

Patient and staff experience of supported self-management information and education for lower limb wound care during a pandemic

KEY WORDS

- ▶ COVID-19 pandemic
- ▶ Lower limb wound
- ▶ Shared care
- ▶ Wounds

Background: The drive for patients to be actively involved in their own healthcare received significant attention during the COVID-19 pandemic. For patients living with wounds, shared care usually encompasses aspects of care planning, and wound care tasks, but the suddenness of the pandemic meant many patients were unsure how to do this sufficiently. **Objectives:** The aim of this project was to explore experiences of shared wound care during a pandemic from a patient and healthcare professional perspective. **Methods:** Semi-structured qualitative interviews were undertaken with 25 patients living with wounds and five informal carers. A healthcare professional focus group (n=5) explored experiences of providing shared care information to patients. Thematic analysis was used to analyse the data. **Results:** The patient and carer interviews revealed five main themes (explanation of wound and wound type; access to healthcare services and the impact of the COVID-19 pandemic; wound education; patient and carer involvement in shared care tasks; the type of wound education that would be most helpful) and eight subthemes. The healthcare professional focus group revealed three main themes (patients who could be involved in shared care; trust education and standardising guidance; supporting people to share care) and five subthemes. **Conclusions:** This study has highlighted the importance of targeted education for patients living with wounds and their informal carers. Standardising education and guidance for healthcare professional is important to build confidence. Early patient engagement in shared care and personalised care plans are key to maximise acceptance.

Shared care relates to the active involvement of patients (and other members in the patients' social network) in their own healthcare, under the guidance of a healthcare professional (Wounds International, 2016). It typically incorporates aspects of treatment decision making, care planning, and undertaking condition-specific tasks and forms part of the constitution of the NHS long term plan (NHS England, 2019). Shared care is often favoured over self-care with the latter necessitating substantial involvement and responsibility from the patient and informal caregivers, such as family members and friends (Zulec et al, 2019). As discussed by Blackburn, Ousey and Parfitt (2021) differences

in the language used to describe shared care and self-care means that terms are used inconsistently, inducing confusion in expectations and boundaries of each role. Shared care has been shown to have positive impacts on clinical outcomes, improved use of resources, and more appropriate care (Hiskett, 2020) and in wound care, it is particularly beneficial for patient wellbeing and quality of life (Kapp and Santamaria, 2017; 2020).

Shared care during the pandemic

The COVID-19 pandemic changed healthcare delivery and resulted in an increase in virtual GP and hospital consultations (Brown, 2020). Existing

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pressures on the healthcare workforce and its limited resources (Gray et al, 2019) has also increased the urgency to engage more patients in their own health (Zulec et al, 2019). However, there is little evidence on how patients and carers can be supported through this transition. In a narrative review exploring the literature on shared care of lower limb wounds, Blackburn et al (2020) found limited evidence on how people with lower limb wounds can be supported to share their care. Furthermore, only one of the seven studies included in the review explored patient experience during the COVID-19 pandemic.

Guidance for shared wound care

General advice for shared wound care focuses on patients undertaking simple tasks on a regular basis such as wound cleansing, inspecting their wound for possible infection, and applying and removing wound dressings (Kapp and Santamaria, 2017; Zulec et al, 2019). Taking on these duties is associated with patients feeling empowered about their general wellbeing and wound, as the increased responsibility enables flexibility and control over one's health. The added support of a healthcare professional means patients are less likely to feel fearful about their wound deteriorating (Kapp and Santamaria, 2020) and research internationally shows that patients regard the healthcare professional as being central to enabling them to share the care of their wound (Kapp et al, 2010). Importantly, consistent and ongoing input from healthcare professionals provides support and reassurance, ensuring people maintain involvement throughout their patient journey (Moore and Coggins, 2021).

