A FUNDAMENTAL ROLE for clinicians is to improve patients’ experience of their condition, as well as their overall experience of health care. For those who work with patients with lower limb ulceration, knowing which management strategies are effective is not enough to influence this process. Understanding the effect of a leg ulcer on patients’ lives and using this information to influence care and service provision is where science and nursing care meet.

As part of World Class Commissioning (Department of Health (DH) 2009), clinicians are required to demonstrate that the service they deliver includes patient-related outcome measures (PROMs), patient involvement in service review and a focus on improvement in patient wellbeing. It is therefore appropriate to revisit patients’ stories from some key qualitative studies, drawing on patient feedback on the care received and using this information to develop services and deliver outcome measures in tissue viability.

The patient’s perspective

Patients’ quality of life has been investigated using various measurement tools, either generic or disease specific (Franks and Moffatt 1998, Price and Harding 2000). Some of the physical parameters measured include sleep, pain and mobility. Emotional reactions have also been studied, such as isolation, anxiety and depression, and disruption to the self (Noonan and Burge 1998, Chase et al 2000, Liew et al 2000, Hopkins 2004, Heinen et al 2007). These quantitative studies have provided conclusions based on statistical evidence. However, they lack evidence from the patients’ perspective. The increasing number of qualitative research studies published over the past 15 years provides these stories and gives detailed and personal accounts about the actual experience of leg ulceration from the patients’ perspective.

These personal accounts allow practitioners to understand more about key areas associated with ulcers, including pain, odour, difficulties with tolerating treatment, and the detrimental effect of these factors on patients’ quality of life. Consideration of these factors can help to influence the way in which healthcare professionals assess and provide management strategies that influence the promotion of good patient outcomes. This article suggests ways of assessing the effect of a tissue viability team on patients’ lives, and so make it possible to demonstrate the efficacy of the service provided and that evidence from qualitative research has been used proactively to improve care.

Patient-related outcome measures

PROMs are a measure of a ‘patient’s health status or health-related quality of life’ (DH 2008). The development of PROMs is in its infancy. Patients are asked to complete questionnaires before and after a procedure, with the aim of demonstrating the role of the intervention in any changes. PROMs are viewed by commissioners as a way of
To manage pain effectively and promptly it is imperative that pain theory is understood and the different descriptors attributed to nociceptive and neuropathic pain are recognised (World Union Wound Healing Societies 2004); this will ensure that the correct medication is provided.

**Action plan** The clinician should listen to how the pain makes the person feel and how it affects the individual’s life and relationships. It is important to ensure that documentation encourages the identification of the type of pain through descriptors and prompts. Assessment tools can be used to achieve this, such as the Verbal Rating Scale. The healthcare professional must ascertain when the pain is at its worst, what exacerbates it and which strategy is most effective in relieving it. Creating a personalised pain plan and scoring at each dressing change can help to ensure that effective pain relief is provided, as required. It is unacceptable to tolerate pain or allow it to remain uncontrolled.

**Outcome measures** Measuring pain reduction is important. Service providers need to be able to report that they have reduced pain in the target population. A simple outcome measure may be: ‘Has pain significantly decreased in all patients over a four-week period?’ The outcome will hopefully be ‘yes’ and each patient should then be assessed to measure the patient specific outcome. Using a scoring system can be complicated unless a good electronic database is accessible. Calculating the percentage of patients who no longer have severe pain, and describe their pain as being well-managed is a good indicator of patient-focused care. This outcome will be associated with improved quality of life and adherence with treatment, as well as ulcer healing rates, patient-centred care and the value of expert practitioner skills.

**Poor tolerance of treatment**

Non-adherence is a term often used by practitioners managing people with leg ulcers (Van Hecke et al 2008).

Non-adherence is more likely if patients cannot tolerate compression therapy because of unresolved pain or eczema, if the practitioner has a poor application technique, or if the patient has had little choice in the treatment plan. Pain or a lack of appropriate or well-fitting footwear may affect the individual’s ability to tolerate compression therapy. This was highlighted in Edwards’ (2003) exploration of patients who did not adhere to treatment.

For patients with complex or long-term wounds, healing is not a straightforward process. However, there are PROMs and other outcome measures that clinicians can use to establish their worth and the cost of the service to their organisation.

To evaluate the value of a service, managers of provider organisations may ask clinicians:

- Why should a commissioner invest in your service?
- What do you uniquely have to offer this patient group?
- Can you make a difference?
- What specific contribution do you make to improved patient outcomes? Can you provide evidence of your contribution?

Service commissioners may not know how to evaluate clinicians’ contribution except through activity or the number of complaints. Therefore clinicians need to be proactive and develop PROMs and other outcome measures that demonstrate improved patient wellbeing.

**Pain**

In a systematic review on the effect of leg ulceration on patients’ quality of life, Herber et al (2007) found that pain was the worst aspect of having an ulcer, as it interfered with individuals’ social lives, mobility and sleep. Heinen et al (2007) reported that pain is poorly managed and controlled. If healthcare professionals are to have empathy they need to understand the effect of pain on patients’ lives. Pain can make people more vulnerable, and they tend to feel ignored: ‘Can’t they hear what I say? Why don’t they listen to me?’ (Ebbeuskog and Emami 2005). Some may be angry because ‘they don’t believe me’ (Morgan and Moffatt 2008a). People expressing their pain have said: ‘I’ve never had nothing hurt like this...The damn thing never stops hurting’ (Krasner 1998) and: ‘It is like a very bad nagging toothache, all the time, all the time, and there is nothing you can do’ (Walshe 1995).

