

Table 2. Summary of the Kennedy terminal ulcer scoping review sources ($n = 32$)

Author/Year/Title publication	Country	Discipline	Aim	Scholarly source/Type	Clinical setting	Methodology /Sample size	Key findings and recommendations
1 Alvarez et al. (2016). <i>The search for a clearer understanding and more precise clinical definition of the unavoidable pressure injury</i>	USA	Inter-disciplinary	Outlines the unavoidable Pressure Ulcer Committee (VCU Pressure Ulcer Summit) findings associated with unavoidable	Journal, Report	N/A	N/A	Unanimous consensus that some PIs are unavoidable, including KTU. KTU considered a PI sub-type. Precise KTU aetiology is unknown. Two KTU presentations outlined: 1. Bilateral coccyx or sacrum: pear, butterfly or horse-shoe shaped, erythematous and/or purpuric skin with/without epidermal erosion with irregular margins; sudden onset (2-weeks to several months prior to death); progressing to yellow or black colour.

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			or preventable PI				2. Unilateral ulcer on either buttock; rapid development (called 3:30 syndrome) 8-24 hours prior to death; small black or purple macular lesion with irregular margins; typically, no skin erosion present.
2 Beldon (2010). <i>Skin changes at life's end (SCALE): A consensus document</i>	UK	Nurse	Commentary on the 2009 SCALE consensus statement Sibbald et al.	Journal, Report	N/A	N/A	KTU: butterfly shaped subgroup of PI, generally located on the buttock, which can develop when patients are dying. Need to raise clinicians' awareness that some PI such as KTU are unavoidable and are a normal part of the dying

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			(2010)				process.
3 Beldon (2011). <i>Skin changes at life's end: SCALE ulcer or pressure ulcer?</i>	UK	Nurse	Commentary on skin changes at life's end (SCALE)	Journal, Clinical update	Hospice	N/A	Factors that contribute to the development of KTU are unknown. Despite receiving appropriate PI care, some patients quickly developed pressure damage to their skin, in the immediate period prior to their death. Skin deterioration is not a predictable part of the end-of-life, with active and appropriate PI prevention and treatment

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							required as a part of usual nursing care.
4 Brennan and Trombley (2010). <i>Kennedy terminal ulcers- A palliative care unit's experience over a 12-month period of time</i>	USA	Nurses	Description of KTU among palliating patients over a 12-month period	Journal, Original research	Palliative care unit	Prospective observations Sample $n = 22$	Sample: males = 9, females = 13; mean age 73 years (49-95); time of ulcer development to death ranged from 2-hours to six-days. Ulcer rapidly increased in size. Due to the influence of comfort medications, many participants unable to verbalise pain or discomfort. More KTU research needed. Data collection method (structured or unstructured observations) and analysis

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							not outlined.
5 Buscemi (2015). <i>Kennedy terminal ulcer: A case study</i>	USA	Nurse	Description of elderly patient with KTU	Grey literature, Conference poster	Community: home setting	Case study, Sample $n = 1$	Despite the implementation of wound care and strict offloading measures, the patient's ulcer suddenly deteriorated; turning black in colour. Referral to an Advanced wound specialist nurse resulted in KTU diagnosis. Patient expired six-days later. Hospice referral, patient and family education about imminent death may allow them to spend quality time

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							together.
6 Center for Medicare and Medicaid Services (2013). <i>CMS recognizes Kennedy terminal ulcer in long-term care hospitals</i>	USA	Unknown/ not stated	Update on PI reporting to the CMS	Journal, Report	Long-term care hospitals	N/A	KTU no longer a reportable quality measure in long-term care hospitals. Highlights that KTU are unavoidable and not caused by a lack of patient care.
7 Center for Medicare and Medicaid Services (2013). <i>CMS recognizes Kennedy terminal ulcer in long-term care hospitals</i>	USA	Unknown/ not stated	Update on PI assessment	Journal, Clinical	Long-term care	N/A	In patients with a terminal illness or end-of-life, should have PI thoroughly

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Medicaid Services (2013). <i>Kennedy terminal ulcer, mucosal pressure ulcers, and revised IRF-PAI</i>			for patients with terminal illness	update	hospitals and inpatient rehabilitatio n facilities		assessed to determine if they are KTU. All KTU should not be coded as a PI.
8 Graves and Sun (2013). <i>Providing quality wound care at the end-of-life</i>	USA	Nurses	Describes end-of-life wounds and their management	Journal, Clinical update	Palliative care	N/A	KTU occurs at life's end. KTU suddenly appear on the sacrum. Pear, butterfly, horseshoe shape, ulcer is coloured red/yellow/black. They are frequently larger than PI; beginning

