

Chronic venous leg ulcer care – are we missing a vital piece of the jigsaw?

KEY WORDS

- ▶ Consultation
- ▶ Leg ulcers
- ▶ Person-centered
- ▶ Wound care

This project explored the lived experiences of patients with leg ulcers to ascertain impact on their quality of life. The aim was to develop a new Leg Ulcer Consultation Template (LUCT). Unstructured interviews were undertaken. Themes raised as significant were incorporated into a checklist and used to assess the extent and depth of exploration during the consultations. Several key themes were identified, including the dominance of pain. Observations revealed that issues emphasised as important by participants were not raised during consultations. A new consultation template was developed. The results of this study reveal that participants have concerns far beyond their actual wound care. Application of the new consultation template may go some way to redress the balance of the consultation.

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Chronic venous leg ulcers (CVLU) are common, expensive and impact on quality of life (QoL) (Posnett and Franks, 2007; Guest et al, 2015). They affect 3 per 1,000 of the UK population, with prevalence increasing with age (Nelson and Adderley, 2016). Ulcers are notoriously difficult to heal; many patients have their ulcer for over 12 months and, if healing is achieved, they frequently recur (Nelson et al, 2006). Statistics for healing and recurrence have improved little since the 1990s and for some, their ulcers last for much of their lifetime (Harding et al, 2015).

QoL is diminished by the debilitating symptoms and indolent nature of CVLU (Rich and McLachlan, 2003; Persoon et al, 2004; Guest et al, 2015). Life is complicated by pain, limited mobility, odour, depression and social isolation (Franks and Moffatt, 2007; Green et al, 2013a). To date, much of the care for patients is delivered in the community and research evidence is of varying quality with a tendency to focus on wound care with little regard for its wider impact (Rich and McLachlan, 2003; Briggs and Fleming, 2007).

This article summarises three phases of a project that established the factors that impacted on those with CVLU, explored whether these issues were addressed within consultations and then developed a

consultation template, specifically designed to direct the consulting nurse to consider issues that impact on the patients' QoL (Green et al, 2013a; 2013b; 2014; 2015). Ethical approval for the study was granted by Mid Staffordshire Local Research Ethics Committee and data collection was undertaken between in Staffordshire 2010–2013.

PHASE ONE

A two-stage sampling procedure was applied for both phase 1 and 2 of the project. Firstly, District Nurses (DNs) who were experienced in the care of patients with CVLUs were recruited from a team in each of two local primary care trusts (PCTs). All consenting DN participants were asked to purposively select potential patient participants from their caseload; this approach protected confidentiality, with the DNs responsible for distributing study information and consent forms. Inclusion criteria for patients were: CVLU of venous or mixed aetiology for over 6 weeks and the ability to provide written informed consent.

During phase 1, unstructured interviews were undertaken with the patient participants. These commenced with a single open-ended question: "What is your experience of leg ulceration?" Interviews continued until data saturation, were audio recorded, transcribed verbatim and analysed

