

A focus group study into patients' perception of chronic wound pain

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Abstract

Background: Dressing changes during the management of chronic wounds are often associated with pain, yet little qualitative research has been completed to gain an understanding of the impact of this on patients. **Aims:** This study aimed to involve patients in discussions about their wound pain in order to inform the development of a questionnaire based on their views. **Methods:** A purposeful sample of six participants with chronic venous ulceration was recruited to take part in a focus group discussion about pain. Free-flowing conversation was encouraged so that participants could discuss issues that were important to them. **Results:** The participants described two distinct types of pain — acute and constant. The impact of pain on everyday life led to isolation, loss of independence and sleep deprivation. The participants described a tendency towards habitual behaviour that led to a sense of vulnerability in the clinical environment. Cooling of the surrounding skin, having a support network and the use of medication were perceived to improve the experience. **Conclusions:** It is clear that living with a chronic wound has a huge impact on a person's life. Healing is often a lengthy and uncomfortable process, yet the issue of patients' perceptions of pain is still an area in which relatively little research has been conducted. **Conflict of interest:** This work is supported by an unrestricted educational grant from Mölnlycke Health Care.

KEY WORDS

Chronic wounds
Pain
Dressing changes
Quality of life
Sleep deprivation
Support networks

In recent years there has been growing evidence to suggest that the experience of living with a chronic wound has a huge impact on a patient's quality of life (Franks et al, 1994; Price and Harding, 1996). One of the most consistent findings is that pain is one of the symptoms that patients find most distressing (Oswald and Adam, 1984;

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Charles, 1995; Ebbeskog and Ekman, 2001; Rich and McLachlan, 2003; Price, 2005). Pain is particularly problematic during the dressing change process (dressing removal, wound cleansing and dressing application) (Hollinworth and Collier, 2000; Briggs and Closs, 2006).

Wound-related pain is multifaceted, and manifests itself in a combination of chronic persistent pain (caused by the underlying condition) and acute pain (caused by regular dressing changes) (Krasner, 1995). What patients tell healthcare professionals about their wound pain can be very revealing and this information, together with a comprehensive knowledge and understanding of the complex mechanisms of the central nervous system, is essential if healthcare professionals are to understand a patient's experience of pain. Although work has been completed on healthcare professionals' perceptions of patient wound pain (Moffatt et al, 2002), little qualitative research exploring the views of patients has been completed.

Aims

This study was conducted to collect data from the patients' perspective to inform the development of a questionnaire that could be used to collect data on patients' wound-related pain experiences globally. It was supported by an international advisory panel, comprising medical, nursing and social science experts from the field of wound healing.

Similar focus groups studies were also conducted in France and Canada and the combined results of all these are due to be published. A questionnaire was developed based on what the patients (who participated in the focus groups) felt were important issues for them. The main study used this questionnaire to collect data from 2,018 patients in 15 countries during a three-month period. The aims of the main study were to explore the extent of problems related to pain and the dressing change procedure, compare pain experience between wound types and compare pain experiences across a number of countries.

Method

A focus group involving six patients with chronic leg ulceration was set up as it represented a simple and convenient way to collect data from several patients simultaneously. Systematic, non-probabilistic sampling was used to identify patients who had experienced discomfort and/or pain related to chronic wounds. Only adult patients (over 18 years of age) with an ulcer that had been active for longer than six weeks were invited to participate.

There was no exclusion criteria based on whether patients were experiencing a predetermined level of pain at the time of the focus group, but only those who had some previous or current experience of wound pain were invited to participate. The inclusion criteria were deliberately broad in order to capture the full range of experience and the use of a purposeful sample was deemed appropriate in order to fully explore the participants' experiences of pain.

Following full ethical approval, the patients that had been identified as appropriate by relevant healthcare professionals were sent an information sheet about the study followed by a telephone call one week later. Those patients interested in participating were invited to attend a two-hour focus group meeting.

Focus group were held in France, Canada and the UK. The UK group was run by two facilitators who explained the aim of the group and outlined that the focus would be on the participants talking to each other rather than to the researchers. Initially, the facilitators stayed in the background, a technique known as 'structured eavesdropping', but as the group went on they adopted a more interventionist approach to take the debate further and help the participants expand on their experiences.

During this intervention phase, the facilitators focused the discussion around the topic of discomfort and/or pain during the dressing change procedure, rather than on general wound experiences, which had been the focus of the first half of the discussion.

The facilitators used open questions and prompts to facilitate a deeper exploration of the issue.

