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***"Enhancing end of life skin care to prevent pressure ulcers in primary care: key considerations for nurses"***

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## Enhancing end of life skin care to prevent pressure ulcers in primary care: key considerations for nurses

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**Abstract:**

Good primary care improves the health and wealth of nations as it is the context in which the majority of healthcare is delivered. Improving the quality of palliative care and reducing adverse patient related events are priority areas for improvement in primary care. One aspect of primary care that community nurses can improve is the quality of end of life skin care that. Given that the main objective of all end of life care is to facilitate a comfortable and dignified death for the patient in line with their wishes, it is important for nurses in primary care to be aware of what they can to ensure the consistent delivery of safe end of life skin care. This paper highlights key elements of the end of life skin care to prevent pressure ulcers which community nurses should take into account in their efforts to improve this aspect of primary care.

**Keywords**

Primary care, End of Life care, Pressure ulcers, Community nurses, Quality Improvement

## Introduction

There is a global focus on ensuring universal access to high quality healthcare that is delivered in a fair, just and equitable manner which improves population health and underpins the sustainable development of nations (WHO et al., 2018). The recent Astana declaration (WHO and UNICEF, 2018) reiterated the international focus on improving the quality and safety of primary care as it is an integral part of healthcare systems which enhance the health and wealth of nations. The focus on improving the safety and quality of primary care is apt because it is the context in the majority of health care is delivered and it is route by which most people make first contact with the healthcare system in their country (Cresswell et al., 2013, WHO, 2012). Therefore, primary care professionals play a key role in ensuring the consistent delivery of safe high quality patient centred care and co-ordinating specialist care in line with the patient's needs (Cresswell et al., 2013, WHO, 2012, OECD, 2017).

Palliative care and reducing adverse healthcare related events are two key international priorities for improving the quality and safety of primary care (WHO and UNICEF, 2018, WHO et al., 2018, OECD, 2017). Patient centred palliation is recognised as being central to the delivery of high quality primary care in all contexts through the life span in effective healthcare systems (WHO and UNICEF, 2018, WHO et al., 2018). A key global care quality indicator which is the focus of considerable quality improvements in primary care is the prevention of pressure ulcers. This is because a pressure ulcer is a largely avoidable financially burdensome adverse healthcare related event which results in increased patient morbidity and mortality (NPUAP et al., 2014, Slawomirski et al., 2017). Pressure ulcers are the most common wound that develops in patients who are receiving palliative care especially at the end of life (Sibbald et al., 2010, Maida, 2013b). It is important to acknowledge that improving the quality of palliative primary care in order to maintain skin integrity is challenging. When patients are approaching the end of life, their risk of developing wounds such as pressure ulcers increases due to physiological factors related to their disease progression and or treatment (Sibbald et al., 2010, Maida, 2013b). End of life skin care improvement efforts are also challenged by the fact it is challenging to determine which wounds can be prevented and which wounds are unavoidable (Sibbald et al., 2010, Beldon, 2011, Maida, 2013a).

Achieving the goal of consistently delivering high quality care which ensures patient safety requires individuals in healthcare systems to focus on the consistent delivery of care in an equitable and just manner with due consideration of the preferences of the patient and their loved ones at an organisational level (European Patients Forum, 2017). Nurses have been shown (Kirwan et al., 2013, Aiken et al., 2014) to play a key role in the delivery of safe high quality healthcare in a variety all contexts. In most care settings, patient care is co-ordinated and overseen by a nurse throughout the care trajectory from the start to the end of life (Allen, 2018). Consequently, it is important for primary care nurses to be aware of how they can consistently deliver the best possible end of life skin care which maintains the skin integrity of their patients for as long as possible.

