



Patients ‘acceptance’ of chronic wound-associated pain – A qualitative descriptive study

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ABSTRACT

Chronic wound-associated pain negatively impacts the quality of life of individuals and their families. To date, little research exists that has explored collectively how individuals describe wound pain, strategies they use to manage pain, and the perceived effectiveness of such strategies. Therefore, qualitative, semi-structured interviews were carried out between June and August 2021 with 13 individuals to gain a deeper understand of the experience and impact of chronic wound-associated pain in this population. Data were analyzed following Braun and Clarke’s approach for reflexive thematic analysis using MAXQDA®. Two themes and subthemes were identified. Theme 1 reflects participants’ characterization of pain and how wound-associated pain affected their daily life and how they learned to accept it. Participants felt functionally impaired. In theme 2, participants described how they accepted to live with such a pain even though they received support to manage their chronic wound-associated pain, especially during the dressing-changes. Patients depended on their health care professionals and family support networks to cope with the pain. Coping with pain is exhausting contributing to poorer quality of life. Health care professionals should be aware of wound-associated pain during dressing changes. Patients recommended the need for further research on dressings and not drugs to manage pain.

1. Introduction

Chronic wounds, such as venous, arterial, diabetic, pressure ulcers, or atypical wounds cause several challenges in the individual’s life and that of their families [1,2]. These include social isolation, reduced activities of daily living, management of wound symptoms such as odor, exudate, and pain [2]. Of these, pain is one of the most cited concerns for individuals [2–4]. The International Association for the Study of Pain defines pain as “An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” [5]. Chronic wound-associated pain can be caused either by skin damage, nerve damage, blood vessel injuries, infection and ischemia or their

treatment (debridement, cleansing or dressing changes) [6]. Individuals describe chronic wound-associated pain as an unpleasant sensory and emotional experience mostly associated with wound and dressing change [7–9], the latter being associated with wounds [10].

The exact prevalence of chronic wound-associated pain is unknown. However, evidence suggests that up to 70% of individuals experience moderate to severe chronic wound-associated pain [11] and up to 95% during wound management procedures [12]. Addressing individuals’ wound pain experiences should therefore be a priority in clinical practice, however, this is not always the case [13].

Various therapeutics are available to prevent, manage, and treat individual’s wound-associated pain. Common therapeutics include non-

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opioid analgesic (non-steroidal anti-inflammatory drug) or opioid medications with or without an analgesic adjuvant. Adjuvants include tricyclic antidepressants, anticonvulsants, antihistamines, benzodiazepines, steroids and phenothiazines [14]. Additionally, topical-based therapeutics for the prevention, management and treatment of chronic wound-associated pain such as local anesthetics, anti-inflammatory foam dressings and topical opioid/cannabis medication can be applied [15–17]. However, opioid medications come with side effects [18], and their effectiveness in managing pain, for example, during wound dressing changes has been questioned [19–21].

Inadequate pain control has a negative impact on physical and psychological well-being [22,23], confidence of the individual [12], and adherence to therapy [24]. In an effort to improve current practice in the management of chronic wound-associated pain and to inform development of improved treatment strategies, it is important to understand individuals' perspective of how they experience and live with pain. Most of the current literature describes the experiences in individuals with burns [25–28] or venous leg ulcers [29,30]. We, therefore, conducted a qualitative study to understand in-depth the experiences of how individuals with chronic wounds describe wound pain, identify their strategies to manage such pain, and the perceived effectiveness of these strategies.

2. Materials and methods

A qualitative descriptive design was used. A qualitative descriptive analysis is situated within a constructionist epistemology and was employed to describe individuals' experiences for chronic wound-associated pain [31]. This study was approved by the ethics committee of Saolta Healthcare, Ireland (Ref: C. A. 2595 (B)). All participants provided verbal consent prior to commencement of interviews. To protect anonymity, fictional names have been used throughout this paper.