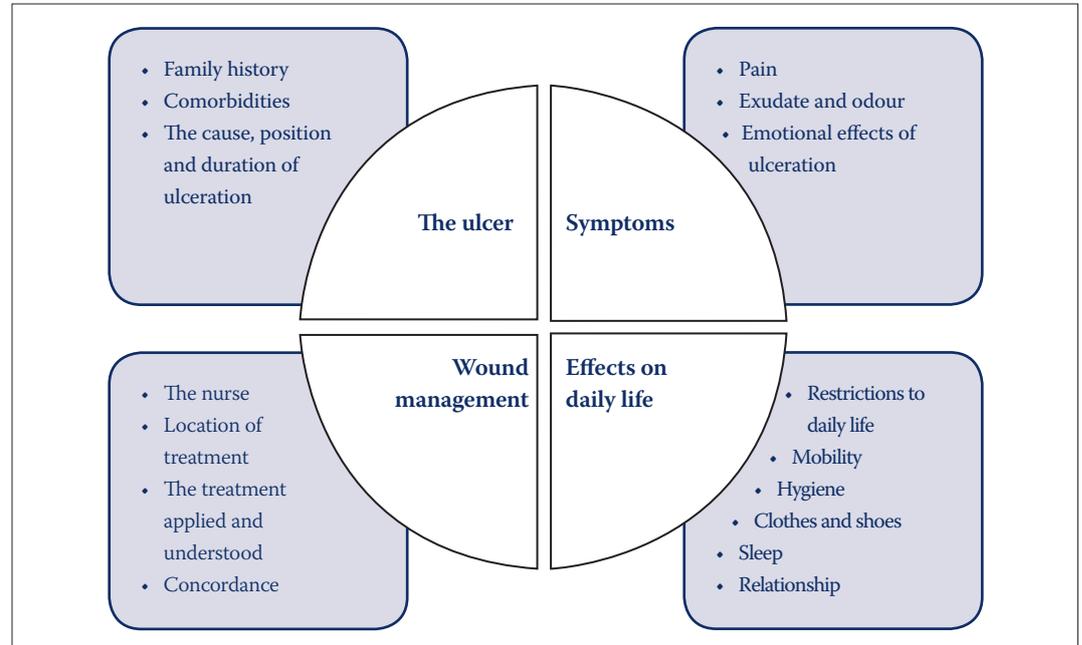


Figure 1. Themes and subthemes from interviews (Green et al, 2013a)

using a structured six-stage framework for thematic analysis developed by Braun and Clark (2006). Data were coded independently to ensure transparency of the process.

Thirteen DNs were recruited into the study; all were female and had worked in primary care for a median of 5 years (range: 6 months to 20 years). Nine patient participants took part in phase 1; 4 were male, 2 lived alone, 4 with a partner and 3 lived in residential care. Participants had a mean age of 75 years (range: 39–99 years). Participants were identified by pseudonyms (Nursing & Midwifery Council, 2015). Thematic analysis (Braun and Clark, 2006) identified four core themes: the ulcer, symptoms, wound management and the effects on daily life. Each theme encompassed several subthemes, outlined in Figure 1.

THE ULCER

All participants reflected on their family history, their comorbidities and the cause, position and duration of ulceration. Comorbidities were common; some reflected on the additive impact of their combined conditions whilst for others, their ulcer was described as a minor irritation compared to their other conditions. Participants spoke of the initial cause and time span of their ulcer; some spoke of an injury, whilst for others their ulcer had 'appeared'

without warning. Some reflected on occupational and genetic factors that, they felt, had predisposed their ulcer development. Participants spoke of initial self-management, before eventually resigning themselves to professional help, often precipitated by wound deterioration or the presence of infection. Others spoke of avoiding 'professionals' and of becoming almost 'non-compliant' when the situation overwhelmed them.

Most had experienced healing, but not all. For one participant, ulcer healing was taking years and was proving to be a significant personal challenge:

'God, they've been doing it ... this Christmas it'll be just over ... 14 years ... it's just been millimetres ... millimetres all the time just going in ... very, very slow ... cause I've not been anywhere, not done nothing for 12 ... 13 ... 14 years.' Steve

Whilst all reflected that healing was slow, for those who had experienced healing, they spoke of their frustration when ulcers recurred.

Personal narratives from the interviews revealed consistent, unsolicited themes and provide us with a rich insight into the person behind the ulcer, the scale of the impact and provide a rich background to personal journeys.

SYMPTOMS

All participants reported a range of debilitating symptoms, which provided three subthemes.

Pain

Pain dominated the lives of participants and was fundamental to every interview. Similarities in descriptions of pain included its unceasing nature, severity and timing, especially throughout the night:

'... all through the night and ... and you just can't get any rest.' Mary

All participants spoke of a reluctance to take analgesia, often due to the cocktail of medications they required for comorbidities:

'... with all that I take for my arthritis, I figured it was covered.' Tom

Where analgesia was taken, respondents reflected that it was ineffectual for both the type and intensity of pain they experienced.

