Ten top tips: end of life pressure Injuries

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Pressure injuries occur due to unrelieved or intense pressure in intolerant tissues. Perhaps, no patient exemplifies this risk as well as the end-of-life patient. Patients at end of their life are often malnourished, immobile, less cognitively intact, and incontinent, when they may have not been before. While most end-of-life patients are under the care of hospice nurses, healthcare providers in any setting may interface with them. This article provides 10 tips to assist in reducing incidence of pressure injuries in this incredibly vulnerable population.

1 Before classifying the pressure injury as end-of-life, determine if the person is actively dying: There is no absolute certainty when anyone will die, but there is certainty that everyone will die. The person who is at this point in life should already be utilising hospice but, at times, the disease process does not take long enough for hospice to be brought in for care. Palliative and hospice care are becoming a more widely acceptable specialty in nursing and medicine. Frequently, hospice and palliative care are combined because the nature of practice overlaps.

According to the World Health Organization (WHO), palliative care is defined as "an approach that improves the quality of life of patient and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems" (WHO, 2005). Many times, a patient will transition from palliative care to hospice when the goals of care align entirely in comfort and quality of life, rather than treatment or cure. The goal and function of hospice care is to assist the person and family with creating a meaningful remainder of life, a dignified life, and bereavement support for those left behind. Some hospices offer continuous nursing presence and/or support for the patient and family during the anticipated last days. The difficulty is determining when the transition to actively dying has occurred.

There are many common presentations when a person is actively dying. Some include: change in level of consciousness, delirium, Cheyne-Stokes or agonal breathing, fluid build-up in the lungs and airway, new onset incontinence, dramatic blood pressure drop from the patient's normal range, mottling, cold extremities, oliguria and inability to swallow (Hospice Patients Alliance, 2018). This list is not all inclusive, nor does it specify in what order or timeframe the body and organs will begin to fail.

2 Determine goals of care for the patient and family: It is extremely beneficial when the goals are well known to family members, caregivers and providers. This conversation is far beyond establishing a 'full code' or 'no code' status. A suggested approach to discussing goals of care is the REMAP approach (LeBlanc and Tulsky, 2017). REMAP is an acronym for Reframe, Expect emotion, Map out the future, Align with values, Plan treatments that match values.

Establishing goals of care ensure that all members of the team, including the family, are in harmony in terms of what the plan will be during the course of dying. It should include what medical interventions will be continued, added, or stopped, the intensity of the care provided (for example, what to do if a wound infection develops), preferred treatment for pain, religious or spiritual discussions, creating a plan for distressing symptoms, what life things need to be accomplished before death, and what is the ideal outcome (for example, die at home?) for the person.

It is crucial in this population to thoroughly discuss the goals of care regarding all aspects of dying. This conversation ideally should take place prior to the actively dying phase, but should not be in the initial conversation regarding prognosis. The provider or initiator of the discussion needs to keep in mind that this can become a long conversation, require multiple parties, or take a few different attempts to get the questions answered and the plan laid out.

It is also important to engage palliative care within the discussion of pressure injury prevention or potential failure to prevent a pressure injury. If a patient already has multiple ulcers at the point of near death, educate and discuss that additional wounds or worsening of current wounds may be unavoidable, in the best circumstances. It is also important to discuss how the preferred care plan may or may not cause pressure injuries. For example, if the family declines turning due to the patient's distress, it needs to be clearly expressed that pressure injuries will likely develop. This conversation and the results should be documented in the medical record.

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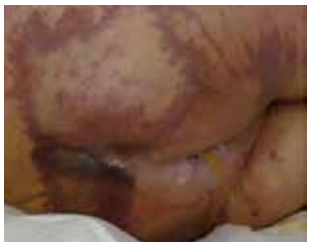

Figure 1. The purple area appeared following surgical repair of an abdominal aortic aneurysm. The patients right iliac artery was embolised. While pressure was likely a portion of the etiology, the primary issue was sudden loss of blood.

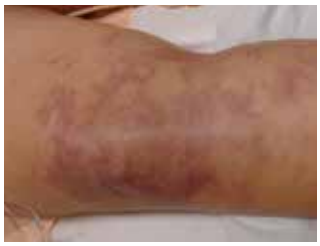

Figure 2. The mottling of this patient's legs appeared about an hour before she died. This change in color is due to physiological shunting of blood near the time of death.

3 Consider the cultural dynamics of the patient and family: Culture can be defined as "ideas, customs, and social behaviour of a particular people or society ... the attitudes and behaviour characteristic of a particular social group" (Oxford Dictionaries, 2018). In this regard, society can be defined as any social group of people. Nursing, medicine, acute care, long-term care and clinic care can all have different cultures. The familial culture is long ingrained into each person and becomes a foundation of conscious and unconscious beliefs about ways to live (McBride, 2006). These cultures create a foundation, but may need to be adjusted in the face of great change or unexpected outcome.

