

A new quality of life wound checklist: the patient voice in wound care

KEY WORDS

- ▶▶ Leg ulcer consultation template
- ▶▶ Person-centred approach
- ▶▶ Quality of life
- ▶▶ Wound checklist

JULIE GREEN

Director of Postgraduate Studies, Senior Lecturer in Nursing, Keele University School of Nursing and Midwifery, Clinical Education Centre, University Hospitals of North Midlands NHS Trust, Royal Stoke University Hospital, Stoke-on-Trent

PATSY CORCORAN

Reach Project Co-ordinator, Asist (Advocacy Services in Staffordshire), Stoke-on-Trent

LAURA GREEN

Project Illustrator, Keele University School of Nursing and Midwifery and a student undertaking the BA (Hons) Illustration with Animation, Manchester Metropolitan University

PROFESSOR SUE READ

Professor of Learning Disability Nursing and Director of Research, School of Nursing and Midwifery, Keele University

Wounds impact on the quality of life of the patient; however, these elements of patient care are often overlooked or are haphazardly disclosed, recorded and addressed. **Methods:** PhD research evidenced that patients with a wound have concerns beyond their wound care. Findings suggested that patients failed to disclose their concerns and nurses failed to explore the impact of the wound (Green et al, 2013a; Green et al, 2013b). The study culminated in the development of a Leg Ulcer Consultation Template (LUCT) which has been adopted across a number of Trusts (Green et al, 2018b). The roll-out of the LUCT highlighted the need for a generic tool for patients with wounds of any aetiology which would be suitable for self-completion, prior to a consultation, thus minimising any increase in the duration of the consultation. In addition, the then new Commissioning for Quality and Innovation (CQUIN) prompted the inclusion of an overall, self-assessed, quality of life score (NHS England, 2016). **Results:** To address these requirements, the principles of the LUCT were reviewed and a new 'Wound Checklist' developed, supported by Reach, an advocacy service that forms part of Asist, to ensure utility for all patient groups. Clear information in the form of images, simplified questions, visual representations and the inclusion of a pain and quality of life score have streamlined and improved the accessibility of the checklist. The checklist was piloted across four teams and a number of alterations made in response to feedback. The final version is included in the article. **Conclusion:** Results of an evaluation of the new Quality of Life Wound Checklist across four District Nursing teams has been positive and have demonstrated the utility and effectiveness of the new checklist which is available as a pilot digital application or as a paper version.

Wounds are expensive; to the NHS as a whole, to local Trusts who provide wound care services with increasingly tightening budgets, to teams within predominantly primary care who deliver the care required and, lastly, but not least, to the patient and their family. Indeed, Guest et al (2015), utilising an extrapolated analysis of The Health Improvement Network (THIN) database, revealed an estimate of 2.2 million patients with a wound, 4.5% of the UK adult population, at a cost of approximately £5.3 billion in this study year (2012/2013). This enormous expenditure funded a projected 18.6 million Practice Nurse visits, 10.9 million community nursing visits, 7.7 million GP visits, 97.1 million prescriptions which provided, amongst other items, 252.2 million dressings. Of

the 2.2 million people with a wound, 730,000 have a leg ulcer, 1.5% of the adult population, of which 19% have no diagnosed aetiology, 278,000 have a venous leg ulcer and 169,000 have a diabetic foot ulcer (Guest et al, 2015).

THE STUDY

This paper presents the development of a new Quality of Life (QoL) Wound Checklist for use with patients with wounds of any aetiology. This new checklist, however, had its origins in the lead author's PhD surrounding an earlier template, which was developed specifically to meet the needs of patients with chronic venous leg ulcers (CVLU). This was known as the Leg Ulcer Consultation template (LUCT) (Keele University,

2013). In order to fully understand the development of the QoL Wound Checklist, it is necessary to explore this work in conjunction with the more recent developments. The authors' earlier work is summarised here (see Green et al (2018a; b) for full study detail).