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							<p>superficially and rapidly increasing in size and depth.</p> <p>Wound care treatment at life's end requires specialist knowledge skills and technology.</p> <p>Wound care aim: wound stabilisation; comfort, pain and wound exudate management; patient and family education; improve quality of life.</p> <p>Specialist Ostomy-Continence nurses should be consulted regarding wound management.</p>

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9	Hampton (2016). <i>Skin changes and skin care for people with diabetes at the end-of-life</i>	UK	Nurse	Describes skin changes in people with diabetes at end-of-life, including management	Journal, Clinical update	N/S	N/A	Many older people at life's end are malnourished, have multiple comorbidities and are unwell, increasing their risk of skin injury. KTU are painful and a lot of care is required in their management. Every effort should be made to prevent PI during life's end.
10	Horn and Irion (2014). <i>The integument: Current concepts</i>	USA	Physical Therapist	Management of end-of-life skin issues	Journal, Clinical update	Hospice	N/A	KTU described within the context of skin failure. Skin function compromised thought to contribute to KTU development within 1-

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<i>in care at end-of- life</i>							<p>2 days of death.</p> <p>End-of-life wounds cannot be healed; symptoms (pain, odour) should be managed.</p> <p>Medical and nursing models of palliative care are patient-centered care, patient self-management, and patient empowerment.</p> <p>Physical therapy and skin management practices are needed for optimal palliative wound management.</p> <p>Best practice guidelines end-of-life wound care have not been developed.</p>

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11 Kennedy (1989). <i>The prevalence of pressure ulcers in an intermediate care facility</i>	USA	Nurse	Examined the PI prevalence in an intermediate care facility	Journal, Original research	Intermediate care facility	Observational: chart audit (1983-88), Sample $n = 469$	Approximately half (55.7%) of patients with a PI died within six-weeks of its appearance. Authors described ulcer as a terminal ulcer, named Kennedy Terminal Lesion, and later renamed KTU. Authors hypothesised the presence of a PI might signal impending death. KTU characteristics: located only on the coccyx or sacrum; pear shaped; develops rapidly; red, yellow and black; death is imminent.

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							Life expectancy once KTU appears: 2- weeks to several months. 1988 data: 21 people died with a PI (21/101) 20.79%. 1987 data: 15 people died with a PI (15/85) 17.64%.
12 Kennedy-Evans (2009). <i>Understanding the Kennedy terminal ulcer</i>	USA	Nurse	KTU overview	Journal, Editorial	N/S	N/A	KTU first described in 1983 and are a subset of PI, sometimes seen in dying patients. Not all PI seen in dying patients are KTU. Updated KTU characteristics since 1983:

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							appear suddenly, generally on coccyx/sacrum, but can be located elsewhere. Pear, butterfly or horseshoe shaped, irregular wound edges, red, yellow or black colour, appears as an abrasion, blister, or darkened area and rapidly develops to a Stage II-IV ulcer. Further research needed to better define KTU aetiology and pathophysiology.
13 Langemo and Brown (2006). <i>Skin fails too:</i>	USA	Nurses	Literature review on skin failure,	Journal, Review	Hospice	Systematic review 1984-2005	Systematic literature review: 1984-2005; on skin failure, acute skin failure, chronic skin failure, multiple organ failure, end-

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<i>acute, chronic, and end-stage skin failure</i>			acute skin failure, chronic skin failure, multiple organ failure, end-of-life skin deterioration and PI				of-life skin deterioration and PI in hospices. Minimal literature published, with 7 articles and 1 editorial included in the review. Multiple studies examine the link between PI and time of death, with Kennedy (1989) publishing the first KTU study.
14 Lepak (2012). <i>Avoidable &</i>	USA	Physical Therapist	KTU overview	Journal, Clinical	Hospice	N/A	KTU are unavoidable despite the delivery of appropriate pressure injury prevention

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<i>inevitable? Skin failure: The Kennedy terminal lesion</i>				update			care. KTU develop due the hypo-perfusion and organ failure associated with the end-of-life, and do not reflect poor healthcare. Open dialogue and education with patient and family about end-of-life process and possible skin changes, can avoid miscommunication and blame. A possible discussion about patient's impending death may be prompted. Treatment: low possibility of wound healing. Management: aimed at effective pain

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							relief and aesthetic issues associated with wound odour, infection and drainage.
15 Lutz and Schank (2009). <i>The Kennedy terminal ulcer- Twenty years later</i>	USA	Unknown	KTU literature review	Grey literature, Conference poster	N/S	Literature review	Limited KTU evidence, which is predominately observational in nature. Additional research and expert consensus is necessary. Kennedy 1989 study: 55.7% of patients died within six weeks of PI development.
16 Martin (2014). <i>Understanding the Kennedy</i>	USA	Nurse	Question and answer KTU website	Grey literature, Website	N/S	N/A	KTU are a type of PI reported in some dying people and hospice patients. KTU aetiology hypothesised as poor