Advice for how clinicians should approach shared care has received more attention during the pandemic. The National Wound Care Strategy Programme (2020) produced advice on how to support the transition to patients being more actively involved in their treatment decisions. Moore et al (2021) developed a tool for healthcare professionals to guide discussions with patients and informal carers about their preparedness to participate in shared wound care. Designed to be used in conjunction with other clinical decision tools (Moore et al, 2019), the shared wound care discussion guide explores knowledge and understanding, willingness to engage in shared wound care, the patients' support system and

the patient-healthcare professional therapeutic relationship, which can influence the extent that patients and their informal carers are likely to be involved in shared care.

Despite these recent developments, it is still unclear how effective information provided to patients about shared wound care, and how it will impact their experiences of care. Further research is required to explore patient experiences of education offered to them to support shared care, how this education is best delivered and an insight into healthcare professionals' experiences of educating and assisting in shared care activities.

Aims

The overall aim of this study was to explore patient experience of shared care for the management of lower limb wounds during a pandemic and to use this information to understand how healthcare professionals can provide better information to patients to enhance their experiences of care.

METHODS

This was a qualitative study involving patient semi-structured interviews and a healthcare professional focus group. Semi-structured qualitative interviews with patients and their informal carers were undertaken to understand their experiences of engaging in shared care during the pandemic. A focus group with healthcare professionals working in wound care, and with experience of shared care during the COVID-19 pandemic, was undertaken to understand their experiences of how shared care education could be best provided to patients.

Participants and recruitment

We recruited patients with lower limb wounds, and informal carers, who were involved in shared care during the COVID-19 pandemic, from different healthcare settings within England. Healthcare professionals that participated were working in wound care in the UK, with experience of shared care during the COVID-19 pandemic. Participants were recruited through a purposeful sampling technique through social media platforms. All participants were provided with an information sheet and consent form and informed consent was obtained by the researcher before the interview or focus group taking place. All participants were

offered a £25 Amazon voucher as a thank you for their time.

Ethical approval

Ethical approval was provided by HRA (IRAS Project ID: 290179) and The University of Huddersfield's School of Human and Health Research Ethics and Integrity Committee (SREIC).

Data recording and analysis

Patient and carer, interviews were conducted via telephone and recorded on an encrypted device. A topic guide was developed using evidence from the literature and explored patient preparedness for shared care/self-managing, attitudes and beliefs towards shared care, support, impact on quality of life, improvements to the shared care experience, and benefits/facilitators. Healthcare professional focus groups, took place via Microsoft Teams and was audio and video recorded. A topic guide, was developed using evidence from the literature and data from the patient interviews.

Interview recordings were transcribed by a trained transcriber from The University of Huddersfield and anonymised. These recordings were stored in a restricted folder on the University shared drive and only accessed by members of the research team. Transcripts were entered into NVIVO 12 qualitative data analysis software for analysis.

RESULTS

Patients and carers

A total of 29 participants (24 patients, 5 carers) with a range of wound types were interviewed. Interviews lasted between 20–80 minutes and were analysed using thematic analysis to identify common themes and experiences across the data set. This revealed five main themes and eight sub-themes.

Theme 1: Explanation of wound and wound type

Participants had surgical, traumatic, and chronic wounds; those with surgical wounds tended to have better information about risk of infection and contact details for further support. Participants with traumatic wounds often perceived them as insignificant accidental injuries that would heal quickly and fail to recognise the potential for future complications. Wound care was received

at either a hospital, GP surgery, or walk-in centre, when these patients became concerned their wound was not healing.

'I didn't think a great deal about it at the time and I didn't realise, I don't know how I did it, but taken a bit of a chunk out the back of my ankle.'
Patient 1 with traumatic wound

Chronic wounds included leg ulcers, haematoma, lymphoedema and cellulitis. Carers were often involved in the management of these wounds and accessed services such as tissue viability, pharmacy for wound dressings, and GP surgeries following a period of self-management.

'By this time it had turned into a haematoma, a right mess, it still is, and she had to sort of cut it and then take all the blood out, what was dried she had to scrape out.' Patient 2 with chronic wound

Theme 2: Access to healthcare services and the impact of COVID-19

Patient perception of severity of wound and COVID pressures on healthcare services

The COVID-19 pandemic negatively impacted access to healthcare and delayed their decision to access services for treatment. Believing their wound was not serious enough to require specialist care, they felt they could manage their wound on their own (with the help of carers in some cases).

