it this way, we’ve sold our house.” (P19).*

## **DISCUSSION**

This research sought to provide a contemporary understanding of the effect of chronic wounds on quality of life. The findings suggest that chronic wounds have a negative effect in the physical, emotional, social, lifestyle and financial domains.

### **The effect of chronic wounds in the physical domain**

#### Pain and discomfort

The detrimental physical effects of chronic wounds are have been previously established. Wound pain has been widely reported (Firth et al., 2011; Hopkins et al., 2006; Kapp & Annells, 2010; Ribu & Wahl, 2004) and was a concern for participants of the present study also.

#### Unwanted physical inactivity

The negative effect of chronic wounds on physical activity is also consistent with earlier research, for example limited activity has been associated with prescribed rest and functional impairment (Chase et al., 1997; Ebbeskog & Ekman, 2001). Participants in the present study were physically inactive because of the frailty of their skin and their perceived risk of injury, and this belief is consistent with earlier research conducted with individuals who self-managed to prevent wound recurrence (Kapp & Miller, 2015).

#### Exacerbation of other health problems

The adverse effect that physical inactivity had on other chronic health conditions experienced by participants is concerning, and this has not been well explored to date among the chronically wounded. The situations described in this study related to swimming. While it has been reported that a very low number of wound infections may arise from exposure to certain gram negative bacteria in coastal and estuary waters in Australia (Austin, 2010), evidence of any negative effects of swimming in chlorinated pools is restricted to expert opinion. Given the considerable benefit of swimming, a better understanding of the consequences of this activity would assist individuals to make more informed choices about whether or not to engage in this activity.

## **The effect of chronic wounds in the emotional domain**

### Feeling disheartened about treatment and progress

The negative emotional effects of chronic wounds have also been previously established. The literature suggests that these effects mostly arise from the burden and challenges of coping with this condition (Beattie et al., 2014; Chase et al., 1997; Ebbeskog & Ekman, 2001), this aligning with the feelings of disheartenment about wound treatment and progress that were expressed by participants of this study. The negative effect of chronic wounds on sexuality has been identified (de Souza & de Matos, 2010; Lund-Nielsen, Müller, & Adamsen, 2005) although not extensively explored. The present study indicates that treatments for wound healing can be implicated in the person's sexual health, and highlights the potential effect on sexual partners.

### Frustration with the healthcare system

Participants experienced great frustration during interactions with healthcare professionals, the situations that they described suggesting that the participant and the healthcare provider were not on the "same page" when it came to treatment recommendations and goals of care. Although quality of care is routinely evaluated in accredited Australian healthcare services (Australian Council on Healthcare Standards, 2013), patient centered metrics that measure patient satisfaction with community based wound care services are lacking. The use of patient centered outcome measures in the United Kingdom is more advanced (Ousey & Cook, 2011) although also not mainstream in the community setting.

### Distrust of healthcare professionals

That some participants did not trust their healthcare professional and questioned their professional integrity is a situation that has not been described among chronic wound care recipients in literature that has been published to date. While one concern arose from a generic issue (billing for consultations), another was specific to wound treatment and reflected the participants concern that he received treatment products for reasons unrelated to his specific needs. While governance of this type of issue has received attention with respect to free drug samples (Chimonas & Kassirer, 2009), this has not occurred for wound dressing products. Evidence suggests that free

pharmaceuticals do not always go to the individuals that need them the most, and may increase their overall out-of-pocket costs (Alexander, Zhang, & Basu, 2008). Further investigation of the appropriateness and clinical and cost effectiveness of the practice of providing free wound products is required.

#### Worry about wound infection

Worry about wound infection has been previously identified as a concern of individuals who have chronic wounds (Pieper et al., 2007), although it has been reported as one of many potential worries and not identified as particularly significant. Worry about infection was a serious concern for participants, this occurring when the participant believed that they were at risk of or were experiencing an infection, or when they thought that the professional care that they had received increased their risk of infection.

### **The effect of chronic wounds in the social/lifestyle domain**

#### Time required receiving professional treatment

The negative social effects of chronic wounds have been previously reported, in particular reduced social participation and social isolation (Brod, 1998; Chase et al., 1997; Gethin, 2011). The former was found in this study, however the latter not, again possibly because the sample was independent, and despite constraints, still socially active. It was the effect of the wound on lifestyle that was most striking, in particular the amount of time that participants spent receiving, or waiting to receive, professional care. Although this effect has been previously reported among wound care recipients (Brod, 1998; Hopkins et al., 2006; Ribu & Wahl, 2004; Wellborn & Mocerri, 2014), major efforts to improve this situation have been lacking. In Australia, efforts have tended to focus on improving the time that patients wait for once only episodes in acute care, such as elective surgery and emergency department treatment (Johar, Jones, & Savage, 2015). Again, if patient centered metrics and outcome measures were prominent in community care settings, this issue could be better understood and addressed.

## Difficulties working in paid employment

Chronic wounds affect people of all ages, and the sample included ten participants who were of pre-pension age. It was unsurprising, therefore, that the effect of the chronic wound on work lifestyle arose. While existing evidence suggests that functional impairment and pain are factors affecting ability to work (Chase et al., 1997), this study found that the presence of the wound was an obstruction to job attainment. Stomal therapy literature provides an indication of the potential repercussions for the chronically wounded. One study found that the stoma was a predictor of number of hours worked in paid employment among those with inflammatory bowel disease (Netjes & Rijken, 2015), and return to work was associated with significantly higher levels of quality of life in another study (Horner et al., 2010). The impact of chronic wounds on workforce participation is an area of interest given the trend for individuals to be working until an older age, the impact of chronic wounds on wages lost, and the potential long term impact of this condition on younger people who may experience wound recurrences over many years.