Exudate and odour

The impact of both exudate and odour was powerfully described, including reflections on the challenge posed to daily lives. These devastating symptoms were all too common and caused embarrassment, shame and stress:

'... it was a really offensive smell ... you know what I mean, like ... it was like rotting flesh ... it was horrible ... and, I smelled.' Steve

Participants reflected that to control the impact of odour and exudate, they had made a conscious decision to limit social contact, creating an almost self-imposed social isolation. This was preferable to the embarrassment caused by their symptoms:

'... they stop you from going anywhere, you can't get about ... not the same.' Ellen

Emotional effects of ulceration

Participants reported the emotional impact of their ulcers, which included depression, poor self-image and a fear of people's reactions. Interviews revealed a range of coping strategies adopted with some

striving to maintain 'normal' functioning against the odds, whereas others described severe anxiety and depression, with one divulging that he had had suicidal thoughts:

'... it's just depressing really, if you think about it ... I am on antidepressants ... I just have to put up with it ... it's either that, or kill myself.' Steve

In contrast, another participant stated that despite the impact of her ulcers, she strived to continue her activities as before:

'I don't cry ... but I could cry ...' but despite this went on to say; 'I tell you ... you have to shake yourself ... you have to shake your feathers and when you go out you have to put your outside face on ... you know, you just have to.' Margaret

Despite the significant negative psychological impact, the theme of hope was evident throughout interviews, even for Steve who had experienced an unrelenting 14 years of ulceration:

'... yeh, I'm doing alright now like, I'm getting there ... it's getting there.' Steve

WOUND MANAGEMENT

Participant discourse about the 'management' of their ulcers revealed the central position wound care now held in their lives. The importance of their nurse in their personal leg ulcer journey was evident in all interviews. Some preferred consistency in the nurses that visited:

'... with the consistency of a team ... much better. They did once send another from another surgery ... it wasn't the same ... when you're seeing someone only once ... it isn't the same ... nothing wrong with her ... did the job just the same ... fine ... but I wasn't used to her.' Tom

For many, their relationship with the nurse was special; with some speaking of their nurses as friends, with a close relationship formed over the course of many visits:

'... had some lovely nurses ... they've been brilliant.' Tom

All described a focus on healing as the goal for the nursing team, with many participants accepting that this was often an elusive goal and, when achieved, was difficult to maintain:

'... I've had them twice this year.' Sam

Some had elected to attend clinics for their dressings, whilst others received care at home. Reflections on the time wasted waiting for nurse visits were common with one gentleman, who lived in a residential home, reflecting that he had missed out on activities whilst waiting for the nurse to visit. The decision to attend clinic, for some, enhanced their control:

'... you know, when I first went they said which would you prefer ... do you want to come here or do you want us to come to your house? ... and I just said that I'd come up to clinic ... I just thought moving about a bit would be better ... might do me better than just sitting about.' Sam

One participant, however, described difficulties travelling home following a dressing change:

'... they have a clinic down at our Doctors...on three days a week for dressings ... I'll go to it ... but sometimes, you know, sometimes I have a job to come home when it's just been dressed.' Mary

EFFECTS ON DAILY LIFE

Several subthemes referred to the effects of ulceration on the participant's daily life.

Restrictions to daily life

Some said they 'stayed at home', reflecting that usual activities had become more difficult. Others 'stayed at home' to limit contact with others or to avoid further injury. Often normal daily life was 'interrupted' because of ulceration:

'... I'm frightened in the supermarket ... I am frightened when I'm out ... when I have been at the supermarket cause some people, they do push their trolleys everywhere ... so it means that you're on your guard all the time.' Margaret

In contrast, some rose to this challenge and, with determination, went out despite their ulceration.

'I don't let anything restrict my life.' Pam

This, it seemed, was an attempt to fight back and assert control against the limitations their ulcer imposed on functioning.