It may not be obvious who makes decisions in all families. At times, the dynamic of the family may appear odd or strange to providers, especially if that is not their own culture or preferred method of grief. In some cultures, the oldest male is expected to make all decisions for all parties of the household. If this is the case, the oldest male needs to be present for all education and discussion. Other cultures may encourage that the spouse is the only one who can make decisions. Some cultures teach that females are the only caregivers. Some families or family members may want to be present for all cares provided, while others will always remove themselves from the room. Some families may refuse for the staff to provide care, since that role may be well-established in their specific culture. In all cases, it is imperative to understand the culture of the patient. It may be easiest to ask the patient or family to explain how they function in decision-making and who needs to be present to discuss important concerns.

Culture becomes very important at end of life. Similar to other symbolic points of life, such as birth and marriage, activities associated with death are often well understood and defined by the family. This could include a funeral, burial, cremation, spreading ashes, keeping the body whole and intact and refusing organ donation. Some religions and cultures need to have a religious leader perform a ceremony or ritual for the dying person. At the time of death, families may request that the door or window be left open. Some may want silence or noise, only a few people present or as many as possible present, distracting conversations or no conversation, laughter or a melancholy environment. The role of healthcare providers is to respect the cultural preferences and follow them as much as possible.

4 Understand and differentiate between the terminology of pressure injuries at end of life: There are five different terms used to describe pressure injuries seen in dying patients:

"Decubitus ominosus" was a term used by Jean-Martin Charcot from the 19th century when he saw ulcers in patients with spinal cord or acute brain injury. His observation was that the patient died soon within hours or days after the ulcer was noted. The term is seldom, if ever, used today, but it is important to recognise the early view of skin changes at end of life (Levine, 2005).

"Kennedy terminal ulcer" was coined as a term by Karen Kennedy when she saw this subset of pressure injuries occurring quickly as an abrasion, blister or dark area on the sacrum or coccyx. They were pear or a horseshoe shaped and rapidly became full-thickness wounds. In Kennedy's study, 55.7% of the patients with this ulcer died within 2 weeks to several months. The longer life expectancy may be due to changes in the care provided after the wound developed (Kennedy, 1989).

"Skin failure" was described by La Puma (1991) and later discussed by Langemo and Brown as a component of multi-organ system failure. The skin is an organ and when failing it loses its ability to resist pressure and trauma and cannot assimilate nutrients, therefore, it cannot repair itself. Due to many of the cases involving extreme loss of arterial blood flow, these skin changes may not be pressure injuries at all, but rather skin loss during ischaemia. (Langemo and Brown, 2006)

Skin changes at life's end (SCALE) is an acronym developed to explain tissue, cellular or molecular dysfunction leading to tissue hypoxia. The condition starts with reduced tissue perfusion that leads to both a decreased tolerance to external insults and impaired removal of metabolic waste. A specific wound was not identified with SCALE, but rather observable changes in skin colour, turgor or integrity or subjective reports of pain (Sibbald and Krasner, 2009).

"Trombley-Brennan terminal tissue injury" is a term developed to describe a number of wounds appearing in the dying patient, not just wounds from pressure. The development of these wounds was not impacted by aggressive turning or positioning (Trombley et al, 2012).

The photo shown in *Figure 1* was a patient who embolised his iliac arteries during aortic surgery. The purple appearance led to the diagnosis of deep tissue injury, it could have easily been classified as any of the five types of pressure injuries discussed above. He died within 24 hours of the photograph being taken.

5 Just because pressure injuries can develop in end-of-life, it does not mean that they should: There is a drastic incidence range reported for pressure injuries at end of life. According to Carlsson and Gunningberg (2017), long-term care had the lowest pressure injury rate for hospice patients at 16.8% and inpatient palliative care units had the highest at 29.7%. The difference between patients that are not dying and those that are is that the goals have changed and, therefore, the care plan must also change. For example, when the person is seeking active treatment, another goal is to avoid unnecessary complications of the disease or disability. In the arena of 'cure', aggressive interventions are put in place to prevent hospital-acquired conditions, such as ventilator-associated pneumonia, deep vein thrombosis and pressure injuries. When the goal is comfort, the aggressive interventions are directed at preventing delirium, maintaining comfort and dignity, and assisting a meaningful life and a dignified death.

