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This is an author accepted manuscript version of “End of life skin care – Research informing theory to traverse between Scylla and Charybdis?”

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End of life skin care – Research informing theory to traverse between Scylla and Charybdis?

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Skin care is an integral part of palliation which enhances the quality of the end life and death for the person receiving care and their loved ones. However, there is a paradox that exists with regards to skin care at the end of life, which is a challenging and complex issue. Most pressure ulcers are thought to be preventable or avoidable if the appropriate care is put in place, so their formation is considered to be an adverse patient safety event (1, 2). However, others consider skin failure to be an inexorable part of the dying process for some patients (1-4). The view that pressure ulcers are unavoidable at the end of life is contested because of concerns that it may inadvertently give rise to inappropriate narratives, which obviate the need for healthcare professionals, especially those with limited expertise in palliative care, to deliver care to maintain skin integrity (1).

The pathophysiology of the dying process and changes to the goals of care at the end of life increase the risk of pressure ulcer formation (1, 2, 5, 6). As death approaches, the goals of care shift from active curative treatment focused on prolonging life to the provision of emotional and supportive care to optimise patient comfort, as well as quality of life (2, 6). There are guidelines that set out how to deliver end of life skin care to prevent pressure ulcers for as long as possible in a manner that is consistent with the goals of palliative care (2, 4). However, conflicts can arise between the goals of palliative care and the measures needed to prevent pressure related skin damage such as regular repositioning especially when a person approaches the end of life (1, 2, 6). Consequently, some have argued that it would be apposite to reconsider the appropriateness of monitoring and reporting pressure ulcer formation in palliative care patients as a sentinel patient safety never event (2, 4). However, there is a higher pressure ulcer prevalence among patient receiving palliative care compared to the general population and unwarranted or inappropriate variation in end of life skin care has been reported in different studies (1, 2, 6). One study (1) identified that more than half of the serious palliative care related patient safety incident reports at a national level were pressure ulcer related. Many shortcomings in pressure ulcer related care for palliative care patients were reported to have been caused by uncertainty about the type of care needed to maintain skin integrity in patients approaching the end of life (1). In other cases where unavoidable pressure ulcers developed in people at the end of life, a decision had been taken not to deliver skin care to maintain skin integrity at the behest of the patient in line with their preferences and priorities for end of life care (1).

The pathophysiological, emotional and spiritual frailty of patients approaching the end of life makes them susceptible to dangerous or harmful care (1). However, any interventions, treatments, therapies, or care that healthcare professionals deliver must be congruent with the aims, preferences and priorities of the individual approaching the end of life. It is often challenging for nurses to make decisions about key aspects of end of life skin care such as whether or not to reposition a patient because moving a person at this point may cause them pain or discomfort (4, 6). There have been some anecdotal reports of nurses being wary of repositioning patients who are approaching the end of life due to concerns about the patient dying during, or not long after being repositioned. The contrasting goals of pressure ulcer prevention and end of life care may give rise to moral dilemmas for nurses as they can equally justify a decision to reposition or not to reposition a patient at the end of life (6). However, there is dearth of research that has sought to understand the complexity of end of life decision making especially from the perspective of the nurse, the dying person and their family. Given the limited evidence that is available, nurses making decisions about the end of life skin care of a patient may feel like they are between Scylla and Charybdis or facing the horns of a dilemma. The idiom 'between Scylla and Charybdis' is predicated on Greek mythology (7)

and refers to the challenge of having to make a choice between the lesser of two evils. There is a pressing need for theory informing research to understand how end of life skin care can be improved to deliver the best possible outcomes for people who are dying and their loved ones.

Any such research must endeavour to understand and make sense of the culture that exists with regards to end of life skin care as well as its concomitant narratives. Dying can be understood as a socially constructed process in which a person and those around them come to terms with and deal with the challenges that arise as well as the changes that occur as the end of life approaches (8). Nearly 30 years ago Schou (8) argued that dying was a social process which merits problematisation, exploration, as well as analysis through research with a particular focus on its construction at micro, and macro levels with due awareness of context. Pan et al. (9) contend that there is dearth of literature and theory about how nurses deliver end of life care in a manner that reflects the professional values that they are expected to enact at this point in the patient trajectory. Perhaps then, it would be prudent for theory informing research into end of life skin care to take into account the socially constructed nature of death, the narratives that are at play with regards to this aspect of patient care, and how this relates to the virtues that nurses are expected to exhibit.

Research informing theory is needed to underpin improvement efforts with regards to the organisation and delivery of end of life skin care that contributes to a comfortable and dignified death. Predictive or explanatory and descriptive theories (10) are needed to improve this aspect of care. End of life skin care could be improved through predictive or explanatory theories which provide an insight how the different factors that affect the ability to maintain skin integrity can be mitigated or ameliorated to deliver the best possible outcomes in a manner that is consistent with the preferences of the dying person and their loved ones. Descriptive theories about end of life skin care could provide a better understanding of the factors that give rise to the reported uncertainty and moral dilemmas which nurses are said to face in relation to this aspect of care. This is important because changes to patient care, clinical or professional practice only arise when there is a clear understanding of the situation at hand, and there is a narrative or theory of action which reflects how healthcare professions deal with the situations that they encounter as an individual and as part of a wider collective.

The narratives that are shared or become part of the lore matter because they create and shape the culture. Stories shape people and cultures because they enable us to understand, reflect, learn and make sense of our experiences as well as what others have encountered, endured or overcome in their lives. More research is needed to develop, test and consolidate theory about end of life skin care and its challenges for healthcare professionals. Any novel theories about end of life skin care related decision making that are developed must be capable of simultaneously informing and underpinning patient care, but also transcend the different pressure ulcer/end of life related tools, policies or guidelines. It would be apt for such novel theory to conceptualise end of life skin care as a process in a manner that informs documentation, an organising construct which informs the organisation and delivery of care, as well as a prized professional ethos.

Further research and better theory may help us to tell better stories which shape a culture where end of life skin care is delivered in a manner that promotes the flourishing and wellbeing of the dying person, and their loved ones, as well as the people delivering care. Perhaps then, what at times feels like a tipping point of frightening extremes can become a turning point for delivering skin

care that facilitates flourishing at the end of life. Making decisions about end of life skin care may at times feel like navigating between Scylla and Charybdis, but research and theory are key to improving things in what is often the most important chapter of our life, when we die.

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