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							terminal ulcers blood perfusion and multi-organ failure associated with the dying process. Treatment is suggested as the same for Stages I-IV PI.
17 Merugu and Rosenzweig (2016). <i>Wound care</i>	USA	Doctor	Guide to wound care	Book, Chapter	Long-term care facility	N/A	KTU, indicative of the dying process, and develop prior to death. KTU are pear, horseshoe or butterfly shaped lesions with irregular borders, coloured red/purple, turning yellow then black. They develop suddenly, are often located on sacrum, start as a blister or Stage II PIP, and rapidly progress to

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							Stages III-IV PI. Unknown aetiology, but thought to be part of multi-organ failure associated with the dying process. Most KTU do not heal. Their treatment and management follows PI clinical practice guidelines.
18 Miller (2017). <i>The death of the Kennedy terminal ulcer</i>	USA	Doctor	Author presents new concept 'Miller Pressure	Journal, Clinical update	N/S	N/A	Current KTU knowledge is based on observations and not objective science or pathophysiology. Concept of KTU does not accurately reflect our current understanding of

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			Equivalent Injuries'				<p>pressure based tissue injuries.</p> <p>Author refutes the suggestions that despite appropriate pressure relieving prevention care, the dying process is the primary cause of KTU. Suggests “the most logical conclusion when a solitary pressure based tissue injury is identified is that uniformity of care did not occur” (p. 3).</p> <p>KTU concept used as a litigation defence ‘Miller Pressure Equivalent Injuries’ (MPEI) scenario presented as an alternate to KTU.</p>

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							MPEI concept explains that pressure is the causative factor of pressure based tissue injuries, and not the patient's terminal health status. Recommends further research on the relationship between pressure, dying process and time of death.
19 Miner (2009). <i>Discharge to hospice: A Kennedy terminal ulcer case report</i>	USA	Nurse	Author's experiences with her dying father	Journal, Case study	Hospice	Case study, Sample $n = 1$	Case study of patient diagnosed with a brain tumour, and died seven weeks later. One day prior to death, during the active dying stage, sudden skin changes on heels and calves: turgid, almost black

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20 Nesovic (2016). <i>Kennedy terminal ulcer: A retrospective chart review of ulcers in the hospice setting and educating providers and nurses on the importance of</i>	USA	Nurse	Describes PI and KTU prevalence data, including their characteristic s and location in hospice patients over 18-months.	Grey literature, Dissertation	Hospice	Retrospective chart audit, Sample $n = 363$	discoloration with epidermal separation. Reports 6.1% KTU prevalence rate, however KTU proxy used during data collection: “Ulcers on sacrum/coccyx, identified post hospice admission”. Insufficient detail in chart documentation to accurately determine the difference between PI and KTU. 61.5% of healthcare professional had prior knowledge of KTU. Large gaps in KTU literature, with recommendations for more research.

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<i>skin changes at life's end</i>			Describing healthcare professionals' KTU knowledge.				
21 Olshansky (2010). <i>'Kennedy terminal ulcer' and 'skin failure,' where are the data?</i>	USA	Doctor	Letter to editor regarding Yastrub's (2010). publication	Journal, Letter to Editor	N/S	N/A	Suggests KTU aetiology is not multi-organ failure associated with dying process, rather "the effects of unrelieved pressure or shear that result in an unavoidable skin ulcer" (p. 466). To accurately diagnose KTU, inadequate pressure relief as a causative factor must

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							<p>be first excluded.</p> <p>“before we label an ulcer as “unavoidable,” we should be sure that it was not because we fell down on our care” (p. 466).</p> <p>Yastrub response: a PI diagnosis excludes the presence of a KTU.</p> <p>Tendency for skin integrity breaches to be labelled as PI by medical and legal professions, suggesting that nurses are negligent when repositioning patients, resulting in PI wounds. No empirical evidence supports a specific tuning</p>

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							regime. KTU frequently observed among dying people, and may be caused by hypo-perfusion.
22 Reitz and Schindler (2016). <i>Pediatric Kennedy terminal ulcer</i>	USA	Nurses	Describe KTU in paediatric patient	Journal, Case study	Paediatric palliative care unit	Case study, Sample $n = 1$	KTU not described in paediatric patients, making them an under-recognised issue in this patient group. Case of a 5-month old baby post cardiac surgery. No previous PI, however in the “24-hour period prior to her death... a 15-cm x 4 cm pear-shaped maroon lesion on her coccyx consistent with the appearance of a KTU” (p. 275).

