Exploring concepts and current evidence of shared and self-care in the management of lower limb wounds

KEY WORDS

- → Shared-care
- >> Supported self-care
- >> combined care
- ➤ Wound management
- → Hard-to-heal wounds,
- Chronic non-healing
- >> Partnership working

The SARS-Cov-2 (COVID-19) pandemic saw the introduction of safety measures such as social distancing, isolation and shielding. This has facilitated health care services transformation, particularly in tissue viability services, where a decrease in community nursing visits, limited outpatient appointments and few face-to-face GP appointments have increased the need for patients to be actively involved in their own care. Such a shift has contributed towards patients and health professionals (HCP) sharing treatment and care responsibilities to maintain the patients' health. This shift brings about its own challenges, with patients requiring a degree of knowledge and skills of wound care to be able to confidently manage their wounds. The terms self-care, shared care and supported self-management are often used to refer to patient involvement in their treatment and care but a lack of consensus around the extent of patient involvement and an absence of strategic guidelines for shared or self-management of lower limb wounds contributes towards difficulties in understanding the extent of patient involvement. This paper provides a narrative review of current literature focused on shared, self or supported self-management practices and perceptions in the management of lower limb wounds.

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Institute for Skin Integrity and Infection Prevention, School of Human and Health Sciences, University of Huddersfield pproximately 4.5% of the population in the UK are living with a lower limb wound and this is continuing to grow at an estimated 12% per year (Guest et al, 2020). Treatment and care expenditures for this patient group have been estimated at £530 million per year (Guest et al, 2015) including the costs associated with hospitalisation for inpatient treatment as well as district nursing patient visits for treatment and associated costs including wound dressings. Hard-to-heal wounds, defined as those that do not follow the normal healing trajectory with standard therapy, can be applied to both chronic and acute wounds, and may contain biofilm (Atkin et al, 2019).

Patients with chronic hard-to-heal wounds often endure not only the immediate damaging physical health effects, such as infection and immobility, but also encounter negative effects on their emotional, psychological, and social wellbeing (Kapp and Santamaria, 2017a). Patient supported self-management can have substantial

economic benefits for the NHS (Brown et al, 2014) and is often associated with living with a long-term condition such as a chronic hardto-heal wound. Typically, activities can involve participation in regular exercise, consumption of a balanced diet, and smoking cessation (Hopkins, 2020; Brown, 2020) often being supported through patient-clinician interactions demonstrating the importance of this relationship. Kapp et al. (2010) evaluated implementation of an Australian Leg Ulcer Prevention Programme with participants, which involved promoting self-care activities with the support of nurses who facilitated and monitored empowerment through completion of participant questionnaires. Significant improvements were found in participant's knowledge of ulcer development and in participants behaviours. Importantly all participants (n=155)cited nurse support as the most significant factor in their ability to engage in self-management behaviours, demonstrating the importance of an







effective therapeutic relationship between health care professionals (HCPs) and patients in the management of chronic conditions (Brown, 2020).

The sharing of wound care between patients and HCPs is becoming an area of increased focus, with improvements in patient independence, time management and social well-being cited as benefits (Kapp and Santamaria, 2017b). Limited healthcare resources, including appointment availability, can often lead to patient dissatisfaction with services, as patients become frustrated with the possibility of delayed wound healing that could be attributable to length of time between appointment and assessments (Zulec et al, 2019). Encouraging and promoting supported self-management (SSM) can be especially beneficial if, for example, patients with heavily exudating ulcers can take a more active role in their care, where multiple dressing changes are required thus reducing the need to wait for appointments. The requirement for patients to take an active role in managing their wounds has been amplified during the COVID-19 pandemic, which has resulted in more virtual consultations rather than face-to-face contact (Brown, 2020).

