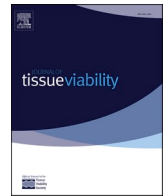




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Resigning oneself to a life of wound-related odour – A thematic analysis of patient experiences

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ABSTRACT

Aims: To determine how patients with chronic wounds describe wound odour, identify what strategies they use to manage it and how effective these are.

Materials and methods: Using a qualitative descriptive approach, semi-structured interviews were conducted between July and August 2021 with seven patients living with an odorous chronic wound at home. Data were analysed using Braun and Clarke's thematic analysis framework.

Results: The results were organised into two main themes: 1) becoming resigned to living with wound-related odour 2) strategies used to manage wound-related odour. Participants were sad, embarrassed and felt isolated but became resigned to living with this odour and accepting of it as a consequence of having a wound. Frequent dressing changes, household cleaning along with the use of sprays were the most frequently used tactics to manage odour none of which were deemed to be very effective.

Conclusion: This study highlights the problem of odour management in clinical practice and how individuals develop strategies to overcome odour. Sadly, patients were resigned to living with wound odour and were accepting of it as part of daily life. This highlights the importance for healthcare professionals to recognise, assess for and ensure a better understanding of how people experience wound odour, the impact it can have on them personally. Frequent dressing changes can help manage wound odour from the patient's perspective.

1. Introduction

Chronic wounds are a burden for patients, and their families and affect approximately 2.21 per 1000 population, with an age associated increase in prevalence [1]. Their clinical manifestations include pain, bleeding, exudate and odour [2]. Wound-related odour is cited as one of the most unpleasant and distressing symptoms associated with these wounds by patients, carers, and clinicians [3]. These odours result in part from putrefying tissue and metabolic by-products of organisms that have colonized the wound [4,5]. Although wound-related odour is not always present, when detected, it can have a profound impact on patients and those around them [3]. Malodours can serve as a constant reminder of the wound and its consequences. Odour can permeate

clothing, living spaces, and can cause embarrassment, anxiety, social isolation, and decreased appetite for the individual [6]. However, there are limited treatment options available to manage wound odour and there is an absence of standardised outcomes and consistent methods of measurement of wound odour within the literature [7]. It is important to understand how patients experience wound odour, and the effectiveness of management strategies used by them in order to deliver person-centred care approaches [7]. To achieve this, a qualitative study was conducted with patients who experience chronic wound odour. The aim was to determine how patients with chronic wounds describe odour, identify strategies they use to manage it and how effective these are. The results will inform a larger research project to develop new interventions for odour management for patients and their carers.

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2. Materials and Methods

2.1. Design

A descriptive qualitative design was employed, enabling rich descriptions of experiences [8], which can potentially inform initiatives that could lead to improved QoL and inform intervention development [9]. To ensure that the interview questions were appropriate for individual patients, the patient panel of our research group reviewed the interview guide and provided feedback.

2.2. Sample and setting

Purposive sampling was used to recruit patients with malodorous wounds via local radio interviews, social media, general practitioner, primary-care settings, and wound-care clinics (GG). Individuals older than 18 years with chronic wounds/history of chronic wounds were invited to participate. We excluded individuals with acute and surgical wounds or burns as the odour origin was likely to be different.

2.3. Data collection

Three researchers (LM, DS, PJC) conducted seven semi-structured telephone interviews between July and August 2021, with participants not known to them. All three researchers (two females, one male) were university lecturers with PhDs. An interview guide (Appendix A) was developed (GG, LM, DS, SP, PJC, CMI) with our patient panel and pilot tested for comprehension of questions before the first interview. Interviews were audio-recorded and transcribed verbatim. No repeat interviews were conducted. The principle of data adequacy [10] was considered, and the richness of the data collected was deemed appropriate to draw inferences from this group of participants.

2.4. Ethical considerations

Ethical approval was obtained from the ethics committee of “[redacted] X” (Ref: C. A. 2595 (B)). Verbal recorded consent was obtained prior to interviews. Confidentiality and privacy of participants was ensured by deleting digital audio recordings following transcription, with no identifiable information in transcripts. Fictional names were used to protect participant anonymity.

2.5. Data analysis

Data was analysed using Braun and Clarke’s [11] six-step thematic analysis framework.

This involved familiarisation and reading of transcripts, initial coding and generation of coding tree, searching, and reviewing themes, defining and naming themes to reflect data, and reporting of themes. During this process, three researchers (LM, DS, SP) worked independently and reached consensus together on the identified themes.