The discussion was tape recorded and the content of the tape was transcribed, confirmed by a second researcher and verified by the participants. The discussion transcriptions were evaluated using content analysis – this enabled systematic identification of a number of emergent themes, which represented the participants' responses.

Results

Pain

All the participants agreed that pain was a constant presence, but that it varied in intensity throughout the day. Two main types of pain were identified – the first was classed as 'ordinary' or 'constant' and variously described as 'burning', 'throbbing' and 'itching'. This pain was portrayed as a permanent feature of the participants' ulcers, rather than something that came and went.

The second type of pain was described as 'acute'. This appeared to be much harder to cope with than the 'ordinary' pain and was said to occur a number of times throughout the day and night, often catching the participants unexpectedly. These episodes were described similarly by all the participants:

'It's like an iron band with spikes inside pressing hard.' (Participant E)

'It's a deep pain, a burning pain – like a red hot poker.' (Participant A)

'It's out of the blue, no warning. It takes your breath away.' (Participant D)

Quality of life

The experience of pain had an impact on a number of psychological processes, for example, reduced self-efficacy was particularly evident among a number of the participants. Self-efficacy can be defined as a person's belief in their own capabilities to organise and execute courses of action required to meet given situational demands. Self-efficacy has been proposed as a central concept underlying health-related behaviour. It refers to an individual's confidence in their own ability

to deal with a situation and is related to the level of control that person has in their own life and how they compare themselves to others. If an individual has serious doubts about whether they are capable of performing necessary activities to improve their health, i.e. if they have reduced self-efficacy, this is likely to effect how much effort they will put into helping themselves, their ability to follow healthcare advice or even their capacity to cope with their situation, which can all have an adverse effect on their wound healing.

Persistent painful experiences also affected participants' confidence in carrying out everyday interactions or maintaining social and recreational activities. This had a negative impact on participants' daily lives:

'This is the time of your life when you've brought your family up and now you can go and enjoy yourself. But somebody up there says, "Oh no, you're not doing that."' (Participant B)

'I played squash so I had to give that up – all my mates carried on and I used to sit and watch but it wasn't the same as playing. That was the hardest part, having to drop things you'd done previously.' (Participant F)

A reduced quality of life was illustrated by the strong feeling, expressed by all the participants, that their lives had irreversibly changed:

'You are not yourself any more – that's basically it.' (Participant C)

'It feels like we are being taken along a different route in life to the one we expected.' (Participant B)

These beliefs led to a loss of identity, which was amplified by a loss of independence:

'If you are bandaged up you can't bend your ankles enough to step up onto buses and things like that.' (Participant C)

'I can't go anywhere on my own – I have to have someone with me all the time.' (Participant A)

'I now walk with my head down towards the floor because I'm petrified I'm going to fall.' (Participant B)

These enforced changes in participants' status further reinforced their feelings of isolation:

'A lot of people did not know about my problem for 20 years – I kept it to myself.' (Participant F)

'People might say you are looking well, but they don't know the pain you are in.' (Participant A)

'You can't whinge too much to friends otherwise you won't have any left – you have to keep it to yourself.' (Participant C)

This tendency to keep their feelings to themselves was adopted by all of the participants, due to a feeling that family and friends could not understand what they were going through. Participants felt it was pointless to burden family and friends with their problems.

However, the factor that had the most overwhelming impact on the participants' quality of life was sleep deprivation:

'Every night you'd be rubbing your leg, you don't know what to do. I get up in the night and walk about, anything, then get back into bed and try to sleep.' (Participant A)

'Over the years I've not been able to sleep – I can go to bed at 10 or 2 o'clock and it makes no difference. I can wear myself out and go to bed in a drowsy state and then in no time at all my leg is out of the bed due to the pain.' (Participant F)

All the participants expressed some experience of pain or discomfort at night that resulted in sleep disturbance. This impacted on other aspects of everyday living because the participants felt that they were in a constant state of tiredness.

The dressing change process

Another problem expressed by all of the participants was the anticipation of pain during dressing changes. Feelings of

dread were common and these tended to be based on past experiences. This anticipation of pain led to participants employing delaying tactics:

'I wash my hands five or six times before my dressing is changed.' (Participant D)

Those participants who took pain-relieving medication before having their dressing changed reported that the possibility of the clinic running late would exacerbate their anxiety. This was because they feared that the effect of the tablets would begin to wear off as they waited.