'I've had similar sorts of injuries in the past and I just managed to basically to sort them out myself. I didn't feel at the time, especially with the [COVID-19] pandemic, people have got enough on their plate haven't they.' Patient 3 with traumatic wound

Difficulties accessing GP/district nurse appointments contributed to them engaging in shared care activities without specific knowledge of how to do so.

'It wasn't unbearable, like I say, but I realised that eventually I thought I'm not, I'm not being able to cure this myself if you like.' Patient 1 with traumatic wound

Access to services

Difficulties accessing specialist services such as tissue viability, or problems accessing timely appointments for district nursing visits were common. A lack of face-to-face appointments meant patients relied on telephone or video consultations, where patients were asked to send pictures of their wound before an appointment was offered (which sometimes proved difficult depending on the position of their wound and their own physical health and mobility). Access to services was particularly problematic for elderly patients who relied on family members to contact services on their behalf. Carers were pivotal in these circumstances but carer burden was evident and many struggled with caring for their relative without the necessary support, knowledge and information they felt they needed, and other family and life commitments.

'So her skin became really bright red. But one wound, she'd pierced, almost like a puncture into the leg, they were just leaking like, it was like a tap, you could actually see where it was coming from, oh it was a real mess and it got to a point where I was wrapping kitchen roll round her legs, just to stop it wetting her shoes and her socks. It was horrific. So I was ringing the doctors, they weren't doing appointments and then I noticed that one of these puncture things had started to become a little bit white around it and I just thought I don't like the look of that... because you can't walk anywhere, with dripping legs. It was like her socks were wet, her slippers were drenched, the bed was drenched and we were putting like these massive pads on daily, literally, I put one on at night and by the next morning it would be drenched. It was quite difficult to get the actual things that we needed. I was constantly ringing people, we always got stuff eventually, but it was difficult and probably because of COVID that did probably have obviously an impact in her treatment.' Carer 1 of patient with chronic wound

Specialist versus generalist treatment and care

Specialist services (such as tissue viability) provided more specific and individualised care than generalist treatment with some patients feeling that

the latter failed to acknowledge the severity of their condition and dismissed some of their concerns around wound deterioration and infection.

'What surprised me was that the District Nurses didn't put me in touch with that [Tissue Viability] service, or go through to the vascular nurses, it felt so good to speak to somebody who I felt understood what I was explaining.' Carer 1 of patient with chronic wound

District nursing teams providing care

Home visits from the district nursing team, or patient clinic appointments provided opportunities to ask questions about wound healing progression and shared care tasks such as trying different wound dressings, or techniques that could help with difficult tasks such as applying bandages or compression. Accessing appointments was difficult during the pandemic and patients were 'stressed' by not knowing when a visit was scheduled, which was a common reason for engaging in shared care, or having carer involvement in wound care.

'I'd hate to be reliant on the District Nurse coming twice a week or whatever because it ruins your life a little bit doesn't it. It means that one particular day could easily be totally taken up with that, attending to the procedure, so I prefer to do it myself.' Patient 4 with chronic wound

Theme 3: Wound education

The value of wound care education was emphasised throughout the interviews to facilitate understanding of wound healing progression, manage expectations, reduce anxieties associated with misunderstanding the severity (or not) of their wound, and reduce apprehension around performing shared care tasks. The patients' experiences of wound education from healthcare services was sparse, but ensuring the wound area and dressing was kept clean and dry, as well as who to contact should their wound deteriorate (although most patients were not told how to recognise this) were the most commonly reported form of information provided to patients.

Patients with surgical wounds received the most comprehensive form of information, perhaps

indicative of the concern around risk of infection. Some patients were provided with a small number of dressings and told to change their dressings after several days. Without formal training, most participants learnt how to change dressings by watching healthcare professionals and some stated they 'could do it better' and developed their own techniques for applying and removing dressings. Most patients were unaware what their wound was and felt healthcare professionals used medical 'jargon' which they found hard to comprehend.