2.6. Rigour and trustworthiness

Rigor was ensured by following the COREQ EQUATOR guidelines (see A.2) [12], and by applying the trustworthiness criteria for qualitative research [13]. To reach dependability, we documented the entire process. To enhance credibility, the analysis was triangulated by three researchers working independently (LM, DS, SP). Confirmability of the results was guaranteed by including direct participant quotes to support the interpretation of results. The entire work process was overseen by another researcher (GG), not directly involved in the analysis of results.

3. Results

We identified two main themes: 1) becoming resigned to living with

wound-related odour 2) strategies used to manage wound-related odour. A total of seven participants (mean age 67.7 years, range 44–83 years) were included. Most (n = 5) were women. The most common reported wound location was the lower leg (n = 3) and the ankle (n = 3). The mean time participants had lived with chronic wounds was 18 years, (range 3–57 years). Socio-demographic characteristics are listed in Table 1.

3.1. Resigning oneself to having wound-related odour

This theme captures how participants became resigned to having wound-related odour. Even though they tried to apply the best available odour containing measures, wound-related odour was still present. They describe their own personal meaning of wound-related odour, and how it affected their lives and others. This theme is subdivided into “wound odour self-perception” and “feeling embarrassed because others can smell their wound”, and “personal meaning of perceived odour”.

3.1.1. Wound odour self-perception

Wound odour was perceived differently by each participant. Five participants experienced wound odour as ‘terrible’ and ‘unpredictable coming any time’. Two participants describe the stressful situation of living with a malodorous wound as being foul from inside because this odour is ‘murdering the nose’ even though they try to manage it with all available containment measures. Other used terms such as ‘unusual,’ ‘so bad,’ ‘terrible,’ ‘very smelly,’ ‘clawing,’ ‘sickly disgusting smell.’ Others compared their wound odour to ‘rotten meat,’ ‘rotten flesh,’ ‘feeling nauseous,’ ‘urine,’ ‘sourish’ or ‘old cheesy smell’ ‘old camembert’ or ‘puss.’

There was a variation in the overall perceived severity of odour amongst participants. Six participants described the severity of the wound odour using a rating scale of 0–10. Mary reported: “If it really was ripe for a week or longer ... they stink the worst, so they are a 10.” Others rated their wound-related odour with 2 or 3. Some participants (Angela, Grace and Sarah) experienced more severe odour at night-time, when dressings were due for changing or a wound infection was present. Participants mentioned that they did not smell the wound immediately because they got used to the smell. Martin reported: “I wouldn’t pick up

Table 1
Summary of participant characteristics (n = 7).

Participant Name †	Age	Occupation	Wound Type	Wound Duration in Years	Wound Location
Jane	72	Retired	2 Ulcers (aetiology unknown)	15 years	Ankle
Sarah	69	Retired	2 Ulcers Varicose Veins	3 years	Leg
Angela	65	Homemaker	4 Ulcers (aetiology unknown)	10 years	Ankle
Grace	67	Homemaker	2 Ulcers (one on each leg) (aetiology unknown)	7 years	Leg (1 on each leg)
Darren	83	Retired	4 small chronic wounds (aetiology unknown)	4 years	Leg (3 on right leg and 1 on left leg)
Martin	74	Employed	2 Ulcers (aetiology unknown)	57 years	Ankle (1 on right ankle and 1 on left ankle)
Mary	44	Unemployed	2 chronic wounds due to Hidradenitis Suppurativa	30 years (neck) 4 years (thigh)	Neck and Thigh

Name † = fictional names were used for participants to protect their anonymity.

on the odour as quick as somebody that wasn't used to that type of thing". He also felt other people could smell it before him: "... you don't always smell it yourself, it's other people." All participants realised somehow that their wound was smelling whether they realised it themselves or perceived others to smell it. All participants mentioned that they were becoming resigned to a reality of having wound-related odour because all applied measures were not helpful.

3.1.2. Feeling embarrassed because others can smell their wound

Feeling embarrassed that others can smell their wound-related odour was mentioned by all participants. Grace explained that if she could smell it, she assumed others could also e.g., when driving with family members in a car or going to mass. She said, "When I can smell them, surely to God the one behind me and beside me and in front of me can smell them as well". Other participants reported that they sometimes experienced that people around them wonder where the odour comes from. Some family members even asked the individual to change the dressing. Some accepted the odour and felt indifferent as the wound dressings were not containing wound odour. Not only was the wound-related odour restricting their social life but also the containment measures because of the COVID-19 pandemic. Many activities have moved to digital platforms. Participants perceived that having contact with family and friends using a digital platform ensured that others cannot pick up their odour. Mary highlighted: "before Covid I'd say, I am facilitating this group and would try not to sit too close to people ... it's all at home at the moment with zoom ... thank God, nobody can smell you on zoom".