Defining concepts of self, shared care and supported self-management in wound care

Supported self-management refers to the ongoing management of long-term conditions where patients and clinicians work together to optimise the patient experience of living with and managing their condition on a daily basis and forms part of the NHS Long Term Plan (NHS England, 2019). Frosch (2015) and Barnes et al, (2015) demonstrated how individuals living with long-term conditions who were in charge of their own health, and if given the chance and support, would be willing to take on even complex management tasks. Coulter et al, (2014) and Hibbard and Green (2013) highlighted that there was an urgent need for clinical staff training to support individuals and including patients and carers in multidisciplinary teams would allow for tailored support directed towards the patient needs. However, Zulec et al (2019) suggest that many patients still do not feel fully involved in their treatment' decisions, which can influence adherence with care plans and dissatisfaction with care services. SSM differs from self-care in that the latter involves individuals, families, or

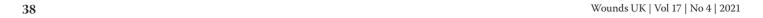
care-givers taking an active role in promoting and maintaining their own health with or without the support of HCPs (Zulec et al, 2019). Although self-management practices are becoming essential due to the increased pressures on the healthcare workforce and its limited resources (Gray et al, 2019), SSM is preferable for many patients, but self-care also has positive impacts on pain management, flexibility associated with patients.

Self-care has positive impacts on pain management, flexibility associated with patients' own treatment regime and the empowerment associated with being in control, responsibility for their own health also positively impacts patient quality of life (Kapp and Santamaria, 2020). However, the physical challenges of self-management and fear associated with amputation, and immobility suggests some patients may favour ongoing support from clinicans (Kapp and Santamaria, 2020).

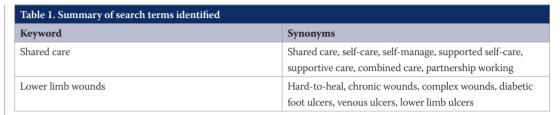
A lack of consensus exists on the definitions of self-care, supported self-care and shared care, which has led to the terms being used interchangeably within the literature. This is problematic, creating confusion for the patient and clinician as to their roles and responsibilities, which can ultimately impact upon adherence and success of the management plan. Hopkins (2020) emphasises that the term self-care can give negative connotations to patients and implies that the responsibility of wound care lies solely with them to compensate for under resourced health services. Currently, there are no definitive guidelines for shared or self-management of lower limb wounds. Selfmanagement recommendation involve wound cleansing, inspection, application and removal of wound dressings, and compression aids (Kapp and Santamaria, 2017a; Zulec et al., 2019). Formalised education and training to support supported self-management' to Formalised education and training for SSM (Kapp and Santamaria, 2017), and this is reflected in evidence demonstrating poor correlations between wound infection identification between patients and healthcare practitioners (Whitby et al, 2002; Iretiola et al, 2020).

Education focused on wound care for patients is essential to optimise patient outcomes and healing rates. The National Wound Care Strategy Programme (NWCSP) has attempted to provide









assistance to patients through publication of free to download self-care advice offering guidance to patients and HCPs surrounding supported selfmanagement to promote the transition to patients being more actively involved in their treatment decisions. The COVID-19 pandemic has seen a raft of literature produced from healthcare areas to maximise patient engagement with supported selfmanagement, yet there has been little exploration as to the effectiveness of the type of information as to whether or not patients and their carers feel equipped to manage their condition on a daily basis. There is also a lack of evidence on the effect this change will have on patient's experiences of care, their perceived ability and willingness to share the management of their lower limb wounds and clinical outcomes such as wound healing and infection rates. 'It is important therefore to develop an understanding of the patient experience of supported self-management and how to improve their overall experiences of care.

Aim

The aim of this narrative review was to provide a summary of published literature that investigates shared care and/self-care/and or supported self-management in the management of lower limb wounds, including patient's perceptions of this care.

METHODS

A narrative review was conducted to allow inclusion of research with diverse methodologies, while adhering to a systematic process to synthesise current evidence on shared care and/self-care/ and or supported self-management practices in the management of chronic wounds (Whittemore and Knafl, 2005). Studies were eligible for inclusion if the sample investigated included patients who engaged in shared-, supported- or self-care activities of a lower limb wound (*Table 1*). Both quantitative and qualitative methodologies were included. Exclusion criteria included those not written in

English, no reference to shared-, supported- or self-care activities of a lower limb wound, comment pieces and papers not identified as research.