There is a wide range of evidence (Sibbald et al., 2010, Beldon, 2011, Maida, 2013a) that focuses on key elements of end of life skin and wound care which is largely based on evidence from secondary care settings. Primary care is distinct from the other elements of a healthcare system in a variety of ways such as the length of care episodes, infrastructure and the level of patient engagement which merit consideration in relation to quality improvement efforts (Makeham et al., 2008, Makeham et al., 2015). It is important for people working in all healthcare systems irrespective of context to

consider how they can use the best available evidence and share learning to improve the quality of patient care that they deliver (WHO et al., 2018). Detailed step by step guidance on the delivery of end of life skin care to dying patients and the strength of evidence underpinning each element of care is set out in international guidelines (NPUAP et al., 2014, Sibbald et al., 2010) and other key documents (Langemo et al., 2015, Maida, 2013a) on pressure ulcer prevention. This paper utilises a diverse range of evidence to highlight key elements of end of life skin care to prevent pressure ulcers that nurses in primary care should integrate into improvement initiatives.

## **Decision making and terminology**

Nurses in primary care who wish to design or implement initiatives to improve decision making about end of life skin care must take into account some of the challenges that exist with regards to this aspect of patient care. Nurses find it challenging to make decisions about the delivery of skin care to prevent pressure ulcers in patient who are dying (Samuriwo and Dowding, 2014). Making decisions about how best to prioritise and deliver care at the end of life is challenging because of changes that occur to the body as part of the dying process (White, 2017). As people approach the end of life they are more susceptible to greater exposure to factors that contribute to pressure ulcers such as the diminished skin perfusion, limited mobility, incontinence, and decreased nutrition (White, 2017, Hotaling and Black, 2018, Langemo et al., 2015, Sibbald et al., 2010). When making decisions about skin care at the end of life, nurses have to take into account a variety of factors such as pathophysiological changes to the patient's body as part of the dying process, how close the patient is to the end of life, how comfortable the patient as well as the wishes of the patient and their family (Samuriwo and Dowding, 2014, Langemo et al., 2015). The complex interactions of these different factors often results in variations in the intensity and quality of skin care that is delivered to the same patient by different nurses (Samuriwo and Dowding, 2014). Therefore, any efforts to improve the end of life skin care in primary care must make it as easy as possible for by community nurses to make the most appropriate decisions in line with the patient's preferences and minimise unwarranted variations quality of care that the patient receives. One improvement approach that could be used to make decision making easier would to develop an end of life skin care decision making aid or care pathway that can be used by nurses in primary care.

It is also important for nurses in primary care to be aware of some of the main viewpoints and terms that are used with regards to pressure ulcers that develop at the end of life. There are two main views that relate to the development of end of life skin care at the end of life which merit consideration because they can have an impact on the manner in which nurses and carers look after patients in the community. One view is that pressure ulcer formation at the end of life is inevitable as skin breakdown is part of end stage organ failure as is sign of the patient's impending death (White, 2017, Ayello, 2017, Langemo and Brown, 2006). The alternative view is that while changes occur to the skin as part of the dying process, it is still important to deliver care to maintain the patient's skin integrity for as long as possible (White, 2017, Ayello, 2017). These two views are also reflected in the different terms that are used to describe pressure ulcers that develop at the end of life in different contexts. Pressure ulcers that develop towards the end of life are also known as Kennedy Terminal Ulcers (KTU), Decubitus Ominosus, Trombley-Brennan Terminal Tissue Injury (TB-TTI), skin failure and Skin Changes at Life's End (SCALE) (Ayello, 2017, Hotaling and Black, 2018, Langemo and Brown, 2006, Beldon, 2011). The terms KTU, TB-TTI and skin failure tend to be used by

people who perceive pressure ulcers at the end of life to be unavoidable. The view of most people who refer to pressure ulcers in the dying patient as KTU, TB-TTI and skin failure they hold the view that these types of wounds are a sign of that the patient's death is imminent.