THE DEVELOPMENT OF THE LUCT

PhD research, conducted between the 2009 and 2014, explored the lived experiences of patients with CVLUs, with the aim of ascertaining the impact of the condition on the patients' QoL. The study comprised four study phases and was prompted by a visit to a patient who had experienced bilateral leg ulceration for over 60 years. Ethical approval for the study was granted by Mid Staffordshire Local Research Ethics Committee and actual data collection was undertaken in Staffordshire between 2010–2013.

Ulcers are a considerable wound care challenge both to the patient and the NHS; they affect 1.5% of the population, with prevalence increasing with age (Guest et al, 2015; Nelson and Adderley, 2016; NHS Choices, 2017) and can be particularly difficult to heal; healing rates range from 93% that reportedly healed within 12 months, however, an estimated 7% do not heal within 5 years. Healing issues are further compounded by high recurrence rates, which are estimated to be as high as 70% at three months (Finlayson et al, 2015; Franks et al, 2016). These estimates represent rather disheartening statistics, however, despite this, Cullum et al (2016) report that complete wound healing remains the number one priority for the patient. During the often haphazard journey towards healing for such patients, it was evidenced that the patient's voice, in relation to the impact of CVLUs on their QoL, within the consultation, was often not prompted and was easily overlooked.

The PhD comprised four phases and applied a mixed methods approach, utilising both qualitative and quantitative research designs to provide a comprehensive exploration of the issues that CVLUs impose. Phases 1 and 2, employed qualitative methods, specifically unstructured interviews in phase 1 and non-participant observation during phase 2. This design ensured the depth of data collected and enabled the researcher to fully explore the lived experience of

patients with CVLU. Utilising interviews followed by a period of observation, ensured that data was effectively 'followed up' across the two phases; a process facilitated by the recruitment of a consistent sample across phases 1 and 2. The observation of consultations in phase 2, thus allowed the researcher to map interview data against observation data for each participant. This design facilitated the deeper exploration of whether the issues that were disclosed at interview were subsequently explored during consultations, for the same sample.

In phase 1, unstructured interviews were undertaken, with consent, with nine study participants who had experienced CVLUs. Interviewing ceased when data saturation had been reached; deemed to be when no new themes emerged during data analysis (Guest et al, 2006). The interviews were digitally recorded, transcribed verbatim and analysed thematically using a systematic process outlined by Braun and Clarke (2006). Analysis revealed several themes that were of significance for patients with a CVLU, including the dominance of pain, issues relating to exudate and odour, social isolation and the psychological impact of having a leg ulcer (Green et al, 2018a).

The themes exposed in phase 1 were incorporated into a simple checklist, which was completed by a researcher during phase 2 consultations. Phase 2 involved a period of non-participant observation of episodes of care for the patients who had been interviewed in phase 1, to assess the extent and depth that the issues raised during the interviews were addressed during consultations. Five patients from phase 1 were available during phase 2; to reduce the potential for bias each patient had 4 consultations observed with a range of clinicians (Denscombe, 2007). Analysis of the completed checklists revealed that, on many occasions, the issues disclosed to a researcher during the interview phase of the study were not disclosed by the patient or raised by the consulting nurse during their subsequent consultations. Indeed, the problem was most pronounced where issues related to pain or emotional/psychological issues. This mismatch between interview disclosure and the observation of consultations evidenced that patients may be reluctant to disclose the true impact of their CVLUs on their QoL, unless specifically prompted to do so.

During phase 3, a nominal group (Carney et al, 1996) of patients, experts and researchers including a representative from industry, enabled the development of a new leg ulcer consultation template, the LUCT, in a single meeting. The LUCT was designed to address the issues highlighted as being problematic but overlooked in phases 1 and 2. The LUCT was designed to specifically 'direct' the consulting clinician to consider the range of issues that impact on a patient's quality of life (QoL) (Green et al, 2018a; b).

Finally, in phase 4, the LUCT was evaluated in terms of its utility, significance and clinical potential in a small-scale feasibility study. For this phase, a within-subjects design feasibility study was undertaken across two caseloads. Although recruitment was challenging, the pilot demonstrated that the application of the new template, the LUCT, during routine consultations, appeared to encourage patient disclosure of issues that were important to them and would otherwise have been overlooked. An evaluation of the statistical and clinical impact of the LUCT in relation to improving QoL scores and patient satisfaction, demonstrated improving outcomes (see Green et al, 2018b for more detailed study detail).