Mobility

Most respondents described difficulties walking, with some attributing this to wound discomfort whilst others to their dressing. Some also consciously limited how far they walked as they feared they would fall:

'... I can't walk...yes, you walk but I'm frightened, because I put my foot out, you're frightened of falling' Margaret

Personal hygiene: Due to the dressings, many described having difficulties with personal hygiene. Some had used a new shower appliance, supplied on prescription, which had improved their functioning in this area. Others said how much they would appreciate it if their legs were washed during dressing changes. A respondent described how upset she was that her legs weren't washed:

'No ... they cut it all off ... and then she just puts a bit of cream on ... and ... that's it ... another bandage on.' Ellen

Limited choices for clothes and shoes: Everybody described the challenge of choosing suitable clothes and shoes, most often due to the bulk of their dressings. Some respondents spoke of wanting to conceal their dressings:

'... it's horrible ... you can't dress as you want to ... I've got nice fine skirts as I could have, you know, printed skirts for the summer, ever so nice.' Margaret

Sleep

Sleep was an issue for all respondents, most often due to pain. One participant commented that night times were particularly difficult:

'Some nights ... err ... I had no sleep with it all night ... it was going like this (indicates clenching motion) ... every few minutes ... and you're there trying to find

... somewhere to put your leg ... you know ... it's awful.'
Margaret

The lack of sleep seemed to accentuate the debilitating nature of the condition and made day-to-day functioning more challenging.

Relationships

Participants described the impact on relationships. One gentleman reflected sadly that he now required family members to assist activities and for others, carers had become cared for. One participant sadly reflected on his inability to provide the level of care for his wife that he previously had done

:

'... I haven't been able to go round the supermarket ... I just haven't been able to manage it ... I'd have to sit down and my wife would struggle round.' Sam

Day-to-day living was a challenge for everyone, with leg ulceration impacting on every aspect of their lives.

PHASE TWO

DN and patient participants were consistent across phase 1 and 2; however, of the nine patient participants in phase 1, only five patients (three male; 60%) were available for recruitment in phase 2 (median age: 76 years; range: 39–86 years) for a number of reasons. For 2, their ulcer had healed, one was in hospital following a fall, and one had been discharged. Consecutive wound care consultations were observed on four occasions for each participant, to determine the extent to which themes disclosed in phase 1 were explored by the nurse. The researcher

took a non-participant observer role; analysis was concurrent and aimed to establish the proportion of occasions that themes raised in phase 1 were subsequently raised during the consultation and the extent to which the nurse dealt with the theme. For several reasons, only 5 phase 1 participants could be involved in phase 2.

A 28-item checklist based on the phase 1 findings, was completed during each observed consultation. For ease, the checklist included tick, comment and 'scoring' boxes to minimise distraction for the researcher. A 'scoring' scale based on those used in similar studies (Ebbeskog and Ekman, 2001) facilitated rapid assessment and recording of the depth of exploration of each theme (*Table 1*).

The five patient participants consulted with 13 nurse participants during 20 observed consultations. Results for the themes and subthemes are displayed in *Table 2*. To summarise, 38% of concerns that had been disclosed unprompted during the phase 1 interviews were not raised by patient participants during their consultation. Of the 62% that were raised by the patient, 8% were missed by the nurse. Moreover, 30% of the phase 1 issues were discussed but not managed, leaving 24% which were at least partially managed. These overall results are statistically significant (Chi-squared = 55.0, df = 20, $p < 0.0001$). In review, wound management concerns were more likely to be acknowledged and managed

Table 1. Scores for checklist themes

Score	Criterion
0	Theme not raised by nurse or patient.
1	Nurse did not identify cue from patient.
2	Nurse picked up cue only.
3	Nurse identified patient cue and asked about the issue.
4	Nurse picked up cue and partially dealt with it.
5	Nurse picked up cue and dealt with it fully.