Husband (2001) found that patients with leg ulcers often believe they have to endure pain. It appears that this is still a common misconception and many patients are not given effective or adequate analgesia. This affects adherence to treatment (Woo et al 2008, Van Hecke et al 2009). For example, where compression therapy is required for healing, but cannot be tolerated, non-healing may be the result of poor pain management.
The only reason I cut it [the bandage] down was because it was hurting and it became unbearable.’

‘When A does it... it feels lovely, but when the others finish it I have hurt and pain.’

Patients are aware that questioning or expressing dissatisfaction can be seen as deviant and there is a danger of being labelled ‘difficult’, or even being accused of causing deterioration (Edwards 2003):

‘She was quite cross and said... it was the way they did it and I was expected to try and put up with it, cope with it’.

This was also reflected in a study by Hallett et al (2000) who explored nurses’ perception of adherence, with one practitioner saying: ‘I felt that every week they were deteriorating – partly from her own doing I think.’ Patients have referred to feeling as if they are being blamed: ‘I got fresh flesh breaking out and then they say “you scratched it”. I can’t even get at it. They try to blame me’ (Edwards 2003). Morgan and Moffatt (2008a) found that patients who tried to exert control over their clinical situation were labelled as difficult and not adhering to treatment.

Lack of continuity in treatment, lack of choice of treatments and lack of practitioner competence may result in poor tolerance of treatment and slow healing. Changes in treatment that are not accompanied by adequate explanations often result in patients’ doubting the practitioner’s competence, while patients feel objectified when treatment is performed in a perfunctory manner (Ebbeskog and Emami 2005). Patients know which nurse in the team they trust and are aware that knowledge is often accompanied by a caring attitude. They are conscious that consistent care is required, but feel they have little control over how care is delivered, which may, in turn, cause frustration (Mudge et al 2006).

With regard to compression therapy, practitioners have a duty to understand the scientific evidence so that they are able to apply effective compression that can be tolerated by patients (Hopkins and Worboys 2005). Action plan It is important to listen to why the patient cannot tolerate the treatment and what would influence change. The practitioner should be open-minded and non-defensive to allow exploration of the influencing factors. The multidisciplinary team should discuss the importance of consistent care and how this can be addressed within current resources. An action plan should be devised in partnership with the patient to address these issues and encourage patient choice. Healthcare professionals should seek specialist advice so that alternative dressings or compression therapies can be explored to promote tolerance.

Outcome measures Measuring the change from intolerance to tolerance of compression therapy is significant and should be reflected in the outcomes for the service. Improved tolerance to treatment can lead to improved quality of life for patients and healing rates, the delivery of expert practitioner skills and the promotion of positive nurse-patient relations.

Poor quality of life

Patients describe how ulcers affect their quality of life. Non-healing ulcers can have long-term restrictions for the patient. When asked how her life had been affected, one patient replied: ‘What area of my life? My whole life. I cannot do anything I want to do’ (Chase et al 1997). People who are housebound and want to get on with activities of daily living may feel restricted by having to wait for district nurses (Hopkins 2004).

The therapeutic relationship between the patient and clinician is a positive experience for many: ‘We are like mother and daughter in a way’ (Hopkins 2004). A positive relationship and appropriate support can influence the person’s ability to adapt or accept his or her difficult circumstances. For some, the presence of an ulcer becomes part of their lives (Hopkins 2004). Patients’ negative experiences of nursing management can lead them to believe that the nurse is not truly concerned about their plight or the complex issues they are facing (Morgan and Moffatt 2008b).

Odour is a major concern and source of embarrassment for many patients with leg ulcers. It can affect their behaviour, the clothes they wear, the social activities that they engage in and ultimately their quality of life (Walshe 1995, Hyde et al 1999, Hopkins 2004).

Action plan It is important to listen to how patients cope with a leg ulcer and how they feel about possible odour and exudate leakage. The healthcare professional should listen patiently as this may be one of the first occasions that the patient has felt comfortable enough to be open about his or her feelings. The practitioner needs to ascertain ways in which more support can be offered, and ensure that the patient’s management plan addresses his or her specific needs and concerns.

Outcome measures The change from poor quality of life to an improved quality of life can be an important outcome measure for service providers. A simple outcome is whether intervention has improved patients’ quality of life. This subjective assessment needs to be
obtained from the patient by asking, for example, ‘how would you describe the quality of your life at the moment?’, and then asking them the same question at a suitable review date, for example eight weeks later.

They may also be asked: ‘Has the intervention made a difference to your quality of life?’ A simple ‘yes’ or ‘no’ answer cannot be considered in isolation as there is an inherent risk of bias, but in a context of reviewing the service’s pain reduction or healing data, this will provide additional evidence for the value of the service.

Conclusion

It is vital to ensure that services are influenced by the patient’s experience and that the value of these services can be demonstrated. Patient and public involvement with the aim of improving the patient’s experience is now central to any work plan or service level agreement; this work can be guided by patient stories from qualitative research studies. Yet, when patients are asked about their experiences, it is clear that they are mixed; while some discuss positive themes and outcomes, many feel that they are not being listened to and that practitioners are not supportive enough.

Practitioners need to demonstrate that the service they provide is effective, evidence-based and has a positive effect on patients’ lives, and that the money spent on the service produces clear benefits for the population. This can only be achieved if outcomes are measured.

References