THE DEVELOPMENT OF THE QUALITY OF LIFE WOUND CHECKLIST

The LUCT was made available in 2015 and has been utilised, with considerable success, across a number of Trusts in Central England. Indeed, for some it has been incorporated into their leg ulcer pathways for completion every four weeks. Feedback from both staff and patients has been positive, with the LUCT enabling a more effective person-centred approach to consultations. Feedback revealed, however, that, although the information from the LUCT is useful to direct the subsequent consultation, many patients had required support from their nurse, carer or family to complete the template; this need for support had become an issue as it was, on occasions, adding additional time to consultations in order to gather this specific QoL information.

The LUCT has been presented locally, regionally, nationally and internationally and published widely. However, alongside the feedback in terms of template completion issues, further roll-out of the

LUCT has also been influenced by the then new CQUIN requirement (NHS England, 2016). The issues raised around the LUCT over the 4 years it had been implemented included:

- ▶ The need for a similar tool, for use by patients with wounds of any aetiology, including foot ulcers and pressure ulcers
- ▶ A new 'generic' template suitable for self-completion by the patient or their carer, prior to their consultation, in order to minimise any undue increase in the duration of the consultation
- ▶ The inclusion of an overall, self-assessed, QoL score is included.

In response to this feedback and the developing requirement in terms of utility and applicability of the checklist to all wound types, the new QoL Wound Checklist was developed (*Figure 1*). This checklist is a simplified version of the LUCT, that has been carefully designed to address the QoL issues encapsulated in the LUCT but available for patients with a wound of any aetiology. The new checklist has been developed with the intention of being self-completed, in advance of the patient's consultation. The aim is still, as for the LUCT, for the checklist to refocus subsequent discussions on the areas of the patient's daily life that their wound impacts on. Use of the new QoL Wound Checklist allows clinicians to record and monitor the self-assessed QoL life score for their patients, across visits and interventions, which may further inform the allocation of time for patient visits.

This innovative development has been supported by Reach, an advocacy service, as an iterative process, to ensure its utility for all patient groups. Clear information incorporating simplified questions, visual representations and the inclusion of a pain and quality of life score have streamlined and improved the accessibility of the checklist to ensure its efficacy for all wound care patients. The advocacy service revisited the checklist on several occasions to ensure that questions were clear and transparent, easily understood by a member of the public with a reading age of 10–12 years, which is the average for the population of the UK. The team utilised the Flesch Kincaid scoring model to ensure that this process had been successful (Badarudeen and Sabharwal, 2010). In addition, to ensure the utility of the checklist, an iterative process by the advocacy organisation ensured that every statement effectively