## **The effect of chronic wounds in the financial domain**

Wound treatment, adjunct therapies and professional care was costly

The negative financial effect of chronic wounds on the individual has not been a well explored topic, possibly because a large proportion of published research in wound management arises from settings where wound treatment product are subsidised. One Australian study reported the extent of out-of-pocket expenses among self-funders, suggesting 14% of the pensioner's income may be spent on wound treatments (Smith & McGuiness, 2010). The effect of the expense associated with co-payments for professional care to receive wound treatment is an area that has been overlooked in wound care in Australia, and as demonstrated in this study, is also considerable. This topic has been identified as concerning to older community care recipients, who typically have multiple chronic health conditions (as do the chronically wounded) and who struggle to afford professional care (Callander, Corscadden, & Levesque, 2016). The effect of out-of-pocket costs for wound dressings and treatment related expenses in other settings are unknown, however may potentially have similar detrimental effects.

Wound treatment caused financial stress and stressful life events

These financial implications likely affected the affordability of many things that were required by participants for everyday living, however participants spoke about the effect of their wound on their major financial investments. Two study participants (and their significant others) had experienced significant housing stress that they attributed to their chronic wound. Although not reported in literature to date, such high out-of-pocket expenses among people who self-fund chronic wound treatments may be more commonly experienced than is currently recognised.

### **Limitations**

Due to financial constraints, interpreters were not available to the study, consequently individuals from Culturally and Linguistically Diverse (CALD) backgrounds were not included. The study likely attracted participants who had strong views on the topic of chronic wounds and professional care because they were engaged in self-treatment therefore the sample may be biased in this respect. Had multiple interviews been conducted with each participant there would have been opportunity to explore each quality of life domain in greater detail. The duration of the participant interviews, however, revealed the large amount of information that participants had to share. The potentially biased interpretations of the researcher must be noted as the researcher had a positive attitude toward self-treatment and this likely influenced what participants were willing to share and potentially how their information was interpreted.

### **Conclusion**

A continued effort is required by wound practitioners to minimise the potentially negative effects of chronic wounds on the physical, emotional, social, lifestyle and financial domains of quality of life. Greater attention should be given to developing a trusting relationship between patient and provider, and goals of care must align with the patient's wishes and expectations. Healthcare providers and services must identify

system factors that are unacceptable to individuals who have chronic wounds and develop strategies to change service delivery methods so that they are more responsive to consumer preferences.

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Table 1. Personal, wound and self-treatment characteristics of the sample.

<b>ID</b>	<b>Gender</b>	<b>Age</b>	<b>Wound duration at time of interview (weeks)</b>	<b>Wound cause and diagnosis</b>	<b>Treatment status</b>
1	Male	66	16	Trans-metatarsal, diabetes related amputation	Current wound
2	Male	61	300	Lateral malleolus, venous leg ulcer	Previous wound
3	Male	63	104	Medial malleolus, venous leg ulcer	Previous wound
4	Male	71	260	Lateral malleolus, venous leg ulcer	Previous wound
5	Male	64	6	Anterior gaiter; forearm; thigh; skin tear	Current wound
6	Male	72	70	Medial malleolus, venous ulcer	Current wound
7	Female	81	208	Medial malleolus, unknown diagnosis	Previous wound
8	Female	93	12	Medial malleolus, non-healing skin tear	Previous wound
9	Female	61	156	Anterior gaiter; medial malleolus, lymphatic/venous ulcer	Current wound
10	Male	73	4	Anterior thigh, traumatic wound	Current wound
11	Male	59	100	Plantar foot, pressure injury	Current wound
12	Female	53	64	Medial malleolus, venous ulcer	Current wound
13	Female	64	52	Anterior malleoli, medial malleolus, venous/lymphatic ulcer	Current wound
14	Male	54	250	Groin, abscess	Current wound
15	Female	95	4	Anterior shin, traumatic wound	Previous wound
16	Female	64	104	Posterior gaiter, diagnosis not reported	Current wound
17	Female	95	108	Lateral malleolus, delayed healing from infection	Previous wound

18	Female	81	5	Medical malleolus, venous leg ulcer	Current wound
19	Female	71	572	Anterior gaiter, spider bite	Previous wound
20	Female	75	19	Anterior gaiter, traumatic wound	Previous wound
21	Male	78	55	Anterior gaiter, chemicals	Previous wound
22	Male	69	60	Anterior shin, skin cancer and infection	Current wound
23	Female	74	45	Breast, removal of non-cancerous lump and radiation burn	Previous wound
24	Female	52	12 total	Plantar foot, 2 <sup>o</sup> burns from household cleaner	Previous wound
25	Male	75	50 to date	Anterior gaiter, venous leg ulcer	Current wound

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**The effect of chronic wounds in the physical domain.**

Pain and discomfort.

Unwanted physical inactivity.

Exacerbation of other health problems.

**The effect of chronic wounds in the emotional domain.**

Frustration with the healthcare system.

Distrust of healthcare professionals.

Worry about wound infection.

Feeling disheartened about treatment and progress.

**The effect of chronic wounds in the social/lifestyle domain.**

Time required receiving professional treatment.

Difficulties working in paid employment.

**The effect of chronic wounds in the financial domain.**

Wound treatment, adjunct therapies and professional care was costly.

Wound treatment caused financial stress and stressful life events.

Figure 1. Quality of  
life domains and

themes.