Who’s in charge? Towards a revolution in patient engagement in wound care

Just as most of us will become patients at some point in our lives, many of us have tried to get unscheduled or emergency support from healthcare providers and have been disappointed in their willingness to respond to our concerns, engage with us, or involve us proactively in our treatment, or that of our loved ones.

“The involvement of patients, carers and the public in health decision-making and self-care is core to the UK’s National Health Service and fundamental to quality care,” states the Royal College of Nursing (RCN)’s Principles of Nursing Practice (RCN, 2014). Meanwhile, “patient empowerment is synonymous with high quality care”, explained Tim Kelsey, NHS England’s National Director for Patients and Information (NHS England, 2013). And it probably works. Kelsey quoted a US study that found a patient’s skills and confidence to engage in their own healthcare could amount to a 21% reduction in costs.

Since 2004, the UK government’s mantra has been to ensure that the public and patients are empowered with greater choice, better information, and more control and influence relating to their health and lifestyles. In 2004, Sir Nigel Crisp stated that the NHS Improvement Plan set out the way in which the NHS needs to change in order to become truly patient led (Department of Health, 2004). Since then, measures introduced to build cohesive communities across the UK have had some success, but probably not enough. Healthcare as a whole is traditionally paternalistic and hierarchical and, therefore, seemingly at odds with this ethos of empowerment. In addition, doctors have increasingly limited consultation time and resources, as we know.

Patients, on the other hand, are empowering themselves whether we like it or not. More than 70,000 websites disseminate health information; in excess of 50 million people seek health information online (Cline and Haynes, 2011), with likely consequences for the healthcare system.

With an ageing population, increasing incidence of long-term conditions and a very challenging financial environment, healthcare services across the globe will have a significant challenge. Patients could be coming to their clinicians demanding specific courses of treatment and clinicians will have to respond proactively. Also, patients will be looking at different types of service delivery, such as Leg Clubs.

Meanwhile, the internet offers widespread access to health information, with the advantages of interactivity, information tailoring, and anonymity.

Why is patient engagement so important for us in wound care? Chronic wounds require treatment over a long period of time, and have an enormous impact on a person’s quality of life and wellbeing. Frequent dressing changes and wound monitoring mean that patients with chronic wounds have a higher level of interaction with clinicians than with almost any other disease. Achieving something approaching a 21% decrease in the costs of wound treatment due to increased patient engagement would save billions of pounds.

As with diabetes or HIV/Aids, it is essential for patients to take ownership of their treatment regimen to gain successful management over their disease. Patient forums are now emerging that work in close collaboration with treatment centres, like the Pressure Ulcer Research Service User Network (PURSUN) in pressure ulcer management. Online anecdotal evidence from patients experiencing living with a wound can complement traditional methods of capturing a
range of perspectives on the quality of care.

Similar networks are needed for the treatment of leg ulcers. During the past 10 years there has been an abundance of literature written about the incidence rate of leg ulcers and the high cost of their management. Nursing skill has had to keep pace with the rapid development of wound care products. However, as with diabetes, clinicians have to recognise the changing nature of medical technology and the general public’s expectations of health promotion and education designed to prevent disease.

There are some signs of hope emerging in the management of leg ulcers and I would cite three important examples:

- The findings of the recently published VenUS IV study (see: http://www.fastuk.org/research/projview.php?id=1519), which support the use of compression stockings for some people with venous leg ulcers, demonstrates that the day-to-day application of stockings can be successfully undertaken by patients and carers, as well as a range of clinicians – we might have known this already, but VenUS IV provides powerful proof. From a patient perspective, this may well promote greater independence (Ashby et al, 2014).

- The focus on patient wellbeing and quality of life in wound management, led by several key opinion leaders in wound care, health psychology and related fields, is helping to move the treatment emphasis towards one where patients are much more directly involved in their own treatment.

- The holistic assessment of a leg ulcer is possibly the single most important factor affecting its healing, and it is vitally important to determine the patient’s own perception of the wound and its associated problems. The rapid growth of specialist treatment centres, such as those following the Lindsay Leg Club model – where patients become active participants within a social model of care – addresses treatment, patient, and cost issues all in one, while freeing up the GP surgery resources across the country.

We have much to learn from other areas of healthcare. The phenomena of patient empowerment and advocacy grew exponentially with the development of HIV/AIDS treatment in the 1980s and ’90s, and it was arguably patient advocacy groups that drove down the cost of treatment. Diabetes care has developed enormously with highly sophisticated monitoring systems designed for patients and the quality of health management information for these patients is far superior to that available in chronic wound management. The highly effective fundraising activities of cancer charities show what can be done when the spotlight is shone on a common disease.

In conclusion, patients seek effective treatment in an environment that addresses their psychosocial and physical needs, and this is no less important in wound care than any other disease. The benefits to all in delivering this are enormous but, this may require the healthcare profession to continue to change, and this may create resistance from some quarters.

The paternalistic structures that dominate healthcare are changing, however, and this author believes that in the not too distant future our wound care patients will be thoroughly engaged in the course of their treatment, and will become not just the recipients of care, but its most effective and dynamic agents.

REFERENCES