The following databases were searched for relevant studies using the search terms and Boolean operators: AMED, Cochrane Library, CINAHL, Evidence Search, PubMed, and MEDLINE. No restrictions were made with respects to year of publication to ensure no papers were inadvertently missed, although there was recognition that some practices would have changed over the years. Each database was searched from the date to which they launched to 11th April 2021. Other key journals were targeted within the search to ensure key research not identified in the databases were not missed; Wounds UK, Journal of Wound Care, and International Wound Journal. Articles identified in the search were screened by reviewing the title and abstract for relevance. Reference lists were reviewed from the primary papers to identify any further applicable research not identified through the search.

Studies eligible for inclusion in the review were read and reviewed by the author team (KO, JB, GP) and critically appraised for their methodological quality using the appropriate Critical Appraisal Skills Programme (CASP). Key findings were recorded and summarised generating categories from the outcomes of the studies included (Braun and Clarke, 2006).

RESULTS

An initial search retrieved 153 papers. A total of 146 papers not meeting the inclusion criteria were excluded. Seven studies were considered eligible for full review and were included in the analysis; Exposito et al, 2020; Knapp and Santamaria, 2017; Kapp et al, 2018; Knapp and Santamaria, 2020; Wilde, 2018; Wilde, 2020; Zulec et al., 2019. A summary of the studies included is provided in *Table 2*.

Study characteristics

Among these, five studies were of qualitative design and two studies explored shared wound care







Study	Design	Number of participants	Main findings/conclusions
Knapp and Santamaria (2017)	Qualitative - Survey	100	Independence and ability to perform treatment at the time that suited were the most common reasons for self-management (58% and 56%, respectively).
Kapp et al. (2018)	Qualitative- interviews	25	The quality of life of patients with chronic wounds, who self-manage, is problematic. This patients continuing to report pain, decreased ability to perform physical activity, worry about wound infection, and feeling disheartened about treatment progress.
Wilde (2018)	Pilot study – Flo Simple Telehealth	28	Initial findings show a positive staff and patient experience from the shared care pathway.
Zulec et al. (2019)	Qualitative- interviews	32	Reasons for self-management were lack of healthcare resources and dissatisfaction. No educational materials were provided.
Knapp & Santamaria (2020)	Qualitative- interviews	25	Participants reported mostly positive effects on QoL as a result of self-management, including: physical, social and emotional well-being.
Exposito et al. (2020)	Qualitative- patient feedback	Not stated	Near Me video consultations and Technology Enabled Care (TEC) can be beneficial for providing support and advice to patients with foot wounds, by relieving pressures from healthcare resources and the 'burden' of attending frequent appointments for patients.
Wilde (2020)	Qualitative- interviews	12	Participants beliefs of self-management were mixed. Factors that could discourage self-management included: wound location, duration, previous infection, fear of doing harm.

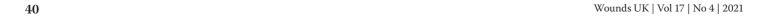
management pathways. There were three studies conducted in the UK (Exposito et al, 2020, Wilde, 2018; Wilde, 2020), one conducted in Croatia (Zulec et al, 2019) and the remaining studies (Kapp et al, 2018; 2019; 2020) were conducted in Australia.

Patients' role and responsibilities in shared care

There were two studies (Kapp and Santamaria 2017a; Zulec et al, 2019) that investigated patient self-management activities, reporting significant variation in the extent of activities undertaken by patients. The most common activities involved the removal and application of wound dressings, wound cleansing and assessing the wound for infection. Kapp and Santamaria (2017) focused on the patient experience of self-management and conducted a survey of 100 participants who self-treated their chronic wound. Almost half of the respondents (46%) conducted wound treatment daily, or more frequently with 91% of participants

regularly cleansing their wound. Most of these participants used an antimicrobial combined solution such as saline, soap-free cleanser and an antibacterial liquid, methylated spirits, peroxide, vinegar, and flushable toilet wipes (60%), rather than tap water (12%). The majority of participants were applying an antimicrobial dressing 66% (n=59) on a routine basis. The study did not report on how participants made decisions about an appropriate wound treatment, however, the average time since participants had last seen a HCP was 16.4 weeks (minimum: 0 weeks; maximum: 572 weeks; SD 68.97), suggesting that they were not receiving continued support and guidance with treatment regimens. The study also found that 94% of participants had never received formalised education or training about chronic wound self-treatment. Measuring the progress of wound healing was one of the least frequently reported activities, with only 9% of the participants recording their wound healing progress on paper.







Few participants performed activities to remove devitalised tissue (40%) and debris (37%) from the surface of the wound.

