Wanted: a theory base for palliative wound care

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Wound care is rightly focused on wound healing. However, there are a number of individuals, who are part of a whole and diverse population, for whom healing is problematic or unachievable. This arises when the diseases and conditions underlying the wounds are difficult or impossible to resolve. Malignant infiltration of the skin, epidermolysis bullosa, and progressive arterial disease are examples of diseases and conditions that come into this category. There are also individuals who, despite good care, sustain pressure damage at the end of life. In all of these cases, management goals shift from curative to palliative to optimise quality of life through the control of physical symptoms and co-morbid conditions, and attention shifts to psychological and social needs, in particular the preservation of dignity and self-worth. The emphasis is on supportive care for the individual with a wound, and for their partners and family. This includes skilled symptom management and disease palliation, and local wound management, with a key role for wound care products.

The role of theory

The overarching focus on wound healing is unhelpful to those in need of palliative wound care, and those who care for them. The theoretical underpinnings of wound care currently, together with this emphasis on healing as the prevalent end point in clinical trials, does not serve the needs of the palliative wound care group. Moist wound healing theory, for example, and the supportive products do not assist the management of a wet, necrotic, fungating malignant wound or pressure ulcer. Selective components of wound bed preparation (restoration of bacterial balance; management of exudate; management of necrosis through debridement) may provide a conceptual framework for palliative wound care. However, this needs critical review and validation. There are circumstances, for example, when dry wound management and the preservation or promotion of the natural eschar is the kindest and most clinically appropriate strategy for managing an individual's wound(s).

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Without coherent theory to guide decision-making supported, crucially, by appropriately designed products, patients and clinicians in the palliative wound care group have to 'make do' with products that were not designed for their level of need. The result is a constant trial and error struggle to make products fit, stay on the body, and not leak and embarrass the individual with the wound(s). A recent exchange on the palliative care web board (http://www.palliativedrugs.com) was a 'cry for help' for suggestions as to how to manage the extensive wet wounds resulting from tumour infiltration of the chest wall. This was being managed with babies' nappies, a suggestion that came from the patient herself. This level of struggle is well known to nurses working in palliative care settings. It is virtually impossible to solve these problems to an acceptable standard without a cogent theory base for palliative wound care, and products that are tailored to the needs of this group.

Evidence of unmet needs

One of the key barriers to research and development for this group, particularly in relation to innovation in product design, is the lack of data and evidence of unmet needs. The population has not been defined. From a manufacturer's perspective, it is difficult to make a business case for new product development when we cannot provide data on prevalence, and gaps in the wound care product portfolio.

Undertaking research on behalf of this group is challenging, particularly when there is a preference for population-derived statistical data, generated through randomised controlled trials, on the parameter of 'time to healing'. Well-designed and conducted case studies, with robust mechanisms for generalisations, would be a better option for generating rich evidence to explain the problems and experiences from the perspectives of patients, families, and clinicians.

Routine data capture, via the clinical notes, could provide a wealth of evidence regarding this needy group, with robust auditable record-keeping systems in place. Such data could comprise outcomes in relation to exudate management and a particular wound care protocol. We waste a vast amount of clinical information and expertise by not capturing data routinely, and by not using it to evaluate the care given against anticipated patient outcomes

or transferring it in an anonymised form on a 'need to know' basis. As a researcher, it concerns me that standards in clinical practice are not matched by those demanded in the collection of data within a research study.

A validated clinical tool

The WRAP collaboration (Woundcare Research for Appropriate Products: http://www.kcl.ac.uk/wrap) validated a clinical note making system (TELER® System of Treatment Evaluation: http://www.teler.com) for capturing clinical data. The system can also be used as a research tool. It has two main elements: a method of clinical note making and a measuring mechanism. The note making system is a method of recording the relationship between the care provided and outcomes in terms of clinically significant change. The validity of the measuring mechanism is substantially predicated on the use of valid knowledge to support the definition of clinically significant change, recorded on the measurement scale, the indicator.

The indicators define observable, patient-centred treatment and care objectives in the form of outcomes that are clinically significant. They are significant when they can be justified by appropriate theory or knowledge, including published clinical guidelines. The system is thereby a method of incorporating theory into practice, delivering evidence-based care, and monitoring the external validity of current evidence and guidelines. The wound care outcomes defined in the indicators address components of good practice that are eminently practical and achievable. For example, turning again to the management of exudate, indicators can be used to assess leakage, and the requirement to re-pad or redress the wound between planned dressing changes. An indicator can also be used to monitor the condition of the peri-wound skin in relation to maceration from exudate. In addition, indicators can be constructed with the patient to capture items of concern to them, which by being documented, can be acknowledged and addressed. Healing potential is not abandoned with this system: if healing can occur it becomes obvious. Where healing is unachievable the patient can still reach an optimal standard of care, measured on parameters of symptom management, local wound care, and supportive care.

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The system can be used in a paper or electronic format. The electronic software systems include an automated facility to calculate two indices: a patient outcome index and a quality of care index. The indices are calculated at the individual level and there is the capacity for a group level measure: the Health Gain Index.

A way forward

If the system were to be adopted in a number of wound care settings we could accrue data, as Gray (2005) has suggested, to inform the NHS and reach the wider audience of manufacturers, purchasers and providers, in the specialty of wound care generally. In addition, we could begin to define the palliative wound care population, to demonstrate the resources that are required when wounds are hard to heal, or fail to heal.

In their recent editorials, Harding (2005) and Lyder (2005) challenged us to think about our readiness to improve our standards of wound care and record keeping. What I am proposing is a single mechanism, a clinical note making system, for doing just that.

Gray D (2005) Promoting 25 years of excellence in wound care. *Wounds UK* **1(2):** 6
Harding K (2005) Are you ready to improve standards of care? *Wounds UK* **1(2):** 8
Lyder C (2005) Increasing accountability: are you up to the challenge? *Wounds UK* **1(1):** 8