Skin changes at life’s end (SCALE): a consensus document

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The occurrence of pressure damage in the dying patient has been realised for many years. Charcot (1877) described a specific butterfly-shaped ulcer over the buttocks in patients who died soon afterwards. Shenk (2003) noted the development of pressure damage in a patient, ‘at the end she was confined to bed, in a fetal position, was incontinent and in spite of all care and attention she suffered from decubitus’. More recently, Kennedy (1989) recorded the Kennedy Terminal Ulcer (KTU) as a specific subgroup of pressure ulcers developed by some individuals as they are dying, usually butterfly-shaped and situated predominantly, but not exclusively, over the buttocks. This generated interest and investigations were undertaken within palliative care settings. Hanson et al (1991) reported that 62.5% of pressure ulcers in hospice patients occurred within two weeks of death. Reifsnyder and Magee (2005) noted that pressure ulcers on individuals in a hospice setting were more prevalent in those who had a previous history of pressure ulceration or dementia. While Bale et al (1995) found a prevalence of 24% in hospice residents, Galvin (2002) performed an audit cycle in a hospice setting to discover whether the incidence of pressure ulceration could be reduced, and concluded that pressure damage at the end of life in some individuals may be inevitable, coining the term skin failure. This term is rarely used, but perhaps the time has come for healthcare professionals to acknowledge openly that prevention of pressure ulceration is not possible in all patients, and to begin to familiarise themselves, colleagues and the public with this term, in order that realistic expectations of outcomes of care can be made.

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In 2008 an expert panel was established in the USA to formulate a consensus statement on skin changes at life’s end (SCALE) (Sibbald et al, 2009). The panel discussed the nature of SCALE, the concept of the KTU and skin failure towards the end of life. The panel concluded that: ‘Our current comprehension of skin changes that can occur at life’s end is limited: that SCALE process is insidious and difficult to prospectively determine; additional research and expert consensus is necessary; and contrary to popular myth, not all pressure ulcers are avoidable.’ Specific areas requiring research and consensus were identified by the panel:

- The identification of critical aetiological and pathophysiological factors involved in SCALE
- Clinical and diagnostic criteria for describing conditions identified with SCALE
- Recommendations for evidence-informed pathways of care.

Healthcare professionals have been conscious for some time that, as a person reaches their life’s end, this fact is reflected within the body. Most signs are hidden, such as diminishing renal function, however some are more pronounced and may cause distress to that person and their family. End of life is defined as a phase of life when a person living with an illness will experience deterioration due to that illness, which will eventually cause death. This time period is not restricted to that short time period when the person becomes moribund, when death is imminent, but may begin some weeks beforehand (Qaseem et al, 2008).

The SCALE (2009) document proposes that the skin, the largest organ of the body, is not impervious to dysfunction at the end of life and that this may result in varying degrees of skin/tissue damage, including pressure ulceration. Skin compromise may include decreased cutaneous perfusion and localised hypoxia, resulting in a reduced availability of oxygen and the body’s ability to utilise vital nutrients and other factors required to maintain skin integrity.

Healthcare professionals engaged in caring for those patients who suffer extremely debilitating effects during the final months of their lives have noted that despite providing good skin care, repositioning, appropriate pressure-relieving equipment and optimising nutrition where possible, some patients will still develop pressure damage. This has been a source of frustration for the professional and regarded as a failure in care by patients/relatives, leading to complaints and litigation. Clearly
communication has a large part to play. Healthcare professionals need to engage with patients and their relatives to alert them to the possibility of pressure damage as a result of SCALE.

Many tissue viability nurses (TVNs) will have encountered the phenomenon of assessing a patient with pressure ulceration to their heels, only to discover on performing a Doppler ultrasound that the patient’s vascular supply has become dramatically diminished or vanished. This is often due to a combination of factors, diabetes and peripheral vascular disease being the most obvious, but also in the extremely aged patient, this may be a natural consequence of their extreme age and should not be regarded as abnormal. It then becomes imperative that professional colleagues and relatives acknowledge that this person may be coming to the end of their life and so provision should be made for a comfortable and dignified demise.

The Liverpool Care Pathway (LCP), (Marie Curie Palliative Care Institute, 2009), which has been implemented in many care settings has been demonstrated to be an invaluable tool in caring for those patients at life’s end, when no further active treatment is delivered and the emphasis of care lies in symptom control to enable the individual to die with comfort and dignity. The publication of SCALE raises the question that perhaps the inclusion of a risk assessment process within the LCP is required, to indicate the use of specific pressure-relieving equipment, according to whether the patient has flexion contractures which limit repositioning, or the patient’s wish not to be repositioned, etc. Currently, the LCP indicates that the pressure ulcer risk assessment tool for that individual organisation is utilised. However, this may not assist healthcare professionals in making the correct selection of equipment — it would surely be more correct to utilise a risk assessment tool specifically for the terminally ill patient to gain direction in management of the patient, for example, skin care (Chaplin, 2000). SCALE recommendations would support this change within the LCP, which could be achieved at local organisational level following discussion with the palliative care team, TVNs and other interested parties, especially patient groups.

The statements within the SCALE (2009) document would support the inclusion of a palliative care risk assessment tool and do bear a distinct resemblance to the aims of the LCP, specifically with regard to communication with the individual, family and friends, considering the patient’s desire to mobilise or sit in a chair rather than be nursed in bed, working in accord with the patient’s desire to take nutrition and whether any artificially delivered nutrition/ fluids should continue in a reduced amount or totally discontinued, skin care and symptom relief. However, the difference lies in that SCALE (2009) makes an overt statement that, ‘physiological changes that may occur as a result of the dying process may affect the skin and soft tissues and manifest as observable changes in skin colour, turgor or integrity’. This is not made clear within the LCP, nor is there any provision made for a specialist skin assessment under the circumstances of the dying patient.

It could be argued that the SCALE document has arisen from a need to avoid complaints or litigation. Regardless whether that is in part true or not, the SCALE document is the first of its kind to be frank and admit that pressure ulceration may be part of the dying process. Now that this is in the open arena, it falls to healthcare professionals, whether working in primary, secondary care, nursing homes or hospices, to ensure that this is acknowledged and that all appropriate means are taken so that the dying patient’s skin remains intact where possible.

There may be a danger in those care settings caring for the older person of making an assumption that the development of pressure damage at the end of life is a natural occurrence for all, and using the SCALE consensus in order to avoid the implementation of more technical, and therefore expensive, pressure-relieving equipment. To avoid this scenario, it will be necessary for all care settings to provide robust evidence in the form of risk assessment and documentation of care delivery, perhaps the employment of a TVN to provide an expert opinion as to whether the patient’s pressure damage could be avoided or not.

The SCALE (2009) consensus document is long overdue and will provoke examination of current practice in many care settings. It is to be hoped that this will, in turn, lead to a change in practice and the delivery of appropriate care to the dying in all care settings, not just the hospice.

References
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