Knowledge of infection

There was a general awareness and concern of infection, how to mitigate risk, and who to contact if they were concerned. Although some participants were told who to contact if they suspected an infection, they were not necessarily told how to recognise one. This, and their perceived pressures on services because of the pandemic meant many were reluctant to contact services between their scheduled appointments.

'Well that's why I like to go back to (the nurse) because I don't know what I'm looking for. I don't know whether its infected. My husband will say oh yeah it's looking a bit better. But he's not a medic, he doesn't know. Sometimes it's very red round it and I think I wish I hadn't to go four week without seeing her because if I go one week and its red, she can do something about it, but if its red for four weeks, its four weeks build-up of something going wrong.' Patient 2 with chronic wound

Theme 4: Patient and carer involvement in shared care tasks

Most patients had been involved in some form of shared wound care with the most common tasks being dressing removal and application, cleaning the wound, checking for signs of infection and applying creams. Unnecessary dressing changes were evident and was primarily so the patients could 'see' their wound was healing. Undertaking some tasks were difficult, for example, dressing changes, applying compression, which required help from a carer or finding alternative strategies.

'I was keeping it clean, I used Savlon and we had some wound healing cream, it was like an antiseptic, but it had something else in it and I just kept it like dressed with these plasters and I just kept it covered with like a tubi-grip over the top.' Patient 3 with traumatic wound

The importance of managing patient expectations regarding speed of wound healing was crucial to reinforce continued involvement in shared care and not to be concerned if the wound did not heal quickly.

'He [the doctor] just said get this cream and put it on four times a day, which I started doing and then I thought well is it not getting better, and then I did it a couple of times a day, in the morning or at bedtime and then I just kind of fizzled off with it. I just stopped using it and forgetting to use it. I was expecting a miracle really, I thought within the week it'll have gone and obviously not, it is disheartening.' Patient 5 with traumatic wound

Carer involvement in shared care

Carers played an important role in shared care, particularly for elderly patients, or for those whose wound was in a hard to reach place. There was a perceived expectation of carer involvement in shared care, but individual circumstances meant that this was not always feasible.

'It wasn't fair on her because she was still working and I wanted it doing on a morning after I'd had a shower... it soon became apparent that it was not the best way of doing things at all.' Patient 4 with traumatic wound

Carers also felt helplessness in the absence of knowledge or training as they tried their best to care for their relatives. One carer stated;

'We're not stupid people, but then we're not medically trained. So a little bit of knowledge is a dangerous thing, because I would have been bathing it in TCP and all sorts.' Carer 2 of patient with chronic wound

Access to wound dressings

There were both difficulties accessing wound dressings, but also instances of having an abundance of dressings, the latter making patients believe they had to change their dressing more often than necessary.

'I had plenty of these dressings and even when I went to see the dressing nurse, she gave me even more. So I had loads of these dressings' Patient 6 with traumatic wound

Those who found it difficult to access wound dressings from pharmacy services or GPs purchased their own dressings or used substitutes such as puppy training pads. The financial implications of buying their own wound dressings was a concern.

'So it now rests on me totally to find my own dressings. When I go to an appointment I'll probably sometimes ask if I can have some of theirs, but not very often, because I know that they're also stretched with their dressings.' Patient 4 with chronic wound

Theme 5: The type of wound education that would be most helpful

The format of education was discussed; leaflets (with pictures of wounds/normal wound healing/infection), websites providing general and specific information about wound care, personalised emails, or virtual workshops (for carers) were felt to be most helpful form of education. Regular contact (through phone calls for example) were favoured for those doing long-term shared care. Some felt leaflets would be easily lost or discarded, whereas online resources would be useful for participants to refer to. One participant said:

'I mean even if you had a letter or something.. or a leaflet, I know it's a lot to take in, so take this leaflet away and then you can have a right good read up on it and get this cream and this should help sort it out kind of thing.' Patient 7 with traumatic wound

Using simplified language was essential to aid understanding and descriptions of the

participant's specific wound, rather than generic information, was thought to be most valuable. Information on functions of wound dressings (for example, how they promote wound healing), and how often they should be changed (including the importance of not undertaking unnecessary dressing changes), signs and symptoms of infection, and descriptions of the normal wound healing process were fundamental to supporting shared care.