2.1. Recruitment

We included adults aged 18 years and older with chronic wounds, who experience chronic wound-associated pain. Participants were excluded if they had acute wounds, surgical wounds or burns as the perception or cause of pain could be different. We recruited participants by local radio advertisements and interviews, social media, general practitioner primary care settings, and wound care clinics between June and August 2021.

2.2. Data collection

We used purposive sampling. Data was collected until data saturation has been reached. Telephone interviews were conducted using an interview guide developed in conjunction with our patient panel based in the Alliance for Research and Innovation in Wounds (ARIW) at the University of Galway, Ireland. Using the telephone for data collection is described as a valid tool [32]. The interviews were conducted during the COVID-19 pandemic and government restrictions, and the high risk category of many participants meant that the option for face to face interviews was not available. All interviews were conducted by three members of the research team (LM, DS, PC) who were experienced in interview techniques. Reflections and impressions were documented immediately following the interviews. The interviews were recorded digitally, lasted 10–41 min, and consisted of open-ended questions, semi-structured around the description of wound pain, strategies used to manage wound pain and perceived effectiveness of these strategies. At the end of the interview, individuals were also asked what they think should be researched in relation to wound pain.

2.3. Data analysis

We transcribed all interviews verbatim and conducted thematic analysis following Braun and Clarke [33] framework using the computer software MAXQDA® [34]. During data analysis, we used both interview transcripts and field notes capturing participants' responses to questions. In phase 1, all of the transcribed data was read multiple times to develop familiarity. During phase 2, open coding of the transcripts generating first cycle codes was used. Additionally, we revisited data for clarity by two researchers (SP and GGs) and a coding tree was generated. Code mapping facilitated grouping of codes. Preliminary themes (phase 3) were constructed from code mapping and reorganization in relation to the associated quotes. In phase 4, we checked the themes against the highlighted frequently occurring areas to ensure that the themes and sub-themes reflected the data and answered the research question. We then refined themes and sub-themes until we gained consensus (phase 5). During phase 6, we underpinned the syntheses using direct participant quotes.

2.4. Rigor and trustworthiness

To improve the rigor of this thematic analysis we used a computer software to systematize coding [35]. We followed the COREQ guidelines [36] and applied the trustworthiness criteria for qualitative research following Lincoln and Guba [37]. To reach dependability, we kept a reflective journal throughout to keep track of any biases, assumptions, and impressions we may have had. Credibility was enhanced by triangulating the analysis by two researchers (SP and GGs) working independently. Additionally, confirmability was guaranteed by providing verbatim quotes [38]. The entire work process was overseen by the last author (GG), who was not directly involved in the analysis process.

3. Results

The sample included thirteen individuals with a mean age of 66.5 years (min. 44, max. 83; SD 11.7). The mean wound duration was 12.1 years (min. 1.5, max. 57). Sociodemographic characteristics are listed in Table 1.

The study findings were categorized into two main themes with associated sub themes: characterizing wound-associated pain and feeling supported by the care network.

3.1. Theme 1: characterizing chronic wound-associated pain

This theme reflects participants' characterization of pain and how wound-associated pain affects their daily life.

3.1.1. Describing wound-associated pain

Participants used spontaneously vivid images to characterize chronic wound related pain. Words like “niggling”, “dart”, “needles”, “sting”, “sharp knives” or “twinge” were used by ten participants. Other participants (n = 4) described chronic wound-associated pain as a “pressure”, “pulling” or “burn”. For example, Charlotte illustrated chronic wound-associated pain as: “... exudate then burnt, it burnt all down below the ulcers” or “It was like a really bad scald”. Other interviewees mentioned their nerves seemed to be touched. Noah said: “It's really, really bad, it really feels like it would, you know if you have tooth pain, you know if the nerves are touched by the dentist or something, this is really the feeling. ..., like the liquid filling up and something is putting pressure in nerves totally, I don't know but it's horrible really you know.”