Zulec et al (2019) undertook a qualitative study interviewing 32 participants with venous leg ulcers (VLU) about their self-management activities. Specific tasks included wound cleansing, wound inspection and the application/removal of wound dressings and compression aids. The most common time to perform wound treatment was at a weekend or when the pain or itching was causing too much discomfort that the only way to seek relief was to change the dressing.

Implementation of technology to support a shared care

There were two studies that reported the implementation of a shared care approach (Wilde, 2018; Exposito et al, 2020), with both evaluating how technology can be used to maintain regular communication with participants to reinforce advice and support. Wilde (2018) reported on a text messaging system, Flo, to provide patients with key reminders about their health to support shared care. Data obtained from an earlier pilot study (Wilde, 2015) suggested the technology improved patient confidence and competence in managing their own health and was a cost-effective method of encouraging self-management. The text messaging system, supported by leaflets and videos to provide information and education about appropriate wound management was adopted by 36 patients, the majority having surgical wounds. Patients reported having enough information to feel able to manage their wounds and felt involved in decision making about their care. Reductions in hospital clinic appointments and community nursing visits for dressing changes were also evidenced with 115 dressing changes being managed by patients themselves. However, the authors state a comparator group was unavailable therefore it is difficult to assess the impact of this change and it is unclear what other types of wounds patients endured. In the study by Exposito et al (2020), video consultations were implemented using the Near ME application platform (NM) for wound management at an NHS podiatry service in Scotland. It was the only study to explore shared care for wound management during the COVID-19 pandemic.

Patients with current or at-risk of foot ulcers or in-growing toe nails with bacterial infection were offered video consultations. Approximately 68% of patients offered a video consultation accepted during the pandemic compared with 5.2% prepandemic. Fear of technology and believing virtual care would be less effective were reported as main barriers to a lack of patient uptake but the COVID-19 pandemic encouraged patients to seek support from family members, developing skills to use the NM system and becoming more active in their own care.

Patients' experience of self-management

There were three studies that reported patients' experience of self-management of their wound (Kapp and Santamaria, 2020; Wilde, 2020; Zulec et al, 2019). Of these, two studies conducted in the UK (Zulec et al. 2018; Kapp and Santamaria, 2020), found that financial pressures of wound management was a predominant factor for engaging in self-management.

A qualitative study involving semi-structured interviews with 25 participants involved in wound care self-management was reported by Kapp and Santamaria (2020). Participants described a reduction in pain and enhanced psychological wellbeing and improved quality of life as they felt more empowered and responsible for their own health. The patients ability to care for their own wound facilited wound healing and supported a positive patient experience of care.

In a qualitative study involving semi-structured interviews, Zulec et al (2019) asked 32 participants to share their experiences of self-managing their VLU. Participants described how a fear of wound deterioration, non-healing wounds, amputation, and immobility was associated with a reluctance for engagement in self-management. However, those with less complex wounds (less pain and absence of infection) were more willing to perform self-management, a factor also reported in the study by Wilde (2020). The authors concluded that regular support from a HCP could help reduce patients' fear of wound self-management.

The UK based study by Wilde (2020) involved interviews with 12 patients involved in wound self-management and reported that patients who had a wound of long duration, previous infection,







or experienced pain with their wound, were less confident and more reluctant to self-care due to increased apprehension of causing harm.,

Kapp and Santamaria (2020) Wilde, (2020) Zulec et al (2019) reported on the role of the caregiver reporting how support from a family member or carer improved the experience of wound care self-management. Self-management was described as being physically challenging due to mobility issues and if the wound was difficult for participants to visually locate (Kapp and Santamaria, 2020). Wilde (2020) reported that without the support from family and friends during tasks, including the application of dressings, self-management would be troublesome.

DISCUSSION

This narrative review found limited evidence on how patients with lower limb wounds can be best supported to become more independent. Only seven studies were identified as meeting the inclusion criteria for focusing on patients who engaged in shared or supported self-management of a lower limb wound. The findings from the included studies represented three main areas of investigation including patients' role and responsibilities; implementation of technology to support a shared care; and patients experience of self-management. Only one study explored the patient experience during the COVID-19 pandemic.

