Pain is one of the most common symptoms that cause patients to consult healthcare professionals. However, it is often inadequately treated leading to unnecessary suffering, poor quality of life and poor outcome of treatment (Haddox et al, 1997). This article focuses on one patient’s experience of leg ulcers and explores the way her experience of pain affected concordance with treatment.

Studies centred on chronic leg ulceration often find that health-related quality-of-life issues are a major concern for patients (Lindholm et al, 1993; Flett et al, 1994; Phillips et al, 1994; Franks and Moffatt, 1998; Hopkins, 2004), and findings from these studies are generally well known to healthcare professionals. However, there have been limited changes in clinical practice; anecdotal evidence suggests that the assessment of patients with leg ulcers remains primarily focused on the ulcer(s) rather than on the patient.

Organisations such as the World Union of Wound Healing Societies and the European Wound Management Association (EWMA, 2002; WUWHS, 2004) have issued detailed documents to remind healthcare professionals that a thorough pain assessment is part of good wound management practice.

**A PATIENT’S EXPERIENCE OF LEG ULCERS AND PAIN**

Patient X had experienced repeated episodes of leg ulceration over a period of five years before she was seen in the leg ulcer clinic. She was referred for two reasons: her leg ulcers were failing to heal; and she was ‘non-compliant’ with treatment. The clinic staff were informed that she had regularly discontinued dressing or compression therapy bandaging regimens and hosiery that had been initiated by nursing and medical staff.

On Patient X’s first visit to the clinic, a detailed history was taken of her leg ulceration before referral and she undertook a full assessment including Doppler ultrasound. Two venous ulcers just below her right lateral malleolus were diagnosed and a treatment plan was devised and agreed with the patient. During the assessment, Patient X was questioned on the reasons behind her previous attempts to remove the dressings and bandages applied. She reported that pain was a major issue and she appeared quite anxious about the possibility of her pain becoming worse with the proposed treatment. She stated emphatically that previous treatment had resulted in excessive exudate being trapped under the dressing, causing maceration and excoriation to the peri-ulcer skin. She explained that she had repeatedly reported the unrelieved severe pain and had been advised to take her prescribed analgesia at regular intervals (as she was only taking them as and when required). She had also had frequent episodes of wound infection, which again caused the pain to be much worse.

Compression bandaging was the therapy of choice, and Patient X and the nurse reached a clear understanding that she would accept the necessity of compression therapy. At the same time, her pain control was reviewed and adjusted to improve pain relief. Agreement was reached that Patient X would leave the bandages in situ in between attending the clinic and/or being visited by community nurses at home. It was also agreed that if the compression bandages began to cause excessive discomfort and pain then Patient X would contact the clinic immediately and she would then be seen at the earliest time available at either the clinic or her home to review the situation.
This was to provide support and supervision during the initial period of treatment.

With this level of support, we found that Patient X was able to tolerate the compression therapy, while the pain was controlled with regular doses of paracetamol (two doses of 500mg, four times a day). This was discontinued after the first two weeks of treatment as the pain had reduced dramatically because of a decrease in the amount of exudate.

Ten weeks after Patient X began attending the clinic her leg ulcers had healed. As the ulcers began to heal there was a noticeable change in the patient; she became happier and appeared to look younger. She wanted to improve her physical fitness so she joined a weekly exercise class. The change was so striking that it aroused the interest of the author. This led to the exploring of Patient X’s experience during the period when her leg ulceration was active.

Patient X was interviewed at her home one month after the leg ulcers had healed. The following provides an account of her experience of living with active leg ulceration for five years and offers an insight into the relationship between quality of life, pain, communication between healthcare professionals and patient concordance with treatment.

The impact of leg ulceration

The transcript of the interview illustrates how greatly the leg ulcers had affected Patient X’s daily life. Chronic leg ulceration had had an all-encompassing impact on her quality of life, touching all aspects of daily living. The effects ranged from sleep disturbance, reduced mobility, pain, altered body image, reduced level of independence and a feeling of anger and resentment regarding communication between herself and healthcare professionals (Figure 1).

Pain and concordance

The true extent of any patient’s pain experience is often subsumed by the focus on the wound (Hallett et al, 2000). In the case of Mrs Bates, it is likely that the pain she was experiencing had not been explored adequately before her referral to the leg ulcer clinic.

Patient X’s non-concordance was the result of two conflicting actions; while the healthcare professionals were giving treatment based on their expert knowledge according to what they interpreted as the aetiology of the leg ulcers, the patient was instigating actions that she felt necessary to alleviate her pain and discomfort. There was an obvious gap in communication between patient and healthcare professionals; Patient X’s own words (Figure 1) illustrate the nature and extent of the problem. Unfortunately, the actions she took contravened professional advice.

The failure of satisfactory pain relief appears to have been the main motivation for Patient X’s non-concordance; she wanted to avoid pain and, as a result, she did not follow the prescribed treatment. Without concordance with treatment it was not possible to achieve therapeutic goals, resulting in poorer patient outcomes (Finfgeld et al, 2003). While Patient X understood the purpose and necessity of the prescribed treatment, the pain she was enduring was so distressing that she felt compelled to take actions contrary to the advice of healthcare professionals.

MOBILITY

‘Leg ulcers restrict your mobility...you feel frustrated and sometimes you become so morbid. Pain causes sleepless nights. You go mad because of the soreness. Sometimes I had to get up to the surgery frequently every week.’