A majority of the participants (n = 10) rated their chronic wound-associated pain level as high or very high. For only three of the participants the pain was moderate and for two it was light. Participants explained that the intensity of chronic wound-associated pain depended on how the dressing change was conducted by health care professionals. Nine participants specified having procedural pain and the pain level

Table 1
Sociodemographic and wound characteristics (n = 13).

Participant Name ^a	Gender	Age	Occupation	Wound Type	Wound Duration (Years)	Wound Location
Anne	Female	65	Housemaker	4 Ulcers (etiology unknown)	10	Ankle (1 on each ankle)
Beth	Female	67	Housemaker	2 Ulcers (etiology unknown)	7	Leg (1 on each leg)
Martin	Male	83	Retired	4 small chronic wounds (etiology unknown)	4	Leg (3 on right leg and 1 on left leg)
Olivia	Female	47	Employed	Ulcerative Vein (etiology unknown)	1	Ankle (1 on lower left ankle)
Emma	Female	72	Retired	5 Ulcers (etiology unknown)	5	Leg (5 on right inner side of lower leg)
Charlotte	Female	69	Retired	2 Ulcers Varicose Veins (etiology unknown)	3	Leg
Adam	Male	66	Employed	2 ulcers (etiology unknown)	7	Leg and Ankle
Sophia	Female	72	Retired	2 Ulcers (etiology unknown)	14	Ankle
Isabella	Female	54	Employed (on sick leave as nurse last 3 years)	1 Ulcer (Previous history of psoriasis on leg which caused skin to break down)	3	Leg
Mia	Female	44	Unemployed	2 chronic wounds due to Hidradenitis Suppurativa	30	Neck
Robert	Male	74	Retired	2 Ulcers (etiology unknown)	1.5	Thigh
Noah	Male	74	Employed	2 Ulcers (etiology unknown)	57	Leg
James	Male	78	Retired	Ulcer (unclear how many – just refers to leg ulcers)	15	Ankle (1 on right ankle and 1 on left ankle)
						Leg

^a To protect anonymity, fictional names have been used.

was influenced by their activities of daily living. For example, Martin illustrated: “*Well you see it depends on how much I’d be on it (his legs) you know during the day*”. James said: “*Maybe sometimes with dressing changes, the worst pain I had was with the VAC dressing (Negative Pressure Wound Therapy)*”. Participants experienced the level of chronic wound-associated pain depending on their wound-healing phase. Their pain-situation improved when the wound was healing. This was impressively illustrated by Sophia who said: “*Yes actually the most pain on my leg is before it erupts. That is when the pain is intense*” or “*Sometimes when, as they (the wounds) start to heal that’s where you get, the pain ... it will sort of get easier and we’ll be able to knock them down a bit*”.

3.1.2. Impacting the activities of daily living

Participants experienced a range of challenging impairments in response to chronic wound-associated pain and related functional limitations, including low energy-level, altered mood or impaired sleep. To live and to try to treat such pain was very energy-consuming which in turn was very tiring. They therefore could not carry on their activities of daily living. Charlotte described: “*well it felt like that I was constantly worn out trying to cope with it*”. Others (n = 6) mentioned having an altered mood because of the pain. Beth narrated: “*You’re inclined to be more sharpish with them, which isn’t nice ... And then you regret it after*”. In addition, Beth and Adam illustrated that chronic wound-associated pain had an impact on their family. Sleep was also impaired because of such pain. For example, Adam said: “*And of course that kept me awake too*”. Not only were participants’ personal lives impaired because of the chronic wound-associated pain but it also affected their professional life. For example, Anne’s wound with its pain impacted her work. She said: “*And I’d love to be able to do the work like, but I can’t*”. In general, participants found that such pain impacted their quality of life. Mia mentioned: “*You don’t have quality of life with it*”.