There has been a move away from using different terms for pressure ulcers that develop as a person approaches the end of life in some settings. The use of different terms for pressure ulcers that develop at the end of life and the debate about whether pressure ulcers can always be prevented when a person is dying can divert attention from where it should be- on the delivery of safe high quality patient centred end of life skin care. Recent guidance from the NHS in England (NHS Improvement, 2018) has abolished the use of terms such as KTU and clinicians are now compelled to use the term pressure ulcer when skin disintegration occurs in a person that is approaching the end of life. The rationale for this decision with regards to the use of different definitions in England was to ensure that pressure ulcers that develop in patients at the end of life are treated and classified in the same way as pressure ulcers in other patients (NHS Improvement, 2018). This clarification of the terminology used in England highlights the fact that the most important thing for nurses to do is to focus on doing all that they care to ensure that patients at the end of life are consistently given the best possible skin care, irrespective of the view that is adopted about pressure ulcers at the end of life or the terminology that is used. It would be prudent therefore to focus on delivering the best possible individualised care for all people approaching the end of life.

## Assessment and evaluation

The first key element of patient assessment in end of life skin care is to establish the patient's prognosis and if they are dying in order to deliver individualised patient centred care (Hotaling and Black, 2018, Langemo et al., 2015, Sibbald et al., 2010). Once it has been established that the patient is dying, it is important to find out what the end of life care wishes, preferences and goals are for the patient and their family (Hotaling and Black, 2018, NPUAP et al., 2014). This is important as the main focus of any aspect of the care that is delivered at the end of life should be to deliver care in a manner that respects the wishes of the patient and their family in order to bring about what they consider to be a comfortable, dignified good death (Bergman et al., 2011, Hotaling and Black, 2018). Establishing the patient and family's priorities for end of life care is also important because they may opt not to receive some aspects of skin care for personal, spiritual or religious reasons (White, 2017, Hotaling and Black, 2018, Langemo and Brown, 2006). When patients and their families decline some aspect of end of life skin care, it is important that they are informed of the possible consequences and are advised to consider alternative approaches to protect the skin that may be less effective (Hotaling and Black, 2018, NPUAP et al., 2014). For example, if a patient refuses to be repositioned they can be offered a more advanced support surface and or prophylactic dressings to protect their skin at the end of life.

As with any other aspect of healthcare, it is important to carry out a holistic assessment of the patient and their needs, which for patients who are approaching the end of life includes a formal pressure ulcer risk assessment and pain assessment (Burt, 2013, Langemo et al., 2015, NPUAP et al., 2014). Any assessment of pressure ulcer risk in the dying patient must also be taken alongside a pain assessment (Burt, 2013, Langemo et al., 2015). Undertaking a pressure ulcer risk assessment and pain assessment simultaneously is important in order to ensure that any care that is delivered to protect the skin does not cause pain or result in distress for the patient (Burt, 2013, Langemo et al.,

2015). This formal pressure ulcer risk assessment must be revisited and updated when the patient's condition changes (Burt, 2013). The pressure ulcer risk assessment should include a comprehensive inspection of the patients' skin and the use of a validated pressure ulcer risk assessment tool which takes into account key risk factors such as continence, mobility, nutritional status and level of consciousness (Langemo et al., 2015). However, every nurse should use their own clinical judgement to make a decision about how best to deliver skin care to protect the patient's skin. The patient should be reassessed and any skin care that has been delivered should be evaluated regularly as the patient's condition changes.

## Care planning and delivery

Patients who are approaching the end of life must be placed on appropriate support surfaces and positioned in such a way that minimises their exposure to shear, friction and pressure which result in skin breakdown (Burt, 2013). The selection of the support surface and patient repositioning schedule should be informed by the patient's condition as well as their wishes and preferences (NPUAP et al., 2014). If necessary, community nurses should seek further advice and guidance from colleagues with expertise in tissue viability or palliative care on what support specific measures they can use to protect the needs of a specific patient in their care.