Table 2. Observation results

Issue (total number of potential occurrences of each issue)	Number (%) of known issues were raised by patients to and responded to by nurses					
	Not raised (score = 0)	Cue not identified (score = 1)	Cue blocked (score = 2)	Discussed (score = 3)	Partially dealt with (score = 4)	Fully dealt with (score = 5)
Pain (132)	55 (42%)	9 (7%)	1 (1%)	36 (27%)	9 (7%)	22 (16%)
Exudate & odour (28)	9 (32%)	1 (4%)	1 (4%)	5 (18%)	1 (4%)	11 (38%)
Emotional effects (28)	16 (56%)	2 (7%)	1 (4%)	8 (29%)	0 (0%)	1 (4%)
Wound management (32)	3 (9%)	0 (0%)	1 (3%)	9 (28%)	4 (13%)	15 (47%)
Effects on daily life (84)	32 (38%)	8 (10%)	1 (1%)	33 (39%)	3 (4%)	7 (8%)
Total (304)	115 (38%)	20 (7%)	5 (1%)	91 (30%)	17 (6%)	56 (18%)

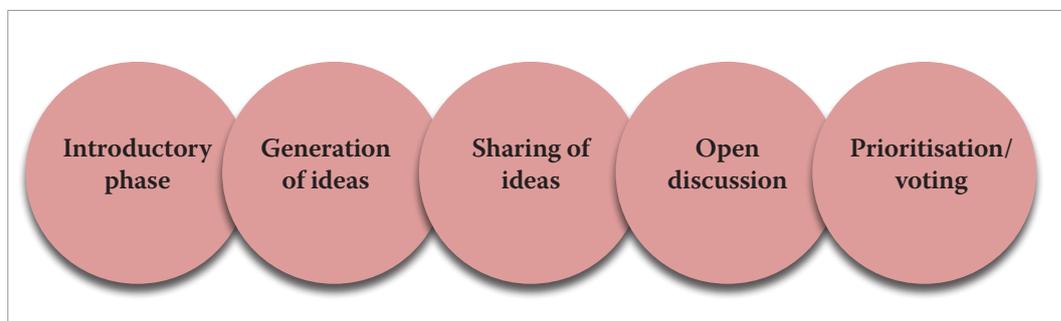


Figure 2. Nominal Group stages (Green et al, 2013b)

whilst the emotional effects of the ulcer were less likely to be disclosed or dealt with.

PHASE THREE

The findings of phase 1 and 2 established that patients were less likely to disclose these issues during regular wound care consultations than at interview and, when themes were raised, on some occasions these were overlooked or inadequately addressed. Phase 3 aimed, in conjunction with experts and patients, to develop a new patient-focused template to encourage the consulting nurse to explore appropriate themes, to activate the patient to engage with their care and to build a concordant relationship with their health care professional (Stewart et al, 2000; Morden et al, 2012; Green et al, 2013 a; b).

To ensure the template's usefulness, a nominal group (NG) approach was employed (Carney et al, 1996). This efficient, cost-effective, face-to-face approach requires minimal preparation by participants (Carney et al, 1996; Vella et al, 2000; Potter et al, 2004). Despite the small-scale nature of NG meetings (5–9 members), evidence suggests that the technique provides representative views of the wider community (Lancaster et al, 2002). The NG approach has five clear stages (Brown et al, 2006) (Figure 2).

Purposive sampling ensured nurses with relevant expert knowledge were invited to the group. Nurse Managers in the local Primary Care Trust (PCT) nominated potential participants who were provided with verbal and written study information and a consent form. In addition, a nurse academic, experienced in research surrounding consultation skills, was contacted and supplied with study information, a consent form and invited to take part.

Patient participants involved in earlier study phases were approached by their DN, provided with verbal and written study information and a consent form. In total, five professionals and three patient participants consented to take part in the development of the template, however, the patients requested that they be seen individually, as they were reluctant to contribute, alongside experts, at a whole group meeting. Although this situation was not ideal, the facilitator conducted individual interviews with the patient participants and relayed their suggestions to the 'expert' group members via email.

Prior to the NG meeting, pre-reading was circulated to ensure prompt engagement with the group activity. At the start of the meeting, background information was summarised and each participant had an opportunity to share their ideas. Once all had contributed, ideas were explored and items prioritised for inclusion in the template by a show of hands (Carney et al, 2013). When no new ideas were generated by group members, key concepts for inclusion were agreed by all members, and the meeting concluded. After the meeting, the template was presented individually to the three patient participants during pre-arranged visits, as they had requested, providing an opportunity for them to comment. One participant (Tom) suggested some minor amendments to the wording of four of the questions and an increase in the size of the comments/problem solving section, to allow more detail to be included. The other patient participants (Mary and Sam) both agreed with these alterations and confirmed that the template was useful, easy to understand and reflected the issues that impacted on their lives each day. Following the patient review and email approval by all NG group members, an

Figure 3. Consensus was reached and the new template agreed with a range of response options from tick boxes to additional comments. Above the first of the two sides of the final template.