Some interventions to assist in preventing pressure injuries in the dying patient are prophylactic dressings, enhanced or upgraded mattresses, optimum turning schedule (for example, every 4 hours), and/or incontinence management/containment systems. Indwelling catheters are placed to reduce the discomfort of frequent skin cleaning and turning. Fecal containment systems may be necessary to promote dignity and comfort and prevent skin breakdown.

Tissue viability or wound nurses would be the ideal guide to help establish an appropriate turning schedule for skin integrity meshed with patient/family wishes and clinical assessment. Including the patient and family in the discussion and decision-making processes empowers the family to further understand the dying process and what is being done to ensure comfort for their loved one.

6 Anticipate high-risk situations for pressure injury development in dying patients: Many patients have dyspnea near the end of life and they sit in high-Fowler's position. In this position, the sacrum and coccyx are exposed to high levels of pressure and shear. When the patient cannot be moved due to worsening dyspnea, pressure injuries can develop quickly.

The loss of adequate arterial flow to the extremities can be seen as mottling *[Figure 2]* or frank ischaemia in patients on high doses of vasopressors (e.g levophed/norepinephrine). As the patient nears the last hours to days of life, blood is naturally shunted from the extremities, leading to mottling. Mottling can be useful in conjunction with other assessments to determine how rapidly the patient is dying.

Patients with marked malnutrition or cachexia have little padding to protect bony prominences. Even areas of the body normally covered with adequate adipose tissue are at risk of developing pressure injuries.

The most commonly occurring symptoms at end of life are nausea, pain and respiratory distress. These symptoms can make turning and repositioning even more challenging. In this instance, it would be appropriate to consider and encourage a higher-grade pressure redistribution support surface (Ripley and Collier, 2017).

7 Choose an appropriate prevention dressing: Preventive or prophylactic dressings have been shown to reduce pressure injuries in high-risk patients (Santamaria et al, 2015 Kalowes et al, 2016). Dressings should be placed on the sacrum to protect it from pressure and shear. A dressing that can be removed for skin inspection without skin stripping should be used. The dressing should be removed during routine care to reduce the number of painful movements required by the patient.

8 Choose an appropriate prevention mattress: Turning patients side to side at end of life will not be a priority and may not be possible in some cases. When the duration of pressure cannot be reduced, reducing the intensity is the only option. The patient should be placed on an alternating pressure mattress with a low air loss feature.

9 Intensely discuss the preferred interventions for potential sequelae: This tip hinges on a thorough discussion with the patient and family in tip 2: determining the goals of care. A wound that leads to sepsis can be fatal, and be independent of the original terminal illness or disease. Deep full-thickness sacral pressure injuries can develop infection with potential sepsis and death (Kohr et al, 2014).

Based on the goals of care, discussion should occur regarding what the intensity of interventions are for easily foreseeable complications. For example, if the patient and family refuse a turning schedule, the next series of questions should ask about the steps that occur after a wound develops. It can also be asked if appropriate prophylaxis can be put into place, such as an upgraded mattress or prophylactic dressing to prevent wounds. Use of antibiotics should be addressed, either for treatment of urinary tract infection, pneumonia or wound infection. This discussion should be clearly documented and reaffirmed with new wounds or changes in status.

If a wound develops prior to this conversation, it should be clearly discussed and documented

what the plan of care is for the wound, including any kind of debridement, frequency of dressing changes and establish a realistic outcome for the wound, with non-healing, worsening or additional wounds being a likely outcome.

10 Create an understanding that not every wound is avoidable in this population: The end-of-life patient population comes with a unique set of problems and circumstances, therefore, it is critical to reinforce with nursing staff that not every wound is avoidable. Nurses can become disheartened and frustrated when they provide the best nursing care they can and get blamed for an unavoidable negative outcome. According to Searle and McInerney (2008), nurses expressed difficulty in maintaining a turning schedule in the last 48 hours of life. The study found that clinical assessment of the patient varied when setting priorities for ensuring comfort, use of relief aids, following the patient and family wishes, and acting on the influence of colleagues.

When the root cause analysis of the wound is completed, it is important to return all findings, especially findings of unavoidable ulcers, to the nursing staff. Reporting to staff that there was nothing more that could have been done to prevent this or this wound would have developed regardless of interventions can help prevent ethical dilemmas in the nursing staff, reaffirm the correct processes are in place to assist patients to prevent and heal wounds, and that this wound is not a failure of nursing care.

Conclusion

These 10 top tips are a starting point for how to prevent pressure injuries at end of life, while still appreciating the patient and family dynamics at this critical point in time. These patients have multiple risk factors for developing pressure injuries and can be vulnerable and reliant on others for almost everything. It is crucial that the patient and his/her family make decisions together, keep communication open, honest and transparent, and allow for changes as needed.

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