Other measures that can be used to protect the skin at the end of life include the use of prophylactic dressings on parts of the body that are at high risk of pressure ulcer formation as well as the use of catheters and faecal management systems in patients with continence issues (Hotaling and Black, 2018). When making decisions about the frequency of patient repositioning, nurses must decide on the best course of action to maintain the patient's skin integrity or to prevent further skin disintegration and give due consideration to the preferences of the patient and their family (Hotaling and Black, 2018). It is also important that patients who are approaching the end of life are given analgesia prior to repositioning if they are in pain or distress from their underlying condition and if changing their position is likely to increase their pain or analgesia (Langemo et al., 2015).

One way to ensure that all patients at the end of life receive consistent high quality care at the end of life is to adopt a hazard reduction strategy where the focus is on ensuring the comfort of the patient as well as minimising their exposure to pressure ulcer risk factors. A hazard reduction strategy at the end of life entails the use of approaches to maintaining skin integrity that are known to be highly effective such as regular patient repositioning (Samuriwo and Dowding, 2014). The frequency and intensity of patient repositioning should also evolve in line with the patient's condition and be informed by their preferences. Therefore, it would be best for community nurses to endeavour to frequently reposition patients who are approaching the end of life regularly alongside other aspects of palliative care. The only circumstances in which it would not be appropriate to reposition the patient is when it is contraindicated by the patient's underlying condition, it is apparent that their death is imminent or there is a specific directive from the patient or their family opting out of regular repositioning.

It is also important to explain to patients, family members and carers what they can do to protect the skin of the patient. Patients are keen to learn about what they can do to maintain their skin integrity and to treat pressure ulcers (Chaboyer et al., 2017). Some family members and carers may also be keen to actively participate in the delivery of end of life skin care of their loved ones.

Providing patients and family members with knowledge and insights into key elements of their care may also bring about patient and family activation. Patient and family activation helps to reduce adverse patient safety events because patients and their families have the knowledge, confidence and attributes that they need to manage key elements of their care (Coulter and Ellins, 2006). Information about key elements of end of life skin care can be provided to patients and their families through online resources and information booklets that use easy to understand everyday language. Information booklets and online resources easy to understand everyday language have been shown (Gethin and McIntosh, 2014) to be effective in informing patients and their families about other aspects of pressure ulcer prevention.

It is also important to bear in mind that in some primary care settings, community nurses and carers in the community may not be able to reposition the patient overnight. Therefore, well informed family members and carers may be able to reposition the patient overnight which helps to maintain their skin integrity. However, if family members wish to be involved in the delivery of end of life skin care such as patient repositioning then it is important that they are informed that the patient could die as they are being turned or not long after they have been turned. If family members also wish to reposition the patient without community nurses then there needs to be a mechanism in place to ensure that the patient has received sufficient analgesia prior to repositioning and the opportunity for family members and carer to seek further guidance from a community nurse at any time of day or night if they have any concerns about the patient's skin or overall condition. It is also important that family members are aware that even in the patient receives the best possible care, they can still develop pressure ulcers at the end of life as they cannot always be prevented (Hotaling and Black, 2018, Langemo et al., 2015, Langemo and Brown, 2006, Sibbald et al., 2010).

## Conclusion

All nurses in primary care have an obligation to improve the quality and safety of care that they deliver and to ensure that the end of life skin care that they deliver to prevent pressure ulcers is delivered in a fair just and equitable manner to every patient. This paper has drawn upon a wide range of global evidence relating to primary care, palliative care, tissue viability and nursing in order to highlight the elements of end of life skin care to maintain skin integrity that can be integrated into improvement initiatives. Therefore, it is envisaged that the information and tips set out in this paper will be of interest to an international audience of primary care nurses with an interest in improving the quality of skin care that they deliver to patients at the end of life. It is also hoped that the insights shared in this paper will enable primary care nurses to better understand what they can do to improve the quality end of life skin care with due consideration of some of the challenges that they may encounter. If efforts to improve the quality of end of life skin care are to be improved, then in it is vital that patients and their families are actively engaged with and any care that is delivered is individualised to meet the specific needs of each patient and their family.

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