3.2. Theme 2: feeling supported by the care network

This theme reflects how participants received support to manage their wound-associated pain, especially during dressing-changes. Most of the individuals (n = 11) mentioned a follow-up by nurses or a physician at home or in a health center. The follow-up was once or twice a week depending on their needs or wound situation. Participants were very satisfied with the wound care by nurses and physicians. Having a trustworthy relationship with health care professionals was important. Four participants emphasized this trusted relationship. Olivia said: “*I suppose I was in good hands with the nurses like. And I know they were doing something right*”. Family members (relatives and colleagues) constituted

another source of support for either dressing or wound-associated pain management. This support helped them to pursue their activities of daily living.

3.2.1. Evolving pain strategies using their care network

Participants described that their pain management strategies evolved over time, often through an exhausting process of trial and error. Through this process, some felt that they had found more helpful strategies such as learning to live with their disease and their wound-associated pain. One of the strategies was to take painkillers as prescribed by the physician, even though they sometimes caused some side effects such as stomachache or illusions. Emma mentioned “*When I was in hospital and the pain was really bad, the doctors prescribed an opioid analgesic. But I got a reaction to that I was seeing pink, blue and yellow things coming at me*.” Other strategies were to change the wound dressing on a regular basis. It was therefore important that nurses educate them how to change the dressings.

Participants felt supported when physicians and nurses prescribed antibiotics especially when their wounds had signs of infection. Antibiotics relieved their wound-associated pain. For example, Sophia expressed: “*Now after about we’ll say three or four days on the antibiotic the pain ceases and I have very little pain*”. Over time, participants identified other effective non-medical interventions for their wound-associated pain. Some (n = 4) used moisturizing creams with paraffin for their legs as they heard that this may prevent ulcers and therefore also wound related pain. Five interviewees indicated doing an activity to forget the pain such as “*looking at a film all night*”, “*read something*”, “*making a phone call*” or “*peeling the potatoes*”. Other participants (n = 4) protected their legs against hits. Robert described, “*... I’ve learned to put my left leg right under the chair and you know guard it with my right leg*”. Using cold water or washing their leg with soap was another strategy.

3.2.2. Making recommendations to their care network

Living for days, months or years with chronic wound-associated pain made all participants experts even though they had to learn to live with it. For example, Emma said: “*You learn over the years just that pain is part of living ... You just put up with it; it’s like living with arthritis*.” Some participants indicated providing recommendations to their care network about research or dressings on managing wound-associated pain. Olivia suggested focusing research on pain relieving dressings rather than drugs. Raising awareness about chronic wound-associated pain was another recommendation. Some participants highlighted the importance that if a wound patient mentions having pain to immediately refer them to a pain manager. Noah said: “*... If you have chronic conditions you*

should automatically be referred to a pain manager ...”.

Some of the interviewees recommended that the most important strategy to manage chronic wound-associated pain was having a positive personality and a strong character as Isabella said, “I’m a sort of positive, I’d took at the bright side of it, there’s people worse off than I am”.

4. Discussion

This qualitative study explored the experiences of individuals living with wound-associated pain. The strength of this study is the sample representing a range of ages, gender balance as well as wound-duration. Two themes were identified reflecting the characterization of pain and how wound related pain affected participants’ daily life and how participants got support to manage their chronic wound-associated pain especially during dressing-changes.

The subthemes are interdependent and demonstrate the journey the participants followed. Participants for example highlighted the impact their wound-associated pain had on their life and with time how their strategies evolved until they could make some recommendations. Journeys of individuals with chronic wounds is described in venous leg ulcer [39,40] or diabetic foot ulcer [41] literature where individuals similar to our study participants described how proactive symptom management helped to improve their quality of life.

