# **Venous Leg Ulcers: What about Well-being?**

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*The impact of having a leg ulcer is well-documented in terms of the pain, restrictions and psychosocial difficulties that patients experience. However, the current focus on quality of life as a patient reported outcome measure overlooks the importance of the individual’s well-being. In this article, we argue that a shift in focus from QoL to well-being will contribute to the more proactive patient centred approach to care to which we should all aspire in contemporary care settings.*

## *Defining quality of life and well-being*

For patients with venous leg ulcers (VLU), the condition can be chronic, painful and debilitating.1, 2 An individual with VLU may have to endure a number of difficult symptoms, including impaired mobility, sleep and daily functioning3 and the presence of exudate and odour.4 Consequently, quality of life (QoL) is often impaired and this has been demonstrated in a wealth of studies. 5-7 However, whilst research into QoL is important, such studies rarely provide insight into an individual’s well-being, a construct which we argue is not only a central concern of the patient, but is also essential to the clinician when assessing the impact of any intervention or care package. Indeed the increasing importance placed on QoL and well-being in the care of the individual living with a wound is evidenced by the International Consensus Document published in 2012 which has at its heart the aim of ensuring ‘that wellbeing is the principle focus of care’.8 Whilst this document provides an excellent starting point for taking this vital work forward, there remains much to be done.

Although QoL and well-being inevitably overlap, and the terms are often used interchangeably, it is important to distinguish between the two. In essence, QoL refers to a person’s cognitive assessment of their overall standard of living, or their ‘personal assessment of life satisfaction’. 9 In contrast, the term ‘well-being’ refers to the presence of positive emotions and contentment, with the absence of long-lasting and persistent negative emotions.10, 11 In short, QoL is the cognitive appraisal of an individual’s situation whereas well-being refers to their emotional appraisal.

To put this in the context of an individual with VLU, QoL is most likely to be used as a patient-reported outcome measure (PROM), which tells us how highly the individual rates their standard of living in relation to their physical health. Due to a variety of symptoms and consequences associated with VLU, this is often lower than in people without ulcers. Since QoL tools typically focus on limitations caused by problems of physical functioning, they tend to give a one-sided picture, which emphasises the deficits in a patient’s standard of living. Furthermore, where emotions are assessed in QoL measures, these tend to be negative ones such as depression and anxiety. However, an individual might judge their standard of living to be good, yet not be happy, and vice versa. It is therefore important that we assess how a person feels, and in particular their ability to experience positive emotions, regardless of the issues they face; this relates to well-being.

## *What do we know about the well-being of people with VLU?*

As already highlighted, much of the literature into the impact of VLU on the individual has focused on QoL rather than well-being, and where a measure of emotional response to VLU has been made, the focus has been on negative emotions. One of the most commonly reported emotional responses to VLU is depression or feeling ‘low’;12-15 some people even report feeling so low that they have thoughts of suicide.15, 16

In addition to low mood, studies have highlighted feelings of embarrassment, anxiety and reduced self-confidence in relation to body image in people with VLU; more extreme emotional responses to body image such as shame, disgust and self-loathing have also been recorded.14-21 Fear of amputation may also be an issue for some (Mapplebeck, 2008; Hopkins, 2004), along with other high arousal feelings such as anger and frustration.16, 20

Several factors may contribute to the presence of such negative emotions in people with VLU, with the most obvious being the physical symptoms they experience. For example, pain and odour have been linked with feelings of helplessness and low control,22 sleep disturbance with despair,15 length of healing time with depression,15 and odour and exudate with embarrassment and reduced self-confidence.14 Other factors which may contribute to negative affect include: limited knowledge of one’s condition and treatment;17, 19 a lack of confidence in healthcare professional;21 being cared for by unfamiliar nurses;15, 20, 22-24 feeling ignored or mistreated by clinicians;18 and finally, conflicts in the nurse-patient relationship due to a difference in focus on treatment outcomes versus symptom-relief.23-24

Clearly these negative emotional responses are an important part of the patient experience and as such must both be acknowledged and addressed. However, it should never be assumed that the *absence* of such problems equates to a positive state of well-being. Indeed, some studies have shown that patients may experience conflicting emotions - for example feeling both hopeful and pessimistic or despairing about the future.18,20 To date only a small number of studies have demonstrated the positive emotions that some people with VLU experience despite living with a range of negative consequences.20, 25 Research into other chronic health conditions suggests that such positivity in the face of adversity can be explained by mediating variables such as coping style, personality, hope, and resilience.26 Certainly hope and resilience have also been reported in VLU patients15, 18,. 20 and we believe that these are protective variables which must be explored further in relation to well-being.

## *Why is this important for healthcare professionals?*

The presence of negative psychosocial factors associated with having a VLU – such as depression and anxiety - have been found to further hinder healing, and have also been associated with ulcer recurrence.13, 27, 28 High levels of bio-psychological issues such as pain and stress have also been shown to have a delaying effect on the time taken for wounds to heal.29 This may in part be explained by the known association between psychosocial difficulties and poor treatment concordance.12 We believe that the opposite of this is also true, and that presence of positive psychological factors associated with well-being - such as hope and optimism - will enable better overall psychological health, increased treatment concordance, and improved healing speed. Certainly in other conditions, positive mental attitude and positive well-being have been associated with better outcomes.30

It is unclear why some people with VLU are able to retain a sense of positivity and well-being in spite of their difficulties, and further research to investigate this is essential. Insights derived from other conditions strengthen the view that it is not the wound per se that is the decisive factor in wellbeing, but rather that fundamental psychosocial factors are protective.30 Identification of these factors is important so that maladaptive elements can be replaced with protective ones.

Furthermore, clinicians are likely to have an important role in influencing patient well-being and the subsequent healing process; for example, treatment factors such as patient knowledge and the quality of the therapeutic relationship are known to affect how patients feel.17, 20 Whilst these issues still need to be explored further, it is important for healthcare professionals to be aware of the indirect impact that they may have on patient well-being.

Most importantly, clinicians need to be aware of the significance of assessing and monitoring well-being. Knowing whether a patient feels positive about themselves and the future is important for factors such as mental health and treatment concordance. The current emphasis on QoL does not allow such insight and we believe that a shift in focus is urgently needed. Clinicians and researchers must move away from solely assessing QoL – deficits of daily living - and towards exploring individual well-being – the presence of positive emotions and hope for the future. With more research and acknowledgement of this issue, suitable assessment tools and guidelines can be produced to support clinicians working with people with VLU and other wounds.

We need to move from the reactive to the proactive; a recognition of the importance of the patient experience of VLU- their emotional reactions, hopes and expectations – will enable health care professionals to better support patients to cultivate positive psychological resources. This will result in improved patient concordance, better healing rates, reduced treatment costs and, ultimately, a better overall outcome for individuals with VLU.

**Key messages**

* People with ulcers face a wide range of challenges. However, it is not the issues themselves that are important but rather how they affect the individual (i.e. their emotional response).
* Whilst assessing QoL allows us to make comparisons and evaluate treatment, important information is missing about the individual’s emotional outlook and whether or not they are able to retain a sense of positivity with regards to themselves and their future.
* The ability to feel good and experience positive emotions (i.e. ‘well-being’) is important because this may have implications for mental health and treatment concordance.
* Research is needed in this area so as to better understand important factors relating to the well-being of people with VLU and to identify appropriate methods of assessment and support.

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