'It's like well what do you mean by hot, and so really it would have been nice to have some information to say it needs to be redressed then and this is what you use and this is how you use it and this is how you put it on and you know, would have been helpful, rather than me guessing and trying my best not to introduce infection into the wound.' Patient 8 with traumatic wound

Healthcare professional focus group

We recruited five participants from England (4) and Scotland (1) who took part in the focus group, which lasted 90 minutes. Participants had varying roles and responsibilities (Senior District Nurse, Community Nurses, Lead Nurse for Tissue Viability, Nurse working in integrated wound care). The data was analysed using thematic analysis revealing three main themes and five sub-themes.

Theme 1: The type of patient who could be involved in shared care.

Enabling patients to engage in shared care identifying the 'type' of patient who could be actively involved in their own care was important to ensure patients were not inadvertently negatively impacting or worsening their condition. Even with education, some healthcare professionals felt patients could struggle to cope with the demands of shared wound care.

'We [healthcare professionals] have to choose our patients wisely because for some of them, it was detrimental to their care, even with education and when they seemed to have capacity and insight.' Participant 1, Community Nurse

The COVID-19 pandemic had prompted a dynamic shift in expectations of patient involvement and where previously patients might have been advised to seek professional treatment, they were now increasingly expected to care for themselves. This sudden change of dynamics meant managing expectations at the beginning of the patient journey was essential.

'It does start at the beginning of the journey for the patient, so you know, 'you're having this procedure done, the expectation in the hospital is when you have had your procedure you will be caring for your wound' The education starts at the very beginning of their journey, rather than us picking up the pieces.' Participant 2, Senior District Nurse

'My thought is not only do we need to give patients permission to self-care, but we need to give the nurses permission to allow them to self-care because I think during the pandemic they were given permission, they were told that it was okay to let the patient care for themselves, and the nurses were like well I'm not getting the blame for this then' Participant 3, Lead Nurse for Tissue Viability

Carers involvement in shared care

The pandemic and associated social isolation saw patients being more reliant on family members and carers to support them with interventions that would previously have required a district nurse. Relaxing of social isolation rules meant many family members who might previously have provided care returned to normal daily activities (such as work and other commitments) resulting in an increasing dependence on health care services to provide care and treatment.

'I think self-care for us miraculously erupted during the pandemic and all of a sudden family, friends, relatives, everybody came out the cupboard to help relatives with their wounds or whatever they needed, but weren't there when we asked them prior to the pandemic. Since the pandemic, that's all gone back again and now they can't possibly help provide care or help.' Participant 2, Senior District Nurse

Theme 2: trust education and standardising guidance

Shared care guidance and risk aversion. Healthcare professionals were confused about what they were 'allowed' to ask patients to do. Interventions that were previously viewed as being nurse-specific were now the norm for patients and carers to undertake. The lack of guidance and standardisation surrounding shared care caused concerns about litigation and blame.

'I think from a nursing point of view it's that 'oh well I daren't, what happens if something goes wrong, what happens if the wound becomes infected and I'm not seeing it?' It's that control that the nurse needs over the wound so they don't get blamed or they're available to see what could go wrong and you know and be able to pick up the pieces and I think during Covid, we gave them that permission to do it.' Participant 2, Senior District Nurse

Education at both a Trust and national level and national guidance that standardised shared wound care tasks was important to give nurses permission to support shared care without fear of being blamed for unanticipated consequences.

'For me it's a lack of guidance as to what we are allowed to allow patients to do... I just think there needs to be more educational guidance for the staff to understand at what level they can allow the patients to take control.' Participant 4, Community Nurse

Staff confidence and risk aversion

Building staff confidence in enabling shared care was a point for discussion. Staff were cautious about how to involve patients in their care and without specific guidance, risk aversion was evident.