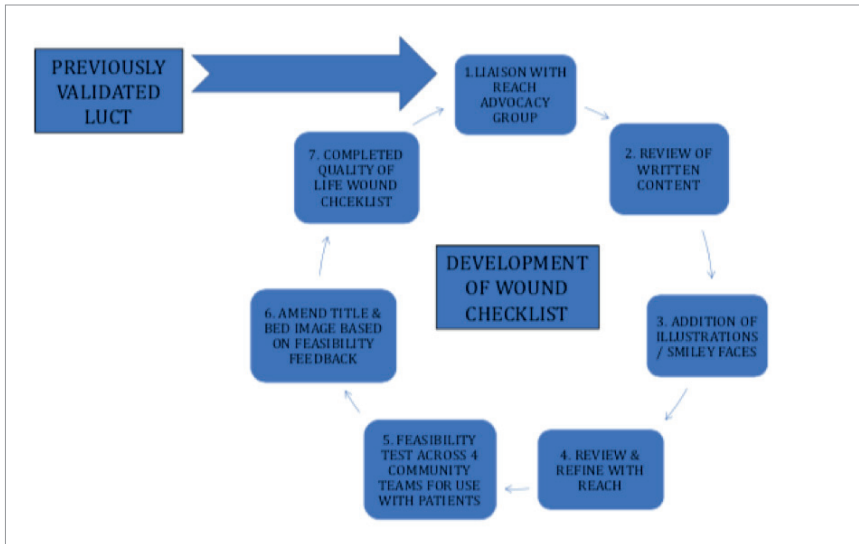


Figure 1. Development process

drilled down to the information required for all checklist users. This process is known as ‘Thinking Aloud’ methodology (Lundgren-Laine and Salanterä, 2010) and is based on the model developed by Newell and Simon (1972). This method encourages participants to verbalise thoughts whilst exploring the new checklist. It represents a direct method to gain insight into thoughts, knowledge and understanding of participants on the utility of the newly developed checklist. Such co-productive working is the essence of ensuring products are ‘fit for purpose’.

Illustrations were incorporated to ensure that this clarified the written statements. This ensured that users of all abilities were supported to complete the checklist without the need for additional support. Versions were piloted with patients to ensure that the checklist remained user-friendly and was providing the information required by practitioners. In order to achieve the requirements, the evidence-based principles of the LUCT were reviewed in order to develop the new QoL Wound Checklist (Figure 2).

Once complete, the simplified Wound Checklist was trialled across four District Nursing teams within the community and their community wound care clinics. This trial provided anecdotal positive feedback both in terms of the suitability of the checklist for patient completion, without additional support, and that the right information was being collected for appropriate interventions to be put in place. The inclusion of a pain score and self-assessed QoL between 1–100 were welcomed as being a positive

inclusion. Two recommendations were made during the patient pilot of this service improvement. The first was to include QoL in the title rather than simply Wound Checklist; this was to avoid any confusion with other checklists that were required within Trust documentation. In addition, a change to the ‘bed’ image in question 7 was requested as patients were confusing the first draft image with a chair. Once these two amendments were completed, the checklist was deemed to be suitable for roll-out with a formal evaluation planned over coming months.

In addition to the development of a paper version of the checklist, the checklist was also developed as an application for download onto mobile telephones, tablets or laptops (currently available as a pilot at <https://woundcheck.hfac.keele.ac.uk/>). This easily downloadable resource was designed to be attractive to those patients who are keen to engage with technology. RCN Foundation funding is supporting the development of the compatibility of this app with EMIS, SystemOne and Rio community management systems over the coming months.

CONCLUSION

The LUCT was developed to focus wound care consultations, for patients, around the impact of their CVLU. Feedback from usage highlighted the requirement of a simplified tool and, as a result, the QoL Wound Checklist was developed. This checklist provides a change of focus for wound care consultations, to encourage the patient to disclose their concerns and serves to raise the profile of patient issues that are beyond their specific wound care, with their consulting nurse. Co-productive working has ensured that the new checklist is user-friendly and available as a paper or mobile application version for completion, ideally, without the requirement for additional support. Use of the checklist promotes a person-centred approach, which considers the whole patient experience of their condition and encourages the consulting clinician to adopt a problem-solving approach towards their patients’ needs and concerns.

Going forward, the aims for the new QoL Wound Checklist, are to publicise and raise its profile to Trusts and Tissue Viability teams nationwide. This template effectively meets the CQUIN requirement for the delivery of wound care to include the holistic assessment of patients and ensures that all are able to engage with the resource (NHS England, 2016).

Quality of Life Wound Checklist



Name..... Date.....

A wound (or cut, injury, ulcer) is a break to the skin that may be taking some time to heal. Please answer these questions about how you are coping with your wound.