QUALITY OF LIFE & LEG ULCERATION TEMPLATE v4.	
Patient Name:	Date:
<p>Please complete this template during each consultation. Assess the themes below with your patient. Record any interventions you make, advice that you give or problems that you solve in the comments boxes. Guidance regarding completion is provided overleaf.</p>	
Assessment of mobility & ability to get out & about:	
Are you able to mobilise as you did prior to having an ulcer?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> If not, what stops you? <input style="width: 100%;" type="text"/>
Are you able to get out and about and socialise as you did?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
Assessment of sleep, nutrition and pain:	
Where are you sleeping?	
Bed: <input type="checkbox"/>	Chair: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
Do you sleep well? If not, what stops you from sleeping?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
Are you eating a normal diet? If not, why?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
Is your pain better or worse since your last visit?	
Better: <input type="checkbox"/>	Worse: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
What pain killers are you taking? Do you take these regularly?	
Medication dose & frequency taken: <input style="width: 100%;" type="text"/>	
Are they effective?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
Assessment of personal hygiene, clothes & shoes:	
Are you managing to shower or bathe?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
Are you able to wear the clothes and shoes that you did prior to having an ulcer?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
If not, what are you wearing? Is this suitable?	
Comments: <input style="width: 100%;" type="text"/>	
Assessment of emotional effects, relationships & fears:	
Do your ulcers get you down? How are you feeling today?	
Yes: <input type="checkbox"/>	No: <input type="checkbox"/> Comments: <input style="width: 100%;" type="text"/>
Do you have friends or family members who support you?	
Comments: <input style="width: 100%;" type="text"/>	
Do you have any concerns about your ulcer?	
Comments: <input style="width: 100%;" type="text"/>	

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updated template was circulated to all NG members for final approval.

A range of decisions were made including structured wording of questions to ensure effective cues were provided for the consulting nurse. Template format and layout, including brevity, were agreed to avoid unduly extending the consultation. Group members agreed the inclusion of guidance to ensure nurses considered the most appropriate topics with their patients. For simplicity, similar themes were grouped to allow the nurse to explore related themes simultaneously. The following groupings were agreed and reflected the activities of daily living expounded by Roper, Logan and Tierney (2000):

- ▶▶ Mobility, ability to get out and to socialise
- ▶▶ Sleep, diet and pain
- ▶▶ Personal hygiene and issues with clothes and shoes
- ▶▶ Emotional effects of ulceration, relationships and fears
- ▶▶ Documentation of care provided, exudate and odour, type of dressings
- ▶▶ Information given to the patient.

Consensus was reached and the new template agreed with a range of response options from tick boxes to additional comments. The final box, entitled, 'comments and problem solving' was titled so as to encourage the nurse to record the goals developed jointly with the patient for review during subsequent consultations. The final template was two sides of A4 paper long and encompassed all features identified by the NG to maximise its acceptability to staff and its impact on care (Figure 3).

CONCLUSION

Templates for chronic venous leg ulcer care have a tendency to focus on physical assessment and the detail of wound assessment, such as an example designed by the Wound, Ostomy & Continence Care Society (2016). Such templates represent a medicalised approach to leg ulcer care and direct the nurse away from holistic assessment of patient needs (Beresford, 2010). Since consultations for CVLU care are known to overlook QoL issues (Persoon et al, 2004), this template redresses this balance, focusing the consultation on issues and concerns that impact the lives of patients. The template was designed in response to a

lack of disclosure of QoL issues during patient consultations (Green et al, 2013b) thus more research would further evidence the utility of the template and establish whether, despite having a small effect, application of the template improves patient outcomes.

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