3.1.3. Personal meaning of perceived odour

Personal meaning of perceived odour captures what it is like for the patient living with odour from a chronic wound. Some participants mentioned that wound odour made them sad. Sarah said 'I would get sad at times and I would go to the bathroom and cry, between putting up with the smell and everything ... but then I'd get over it, and I'd give out to myself ... And say you're not in the hospital, come on you're alright and I'd get on with had to be done.' In addition, wound-related odour limited their everyday tasks by preventing them from going about their daily work and life and often relied on their loved ones instead. Angela reported "I have loads of work that I cannot do with the odour ... going out meeting people and going out shopping and everything really." Grace and Martin expressed concerns about other people's judgement about the odour. For example, Martin described how it limited his activities, "I wouldn't like to be getting into places where people would be, they'd find the smell and then they're thinking well, he could have washed ..."

There were reflections on the perceived impact of odour when invited to attend family events or overnight stays in a relative's house. Sarah described this as "... my son was to get married ... and due to Covid was cancelled ... I was so thankful because I didn't know how I was going to cope with the leg being so bad". Other reflections of the perceived impact that odour had on participants was not being able to wear certain clothes. Grace described "You can never wear a dress as such. Now I know that's a minor detail but summertime you'd love to have a nice new summery dress."

Interestingly, most participants were accepting of their odour and became resigned to living with it. Martin explained that while he would prefer that he did not experience odour or could get rid of it, he became used to it over the years. "It's there and you know it's there and you just have to carry on and get on with what you're doing. You just can't stop everything because of it. You learned over the years, then got used to doing it and just keep going." Similarly, Sarah reported that "I just learned to live with it ... I just felt I didn't have a choice but just to live with it and that was that." Angela was resigned to her odour also 'well what can I do? There isn't much I can do ... just get on with it.'

3.2. Strategies to reduce wound-related odour

This theme captures the strategies patients used to reduce wound-

related odour. While most participants expressed that there were no possible solutions to contain wound-related odour, they identified and developed strategies to learn to live with their malodorous wounds. This theme is subdivided into "changing wound dressings frequency" and "alternative applied wound-related containment measures".

3.2.1. Changing wound dressings frequently

Frequent dressing change was identified by most participants as the most effective strategy to reduce wound-related odour and associated exudate. Some participants were able to self-manage their dressing changes so they could change them as needed. Grace said: "... There was a time when I was only being done on Monday and Thursday and boy was the smell bad ... At home, it's actually not a real problem for me because I am changing them myself. But up to that point it was terrible."

Three out of seven participants (Sarah, Angela and Darren) relied on healthcare professionals to change their dressings. This impacted the frequency of the changes and their activities of daily living. Sarah said 'as far as coping was concerned, all I could do was wait for the nurse to come and change the dressings.' This was especially significant due to the impact of COVID-19, when dressing changes were performed only once per week or every fortnight. Angela mentioned "... if they were changed only once a week, that's when they would be worse ... But if they were changed twice a week it wouldn't be as bad ..." Martin was happy with his twice weekly dressing change by the nurse.

3.2.2. Alternative applied wound-related containment measures

Participants frequently changed their clothes, bedsheets or cleaned the floor as a strategy to manage odour. Sarah explained "There wasn't anything else I could do except keep changing the socks."

Another strategy to reduce odour was hiding or minimising the odour by adding other scents, such as, antiperspirant spray, burning candles or incenses. Martin stated: "... just deodorant to camouflage the thing ... I'd probably do it once a day to try to keep it at bay ..." Similarly, Grace said: "Oh plenty of spray ... burning incense sticks is another." However, some participants were concerned about using topical sprays for odour management due to the potential skin irritation. Mary explained: "I can only use them on clothes ... I don't put them on the skin directly because there's problems then." However, Darren used a cream around the wound to reduce the odour.

Some participants made some suggestions that would make it easier to live with wound odour. Mary said "... if there was medical solutions that would stop it smelling, that would be great for somebody inventing something that stops this smelly smell." Similarly, Grace suggested "A dressing that has a nice scent on the outside but they wouldn't scent on the inside ..." Angela suggested 'maybe look into some kind of plastic bandage for putting over it' but acknowledged if you take the air out of it you may cause more problems.