‘The foot becomes swollen...I couldn’t wear any shoes, which meant I couldn’t go out. Sometimes I am too tired to take care of the ulcer.’

COMMUNICATION

‘They [healthcare professionals] don’t listen…they don’t have the time. They kept telling me I had to keep the dressing on for a week...and there was quite a lot of discharge from the ulcer, it got trapped under the dressing and then it irritated the skin. The pain was so bad I had to take it off. But they kept saying I must leave the dressing on for a week.’

PSYCHOLOGICAL IMPACT

‘Pain monopolises your life...it is there all the time. Sometimes it is so bad and nights become so very long. There were sleepless nights and the accumulation of tiredness and constant awareness of the leg make it difficult to cope with everyday life. The pain was so bad it was indescribable.’

‘I was constantly aware of the pain, I found it difficult to smile or laugh.’

‘Red and raw...you can go mad. Even though they are healed...now I sometimes still think about the time when I sat on the edge of the bed at night and thought to myself, “how do I get through it?”’

SKIN IRRITATION

‘The discharge from the ulcer got trapped under the dressing...and it irritated the eczema...I ended up having to change the dressing...it was impossible to keep them on because the discharge got trapped underneath and it made the pain worse!’

Figure 1. A patient’s descriptions about the effects of leg ulcer pain.
the healthcare professionals. The impact of the psychological distress arising from the pain directly led to her non-concordance.

Studies that investigated patient concordance with treatment (Kyngas et al, 1996; Wainwright and Gould, 1997) found that the success of a treatment regimen depended on patients’ willingness to comply. Also, Elliott and Tunell (1996) and Myers and Macdonald (1996) advocated patient empowerment; they proposed viewing patients and healthcare professionals as equal partners in planning care, giving patients and healthcare professionals an equal share of the decision-making process.

In this case, Patient X felt she had no part in decision-making on the choice of her treatment. This led to her non-concordance and being labelled by healthcare professionals as a ‘difficult and non-compliant patient’. Further analysis of information relating to Patient X’s experience of pain demonstrates that her pain and discomfort were poorly controlled.

Figure 2 illustrates the factors that had the effect of exacerbating the pain she experienced.

Dimensions of pain
Paracetamol had initially been administered to relieve Patient X’s ulcer pain. However, as she explained, at times it failed to provide satisfactory pain relief, such as when exudate was a significant problem. This may have been partly because of the fact that before she came to the leg ulcer clinic only the physiological aspect of her ulcer pain had been addressed. Clinicians acknowledge that if they rely solely on the physiological model, satisfactory pain relief is difficult (and sometimes impossible) to achieve (McCaffrey et al, 2003).

Melzack and Wall (1965) put forward the gate-control theory of pain, which incorporates the affective–motivational as well as the sensory–discriminative components of pain. This theory supposes that the nature and severity of pain are the combined consequence of affective, cognitive domains, as well as physiological processes.

Stressful events can also perpetuate pain or reduce an individual’s capacity to tolerate it (Leavitt et al, 1980; Feuerstein et al, 1985). Keefe and Gil (1986) proposed the idea of a ‘pain anxiety–tension cycle’ to account for the chain of events whereby pain provokes anxiety, in turn enhancing the perception of pain. The anxiety state caused by the failure of the wound to heal, and then the unrelieved pain and discomfort may lead to the enhanced pain perception experienced by Patient X. Chen et al (2000) confirmed the relationship between pain and anxiety. To achieve satisfactory pain relief, both the physiological and affective components must be addressed.

Another psychological dimension of Patient X’s pain was the intense emotional distress associated with it. Her efforts to protect herself from the pain (Figure 1) increased in direct proportion to the emotional distress she experienced. This distress was a powerful motive for non-concordance with treatment.

The protracted nature of the patient’s leg ulceration led to two sets of related, but diametrically opposed, interpretations of the situation: one from the patient’s perspective; and the other from the standpoint of the healthcare professionals. This had a profound impact on communication between Patient X and the healthcare professionals involved in her care.

When such a disparate situation persists over a considerable time, it invariably raises anxiety levels in both the patient and the healthcare professionals. Elliott and Devine...
(1994) concluded that disparity between expectation of outcome and reality brought about a state of cognitive dissonance, which in turn increased anxiety. To reduce the anxiety caused by the disparity, the individuals concerned must be motivated to act in such a way as to iron out the inconsistency. In Patient X’s case, her anxiety about delayed ulcer healing was caused by a perception that the healthcare professionals involved in the treatment of her leg ulcers were not taking a sufficient interest in her situation. However, the healthcare professionals attributed the cause of delayed healing to the patient’s non-concordance.

**CONCLUSION**

It can be concluded from this case report that the root causes for the unsatisfactory and unresolved problems of patient–professional interaction were:

- Inadequate pain assessment
- Healthcare professionals’ over-reliance on physiological bias in interpretation of disease experience
- Inadequate understanding of the psychosocial dimensions of a patient’s pain experience
- Healthcare professionals’ reluctance to orientate their practice towards genuine patient empowerment.

If the experiences of patients with leg ulcers are to be improved, the issues identified in this case must be addressed, namely:

- To improve the assessment of patients with leg ulcers in general, and pain assessment in particular
- To provide appropriate clinical and educational support for the healthcare professionals involved (such as community nurses)

To show an increase in the use of leg ulcer specialist services. **WE**