Removal of the old dressing was perceived as a simultaneously positive and negative experience — there was the relief of having the compression removed and the opportunity to monitor the wound and have the leg washed, but there was also the constant fear of the pain that would ensue if the dressing had adhered to the wound. This caused considerable anxiety.

Participants also tended to perceive the cleansing procedure unfavourably, again due to an expectation of pain, which was in some cases linked to specific incidents that had occurred many years in the past. One participant described her experiences in the 1960s, when the nurses would bathe her leg in Savlon and then scrub it with a nail brush. Although this experience occurred over 40 years before, it still had a huge negative impact on her anticipation of the cleansing process.

While the application of the new dressing was generally perceived as painful, it was also considered a relief as it signified that the process was over. The participants described both immediate and delayed pain after having their dressings changed:

'You change your leg and you've got this time delay and all of a sudden this pain kicks in. If you can wait for 10 minutes it's not going to hurt, but then all of a sudden it really goes into your leg.' (Participant F)

'Once you disturb it doing a dressing you've got to wait at least half an hour afterwards for it to settle down. You just don't want to move from the spot you're in.' (Participant B)

The immediate pain of having a dressing change impacted on the participants' subsequent activities that day. Most just wanted to get home — others said that they would have a treat waiting for them at home, such as a glass of wine or some chocolate, to help them through the experience.

The delayed pain on the other hand was more about wanting to have the bandages removed. The participants tended to see the bandages and resultant compression as being partly responsible for their pain and by about day five after the dressing change they felt that they had had enough and just wanted the dressings taken off.

Factors that make the dressing change experience worse

The participants expressed a sense of vulnerability or insecurity due to a lack of control over the dressing change procedure. This was linked to a fear that there may be inadequate numbers of staff and they would be left waiting. This was especially difficult if the ulcer was left exposed for too long, as many of the participants felt uneasy about their wound being uncovered.

Location also had an impact, with the majority of participants perceiving their home as a safer environment for the dressing change. Many described ritualistic behaviour patterns that they adopted at home, which made the clinic or hospital experience feel more out of their control. One male participant said that he would lay out everything in the same order at home and got very anxious if anything was done out of sequence.

Overwhelmingly, however, the greatest issue was the unpredictability of recurrent infections. The participants all expressed a fear of infection and this was particularly prominent during the dressing change process as it was perceived to be the most infectious

time. Many of the participants spoke of a feeling of insecurity when the ulcer was free of bandages because the wound would be more vulnerable to what they perceived as 'bugs' floating around the clinic.

The fear of infection was amplified by the fact that if an ulcer became infected it would be more painful and because there was rarely an explanation provided by healthcare professionals. This led the participants to make their own lay assumptions about the cause:

'You have all these bandages on and that's fine, but then you get an infection and think: "Where did I go wrong?" But basically you don't, it just happens.'
(Participant D)

'I picked up MRSA three times. The ulcer never sees daylight so how does it get infected?' (Participant F)

'When the dressing comes off, you just feel that you should have something on it.'
(Participant B)

What can improve the experience?

Most of the participants had great faith in certain types of dressings and when new ones were tried this could be difficult for them. However, when asked which dressings they preferred, most participants could only recall the names of those dressings that had made the experience worse.

Having a support network, such as family, friends and familiar healthcare professionals, was deemed by all of the participants to be beneficial, along with consistency of care.

The participants also spoke about the benefits of using distraction to take their mind off the process, such as thinking about the treats they could look forward to after dressing changes.

Taking pain-relieving medication before dressing changes was common for many of the participants and in some cases essential to improving the experience. Anything that was perceived as having a cooling effect around the wound was also seen as beneficial and

some of the participants stated that being able to have an element of involvement in the dressing change tended to make the process easier to bear.

Concerns about medication

Most of the participants were particularly concerned about the effects of the long-term use of pain-relieving medication, mainly due to the fear of addiction, reduced efficacy through overuse and because they felt that there was stigma attached to being reliant on painkillers. The issue of poly-pharmacy created a lot of debate among the participants and stemmed from their reluctance to be seen to be taking long-term medications. They all appeared to be particularly fearful of mixing medications (such as taking painkillers and antibiotics at the same time), this fear was based possibly on ignorance, but mostly on worry about what these combinations of drugs might do to their health.

Discussion

Wound pain has been shown to have a negative influence on a person's well-being, mobility and function. Research in this field confirms that sleep deprivation impacts heavily on a person's ability to perform the tasks of daily living and could increase their perceived sensitivity to pain (Oswald and Adam, 1984).

The regularity of dressing changes ensures that the anticipation of pain is never far from the patient's mind and as such largely dictates how they lead their day-to-day life.