A lack of education to support patient involvement in their own care (Kapp and Santamaria (2017); Zulec et al (2019) and inconsistneices in education delivery were key factors for supporting, or not, patient involvement (Kapp and Santamaria, 2017; Wilde, 2020; Zulec et al., 2019).

Tasks such as wound cleansing, wound inspection, and the application/removal of wound dressings and compression aids were common for patients to undertake at home (Kapp and Santamaria, 2017a; Zulec et al, 2019). Limited exploration of patient decision making around wound dressing and/or cleaning solution choice means it is unclear if patients were supported in making these decisions or if decision making changed over the course of their involvement with self or shared care. Since assessing for wound infection and application of an antimicrobial

solution and dressing were identified as activities routinely conducted by patients with lower limb wounds, understanding patient decision making about self-treatment regimens is integral to supporting self-management, particularly due to the growing concerns within the literature around antimicrobial resistance (Laxminarayan et al, 2013, Lipsky et al, 2016, Wounds UK, 2020). Being overly cautious in identifying infection or abnormal wound healing means understanding patient choice is crucial to ensuring patients have the knowledge and education to make informed decisions and avoid the potential for the unnecessary application of antimicrobial dressings.

Patient motivation was identified as being considerably influenced by the involvement of a health professional. Negative staff attitudes towards patient engagement and involvement in their care were found to lead to patient disengagement and apathy, while patients more likely to perform self-management wound care when support and positive reinforcement is provided (Wilde, 2020). Frequent support from health professionals could also help reduce patients' fear of wound deterioration and encourage those who lack confidence in performing self-treatment (Wilde, 2020). Developing and maintaining a therapeutic patient-clinician relationship must be considered when developing a sustainable model of shared and self-care for wound management. The role of the carer is also important. Support from family members, friends, or carers further encouraged patients to be involved in their own wound care by increasing confidence and capability through aiding with dressing applications, wound cleansing and support with identifying the clinical signs of infection (Kapp and Santamaria, 2017a; Wilde, 2020). Although it is important to involve caregivers in shared care, caregivers have also been found to have a low quality of life due to the burden of caring for someone with a long-term condition and the demand that undertaking daily tasks can put on their overall wellbeing (Miller et al, 2015; Rodrigues et al, 2016).

The COVID-19 pandemic has seen an increase in the need for more patients to be involved in their own care and technology to support self-management has proved favourable for some patients who may lack the confidence to care for







themselves at home. The studies by Wilde (2018) and Exposito et al (2020) focused on the application of technology to provide guidance to patients, incorporated into a shared care programme to help patients feel supported, improve knowledge and empower them to self-care for their wound. An instrument to measure patients' perceived ability to perform self-care activities may be necessary as part of a future framework to ensure suitability and enhance patient outcomes (Brown, 2020). For a shared care pathway to become successful in lower limb wound management it is important that both patient and health professional understands their role and responsibility within the care plan. It is clear from this review that further research is required to gain a greater understanding of patients' and health professionals' expectations of these roles and responsibilities.

Strengths and limitations

This narrative review has provided an insight into how patients currently self-manage wounds, the extent of support received, and their experiences allowing for a greater understanding of this area is important. It should be acknowledged that there are some limitations. Only those studies published in English were included, which may have resulted in the omission of valuable findings of other studies that have investigated this area. Only one study explored the patient experience of supported self-management during a pandemic. However, this demonstrates the importance of further research in this area.

CONCLUSION

Given the increasing number of patients living with lower limb hard-to-heal wounds, the drive to involve more patients in their own care is an important concept in healthcare. Supported self-management can have a positive impact on the patient experience and the development of a shared care programme to help patients feel supported, improve knowledge, and empower them to self-care for their wound could provide a mechanism for the sustainability and spread of care. The limited evidence found from this review highlights the necessity of future research to explore this caveat to further understand how to facilitate patient engagement and adherence in self-management activities. This careful planning

should involve an interdisciplinary approach, including key healthcare professionals, patients, and other caregivers to improve the quality of life of patients. Continued professional support and supervision within self-care practice is essential in lower limb wound management to help recognise good and poor practices and optimise patient engagement and outcomes.

CONFLICT OF INTERESTS

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Keep moving
Incontinence and increased moisture
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