4. Discussion

This qualitative study illuminated how people with chronic wounds were becoming resigned to having wound-related odour even though they tried different measures for odour-containment. Participants descriptions of wound odour was quite profound and that of repulsion and associated with terms such as 'decay', 'rotting' and 'stinking', which is similar to other works exploring the impact of odour from chronic venous leg ulcers [14–16]. As evidenced in our study, this can cause sadness, embarrassment, impact on an individual's mood/feelings, how they think other people view them and their daily activities. This study provides new insights into the patient experience of wound odour whereby sadly, patients were resigned to living with it and accepting of wound related odour despite developing their strategies to cope and live with it.

Interestingly, we found that people initially did not necessarily want to talk about their odour and negatively perceived what others thought of it, which they responded to by avoiding certain situations and

adapting their lifestyle by learning to live with it. Some participants found that COVID-19 helped with this as due to restrictive government measures, they were not seeing as many people and ‘people can’t smell you on zoom’. However, while social isolation is often associated with wound odour, there is limited evidence on perceived odour stigma and other people’s perceptions of malodorous wounds. Internalisation of stigma may subsequently lead to further feelings of distress, embarrassment, prevent people from seeking help, and adhering to treatment recommendations [17].

However, to understand the psychological impact of having a malodorous wound that brings forward such feelings was beyond the scope of this study, but insights were provided through the use of words such as ‘sad’, ‘embarrassed’, ‘learning to live with it’. Nonetheless, we must acknowledge it and include wound odour as part of continuous wound and patient assessment to address psychosocial aspects of care for individuals. Therein lies a difficulty, as validated, reliable, and consistently used methods to assess wound odour are lacking [7]. An integrative review of odour assessment scales for use in neoplastic wounds identified nine scales of which only one was validated and all of which evaluated odour intensity [18]. As a research community and clinicians we need to move forward to gain consensus on what to measure and how to measure it.

Similar to other studies frequent dressing changes were cited by participants as one of the most effective strategies to manage wound odour in addition to other practical solutions [14]. This raises implications for resource planning (e.g., staffing and clinic capacity), dressing selection and patient/carer engagement in wound management practice. Currently many dressings are designed to minimise the frequency of dressing change, a good example being compression therapy, thus necessitating once weekly clinics or home visits. If more frequent changes are required due to odour, this has staffing and clinic capacity implications. But, leaving individuals with the experience of malodour for days while awaiting a dressing change is distressing, increases the persons’ isolation and in essence prevents them from engaging in activities due to odour [14,19]. This is evidenced in the findings from our study and how some participants were not able to attend to their daily duties or avoided public places due to the odour from their wound. That said, services are often under staffing pressures and cannot meet these needs. Therefore, there is a critical need to address this in two ways. One, to support patients and/or their carers or families where possible, to change dressings and actively participate in wound management practice and two, to appeal to industry to design dressings or devices that can manage wound odour and thus release people from such contracted lives. In today’s era, it is not acceptable that patients should be resigned to living with wound related odour and we as healthcare professionals have a role to play in improving the patient experience.

5. Strengths and limitations

A strength of this study was the involvement of our patient panel in the co-design of the study, thus ensuring that questions of relevance and importance were included. The small sample size may be a limitation, however we did reach data adequacy from the seven interviews. It is also notable that our participants have experienced chronic wounds for a mean of 18 years, making them knowledgeable experts in the topic. Interviews were conducted via telephone due to COVID-19 restrictions which prevented the interviewer from observing non-verbal expressions that may have permitted more probing. This was offset by using experienced interviewers.

6. Conclusions

Understanding what it is like to live with a malodorous wound and how it is described, along with the identified strategies used by individuals to manage wound odour is central to the development of future tools and interventions to manage this symptom. The fact that all

our participants were becoming resigned to a symptom they described as ‘rotting’ and embarrassing is truly a call to action for clinicians, researchers and industry to develop improved management options.

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Author contributions

All authors meet the criteria for authorship as outlined below. All entitled to authorship are listed as authors. No other authors were involved with this paper.

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; GG, LM, DS, SP, PJC, CMI.

Involved in drafting the manuscript or revising it critically for important intellectual content; GG, LM, DS, SP, PJC, CMI.

Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; GG, LM, DS, SP, PJC, CMI.

Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. GG, LM, DS, SP, PJC, CMI.

Declaration of competing interest

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There is no COI for all other authors.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jtv.2023.07.004>.

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