All of the participants in this study expressed how their lives had irreversibly changed as a result of their wound regimen and how this had impacted heavily on their independence, confidence and ability to maintain an acceptable lifestyle.

Findings from studies on health-related quality of life suggest that patients tend to adapt to change over time until their new lifestyle becomes the norm (Price and Harding, 1996). A similar phenomenon was observed in this study — nevertheless, the

participants expressed severe feelings of bereavement for their old lifestyle. This was directly related to the pain they experienced, the physical limitations imposed by the bandages and the constant anticipation of the dressing change process.

Research has already established that a deterioration in mobility is directly attributed to ulceration, although how these factors are linked remains unclear (Franks et al, 1994).

In this study, the participants associated their lack of mobility with the pain of the ulcer and the limitations that the dressings inflicted upon them. These feelings were amplified by a fear of falling, which had a direct effect on their desire to go out.

Being at the mercy of others gave rise to feelings of a lack of control and vulnerability among the participants. This was seen in both the home and the hospital environment, where there was particular anxiety about being reliant on others. Furthermore, the participants felt threatened by a constant fear of infection. These feelings were exacerbated by the inability of healthcare professionals to provide an acceptable reason for the cause of infection, which led the participants to make their own unqualified assumptions.

There is little evidence of the impact of wound pain on psychological factors, such as hope and optimism, but it could be hypothesised that constant unexplained episodes of painful infection and protracted periods of ulceration would have a negative influence on a patient's emotional health and ability to maintain a positive outlook.

The impact of past experience also had a considerable effect on the participants' perception and anxiety regarding pain during dressing changes. Their memories of wound-related pain tended to focus on negative experiences of past dressing changes that had become amplified with time and were generally associated with a single incident.

Research has found that the long-term effects of pain can have a direct impact on a person's emotional status and coping strategies and that having positive social support networks is an essential component for psychological well-being (Krasner, 1995). In the study group used here, although it initially appeared that the participants had plenty of practical support from family and friends, most of the group admitted to keeping their feelings to themselves and not talking about their pain with those around them.

Research into social isolation puts great emphasis on a link between a person's perceived social support and their emotional well-being (Roberts et al, 2001). While the participants in this group did not display the usual features of social isolation, such as loneliness and a lack of social life, their reluctance to talk about their pain could indeed have a negative impact on their sense of well-being and their consequent ability to cope with their painful symptoms.

Conclusion

It is clear that living with a chronic wound has a huge impact on a person's life. Healing is often a lengthy and uncomfortable process, yet the issue of patients' perceptions of pain is still an area in which relatively little research has been conducted. Each person's experience is different and a patient's individual needs should always be recognised and re-evaluated regularly. It is essential that healthcare professionals do not underestimate the impact pain can have on an individual's life. Healthcare professionals involved in the treatment of someone with a chronic wound should recognise that having an opportunity to talk about their pain experiences with other people who understand can be an extremely comforting and positive experience for the patient.

However, the intensity of the experience of wound pain is best expressed in the participants' own words:

'I wouldn't mind getting burned, I wouldn't mind cutting my finger; any other pain would take my mind off the pain in my leg.' (Participant A)

'You've got to do your own thing; everybody's probably experiencing different things but the pain element is there for all of us and many thousands of people. It's there permanently.' (Participant F) **WUK**

Acknowledgements

The authors would like to thank the participants, nurses and staff at the Wound Healing Research Unit, Cardiff University, Wales, UK.

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Key Points

- ▶ In recent years there has been growing evidence to suggest that the experience of living with a chronic wound has a huge impact on a patient's quality of life.
- ▶ One of the most consistent findings is that pain is one of the symptoms that patients find most distressing.
- ▶ Research in this field confirms that sleep deprivation impacts heavily on a person's ability to perform the tasks of daily living and could increase their perceived sensitivity to pain.
- ▶ The regularity of dressing changes ensures that the anticipation of pain is never far from the patient's mind and as such largely dictates how they lead their day-to-day life.
- ▶ The impact of past experience also had a considerable effect on the participants' perception and anxiety regarding pain during dressing changes.
- ▶ It is clear that living with a chronic wound has a huge impact on a person's life. Healing is often a lengthy and uncomfortable process, yet the issue of patients' perceptions of pain is still an area in which relatively little research has been conducted.

Roberts R, Golding JF, Towell T (2001) *Foundations of Health Psychology.* Palgrave Publishers Ltd (Macmillan Academic), Basingstoke