'Suddenly we were just getting everybody to self-care but there was no educational sessions for what we're allowed to delegate, to what level... if we're not allowed to delegate it to the HCAs [healthcare assistants], how can we suddenly be allowed to delegate it to the patients and when it's been drilled into you all the time that

even the HCAs can't do it, it's a concern for us. We don't know if it's something we can delegate and delegate it safely.' Participant 2, Senior District Nurse

Building staff confidence was central to maximising the impact of shared care and working with the patient to enable them to feel empowered to manage their own wound was one way of sustaining the impact of shared care.

Theme 3: Supporting people to share care Person centred care and managing expectations

The traditional paternalistic view of the nurse being at the centre of, and directing the treatment plan was considered outdated, whereas adopting a person-centred care approach was fundamental for patient engagement. Involving patients early in discussions about the tasks they would like to be involved in was thought to foster a sustainable model of care. Additionally, managing patient expectations about wound healing was important to avoid patients feeling discouraged from continuing with shared care. Participants highlighted the importance of assessing the patient's capability to be involved in shared care. Problem solving with patients and devising strategies for supporting task management was a central feature of the discussions.

'let them [the patients] be creative in partnership with you to develop a person-centred plan' Participant 3, Lead Nurse for Tissue Viability

DISCUSSION

Patients were generally positive about their involvement in looking after their wound, a finding that is consistent with previous research demonstrating a positive impact on health and wellbeing (Kapp and Santamaria, 2017; Zulec et al, 2019). Most patients and their informal carers in this study undertook shared care activities in the absence of any specific knowledge or education about wound care. Without this knowledge, they were unsure about when to contact healthcare services and had a tendency to believe that their wounds were insignificant. A general concern, risk of infection, suggested that people have an awareness of the potential

complications of living with a wound, but without an understanding of infection prevention and management, patients were unsure if their wound was healing (or not) in a timely manner and often delayed seeking professional treatment. Carers were actively involved in shared care activities, undertaking specific wound care tasks and other activities such as contacting services and ordering dressings. Difficulties accessing services, or obtaining wound dressings sometimes resulted in patients purchasing dressings at their own expense.

The finding that ongoing support from services was important for reinforcing shared care and reducing anxiety is in agreement with previous research about the importance of healthcare professionals continuous involvement in shared wound care throughout the patient's journey (Moore and Coggins, 2021). Many patients valued education and felt that providing leaflets and online resources with pictorial diagrams to demonstrate normal wound healing and infected wounds aid them in their shared care journey. These findings were echoed in the healthcare professionals' focus group, where there was a general concern about what tasks clinicians could 'allow' patients to undertake. The importance of standardising shared care practices so staff feel confident in delegating tasks to their patients without fear of litigation or blame was highlighted, and the sudden shift in attitudes towards patient involvement in care, attributable to the pandemic, had resulted in a view that some staff struggled with this change in practice. An important finding related to the use of terminology, where the terms shared care and self-care were used interchangeably throughout the healthcare professional focus group and perhaps reflects the need for standardisation of these terms. Building staff confidence through education about the varying levels of motivation and ability of individual patients is central to reinforcing this change in a positive way. Early patient engagement in shared care and creating personalised care plans were considered fundamental for maximising the uptake of patient involvement and ensuring patients and carers feel motivated and able to be actively involved in their care.

DECLARATION OF INTEREST

This project was funded through a research grant from Essity. The company had no input into the design, data collection or analysis.

Limitations

This was a UK based study exploring the experiences of shared wound care for the lower limb during the pandemic and it is possible that the patient and healthcare professionals' experiences in the UK healthcare system may not be generalisable to other countries. Although the sample size could be considered small, data saturation was reached and therefore was considered a sufficient number of participants to address the research question.

CONCLUSIONS

This project has important implications for clinical practice and demonstrates the importance of shared wound care education for patients, carers and healthcare professionals. It suggests that general and specific wound care education for patient shared care should focus on the wound healing process and strategies for managing patient expectations, the function of wound dressings (including application and removal) and how to recognise the signs and symptoms of infection and strategies for minimising risk. The format of education should include leaflets, websites/personalised emails and online resources with pictorial diagrams to demonstrate normal wound healing and infected wounds and should use simplified language to aid understanding through education about shared care specific tasks.

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