The level of pain in our study was described as high and was related back to how the dressing change was conducted. Evidence describes that dressing changes of chronic wounds cause moderate to severe pain [42]. This is due to chronic wounds having higher levels of inflammatory cytokines as they have a prolonged state of inflammation [9,43]. Additionally, the etiology can be a contributing factor, as for example, venous, mixed, and arterial leg ulcers are more frequently associated with pain at dressing changes than other types of wounds [9]. In our study, twelve out of thirteen participants had a wound either on their leg or their ankle. Thus, understanding the wider context of living with a chronic wound is crucial to make sense of how individuals experience and manage pain.

One of the strategies was accepting their wound-associated pain. These descriptions are in alignment with those of Upton et al. [44] where participants were pursuing adaptive strategies such as seeking professional help, which they recognized as being helpful. Having a trustworthy relationship with health care professionals was also important for our participants. Health care professionals changed the wound dressings, had knowledge about new technologies, and prescribed pain killers and antibiotics or applied non-medical strategies such as applying creams. Another strategy was being ‘positive’ and ‘learning to cope’ or ‘learning to accept’. This highlights the importance of building or fostering resilience and positive adaptation which are important aspects of living with a wound and subsequent patient pain management which is central to healthcare delivery [45]. The patients have to be commended on their approach but surely it reflects a failing on our part that we do not have in place effective pain assessment and pain management strategies that are available to all. For our part, we need to be cognizant of the high prevalence of procedure related and dressing related pain and factor into our planning an assessment and prevention plan.

Antibiotics were helpful for minimizing the participants’ wound-associated pain. This is not surprising as chronic wounds have a high risk for repeated infection due to wound exposure over weeks and months and it is well documented the high level of antibiotic use among this population [46,47]. A local infection causes a delay in the wound healing process in which there is presence and proliferation of microorganisms that evoke a host response [48]. Such microorganisms further stimulate an inflammatory response causing pain [49]. This pain was impacting their activities of daily living such as sleep. Sleep disturbance caused by pain may impair the key process that contributes to the development and maintenance of chronic pain [50] and may have an impact on the wound healing process [51]. It is therefore suggested that

an appropriate timing, duration, and quality of sleep are important to aid proper skin closure.

Participants in this study made recommendations such as being immediately referred to a pain specialist. Timely referral to a specialist is important as there are positive effects on healing rates as well as on the quality of life of wound patients [52]. Additionally, our participants recommended that research should focus on pain relieving dressings. Evidence confirms that smart dressings are needed to intervene in dysfunctional healing process [53]. Such dressings could have profound effects on therapeutic outcomes.

This study has limitations which we acknowledge. No data on pain-treatment was collected so we cannot know if the pain experienced was influenced by the use of prescribed medication. Only individuals who spoke English were included as we had no resources for interpreters. Our study was conducted in Ireland where individuals are entitled to free public health care and as such we do not know if the access to health care has influenced their responses. A strength of the study is the inclusion of a range of participants with various wound etiologies. Additionally, the study was informed by our public patient panel, thus contributing to public patient involvement in research.

5. Conclusion

This study demonstrates that wound-associated pain has an impact on the individual’s quality of life and activities of daily living. Patients depend on their health care professionals and family support network to cope with pain but worryingly, they report a level of acceptance that having pain is part of their condition and something to be endured rather than relieved. Coping with pain is exhausting and contributes to poorer quality of life, sleep and work practices. Health care professionals should be cognizant of the potential for procedure related pain associated with dressing changes. Patients recommended early referral to a specialist when they had pain and the need for research to develop dressings, not drugs to manage their pain.

Reviewers’ names

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Key messages

- With this research, individuals describe wound pain, strategies they use to manage pain, and the perceived effectiveness of such strategies.
- The aim of this study was to understand in-depth the experiences of how individuals with chronic wounds describe wound pain, identify their strategies to manage such pain, and the perceived effectiveness of these strategies.
- To cope with pain patients depended on health care professionals and family support networks
- Individuals accept that pain is a part of their condition and something to be endured

Declaration of competing interest

We declare no conflict of interest.

Acknowledgement and conflict of interest

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