1. Can you walk as well as you did before you had your wound? Yes Sometimes No

2. Can you go out as easily as before you had your wound? Yes Sometimes No

3. Do you eat well? Yes Sometimes No

4. Are you able to have a shower or bath? Yes Sometimes No

5. Are you able to wear clothes and shoes that you want to? Yes Sometimes No

6. Do you get a good night's sleep? Yes Sometimes No

7. Please circle the picture to show if you sleep in a bed or in a chair.

8. Please circle a number to show how your pain has been recently.
 No Pain Worst Pain
 0 1 2 3 4 5 6 7 8 9 10

9. What medication do you take for your pain? Yes Sometimes No

10. Where do you get your support from? Yes Sometimes No

11. How do you rate your overall quality of life? Please circle the number to show your answer
 0 =worst quality of life 100 = best quality of life

For further information please contact Julie Green at j.green@keele.ac.uk
 © 2017 Keele University. All rights reserved

clear communication by Asist made with photosymbols Illustrations by Laura Green

Figure 2. The quality of life wound checklist

This project was selected as one of the RCN's Celebrating Nursing Practice projects for their 100th-year centenary. It was also one of four projects to receive extra funding, which will be used to develop a system to help access the app across all

platforms within the NHS. In addition, use of the new QoL Wound Checklist will allow nurses to monitor the self-assessed quality of life score of their patients across visits and interventions, which may further inform the allocation of time for patient visits.

WUK

Badarudeen S, Sabharwal S (2010) Assessing readability of patient education materials: current role in orthopaedics. *Clin Orthop Relat Res* 468(10):2572–80

Carney O, McIntosh J, Worth A (1996) The use of the nominal group technique in research with community nurses. *J Adv Nurs* 23(5):1024–9

Cullum N, Buckley H, Dumville J et al (2016) *Wounds Research for Patient Benefit: a 5-year Programme of Research*. Available at: <https://bit.ly/2N8GCIO> (accessed at 11.09.2018)

Denscombe M (2007) *The Good Research Guide for Small Scale Research Projects*. Open University Press, Berkshire

Finlayson K, Wu ML, Edwards HE (2015) Identifying risk factors and protective factors for venous leg ulcer recurrence using a theoretical approach: A longitudinal study. *Int J Nurs Stud* 52(6):1042–5

Franks P, Barker J, Collier M et al (2016). Management of patients with venous leg ulcer: challenges and current best practice. *J Wound Care* 25(6 Suppl 1):1–67

Green J, Jester R, McKinley R, Pooler A (2013a) Patient perspectives of their leg ulcer journey. *J Wound Care* 22(2):58–66

Green J, McKinley R, Jester R, Pooler A (2013b) Nurse-patient consultations in primary care – do patients disclose their concerns? *J Wound Care* 22(10):534–9

Green J, McKinley R, Jester R, Pooler A (2018a) Chronic venous leg ulcer care: putting the patient at the heart of leg ulcer care. Part 1: Exploring the consultation. *Br J Community Nurs* 23(Sup3):S30–38

Green J, McKinley R, Jester R, Pooler A (2018b) Chronic venous leg ulcer care: putting the patient at the heart of leg ulcer care. Part 2: Development and evaluation of the consultation template. *Br J Community Nurs* 23(6):S20–S30

Guest G, Bunce A, Johnson L (2006) How many interviews are enough? *Field Methods* 18(1):59–82

Guest JF, Ayoub N, McIlwraith T et al (2015) *Health economic burden that wounds impose on the National Health Service in the UK*. Available at: <https://bmjopen.bmj.com/content/5/12/e009283> (accessed 11.09.2018)

Keele University (2013) *Leg Ulcer Consultation Template*. Available at: <https://www.keele.ac.uk/luct/> (accessed 7.09.2018)

Lundgren-Laine H, Salanterä S (2010) Think-aloud technique and protocol analysis in clinical decision-making research. *Qual Health Res* 20(4):565–75

Nelson EA, Adderley U (2016) Venous leg ulcers. Systematic review 1902. *BMJ Clinical Evidence*

Newell A, Simon H (1972) *Human Problem Solving*. Prentice Hall, Englewood Cliffs, NJ

NHS England (2016) *2016/17 CQUIN*. Available at: <https://www.england.nhs.uk/nhs-standard-contract/cquin/cquin-16-17/> (accessed 7.09.2018)

NHS Choices (2017). *Venous Leg Ulcer*. Available at: <https://www.nhs.uk/conditions/leg-ulcer/> on 14/7/18 (accessed 11.09.2018)