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							Limited evidence on the appropriate care of KTU. Greater KTU knowledge will assist clinicians, patients and family members to make care choices based on palliative care.
23 Rivera and Stankiewicz (2018). <i>A review of clinical incidents: Skin failure in the</i>	Australia	Nurses	Describe three clinical incidents were acute medical patients with	Journal, Case study	Acute medical unit	Case study, Sample $n = 3$	KTU described as part of the concept of 'skin failure'. The nomenclature surrounding skin changes at life's end is confusing. Patient care includes minimising pain. Specialist clinicians with KTU and skin

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<i>dying patient</i>			Stage III-IV PI subsequently died.				failure expertise needed to accurately diagnose and manage these complex wounds. More research needed on accurate assessment such as body mapping.
24 Sarabia-Cobo (2017). <i>Poly ulceration patient terminal: Kennedy terminal ulcer</i>	Spain	Nurse	Description of KTU definition, aetiology and treatment.	Journal, Clinical update	N/S	N/A	Accurately distinguishing between PI and KTU allows patients and their family to receive the best care.

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25 Schank (2009). <i>Kennedy terminal ulcer: The "aha!" moment and diagnosis</i>	USA	Nurse	Description of two case studies where dying patient developed PIs	Journal, Case study	Long-term care facility	Case study, Sample $n = 2$	Dying patients suddenly developed PI which failed to respond to treatment. Clinicians and families expressed guilt and shame when patients under their care developed KTU. For clinicians, sense of guilt compounded by the common belief in healthcare sector, that most PI are preventable. Further KTU research needed to help clinicians, patient and families understand the causes of end-of-life skin changes and appropriate care options.

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26 Schank (2013). <i>Notes on practice: Elder abuse or Kennedy terminal ulcer</i>	USA	Nurse	Describes the KTU literature. Presents three case studies where dying patient developed KTU	Journal, Case study	Long-term care facility and community	Case study, Sample $n = 3$	A case reported where a family member was convicted of elder abuse and jailed for 3 years, when KTU misdiagnosed. Accurate KTU diagnosis provides the opportunity for patient, family and clinician education, and care wishes to be respected. Author challenges the myth that poor care results in KTU will contribute toward reducing the emotional stress experienced by family and nurses caring for dying patients.

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27 Shepard (2015). <i>Hospice nurses' experience of caring for the elderly with wounds at the end-of-life</i>	USA	Nurse	Understand hospice nurses' experiences for caring after older patients with end-of-life wounds	Grey literature, Dissertation	Hospice	Semi-structured interviews, Sample $n = 13$	KTU are a subset of PI, and a manifestation of the SCALE process. Limited evidence on nurses' perceptions of end-of-life wounds. Five themes emerged: 'difficult to achieve comfort'; 'healing is unrealistic'; 'coping with conflict'; 'hospice wound knowledge deficit', and 'positive affirmation'. End-of-life wound can have legal implications for nurses, because families are often not informed that, despite appropriate nursing care, skin breakdown

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							can occur during the dying process. Physicians and hospice nurses require more information, training and education on how to be manage end-of-life wounds, including patient comfort, pain relief and wound odour.
28 Sibbald et al. (2010). <i>The SCALE expert panel: Skin changes at life's end. Final</i>	USA	Inter-disciplinary	Consensus statement on KTU, skin failure and SCALE	Journal, Report	N/S	Modified 3-phase Delphi method approach	Panel discussed and consensus reached on the concept of KTU, skin failure and SCALE. Most KTU evidence is observational, but supports the premise that the skin becomes compromised during the dying

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<p><i>Consensus document. October 1st 2009.</i></p>							<p>process. KTU definition: “A pressure ulcer that some individuals develop as they are dying. It is usually shaped like a pear, butterfly, or horseshoe, usually on the coccyx or sacrum (but has been reported on other anatomical areas); is red, yellow, or black; is sudden in onset; and usually is associated with imminent death” (p. 234).</p>	
29	Stephen-Haynes (2012). <i>Pressure</i>	UK	Nurse	Review the UK PI policy	Journal, Clinical	Palliative care unit	N/A	SCALE not acknowledged in UK health policy, which indicates that all PI are

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<i>ulceration and palliative care: Prevention, treatment, policy and outcomes</i>			and provide an overview of current PI prevention practice in palliative care	update			preventable; contradicting current pressure injury prevention clinical practice guidelines. Urgent need for SCALE research to better understand why some dying patients are vulnerable to skin breakdown, and if KTU is a real phenomenon and is it preventable.
30 Trombley, Brennan, Thomas and Kline (2012). <i>Prelude to death</i>	USA	Nurses	Describe the observed skin changes in dying	Journal, Original research	Palliative care unit	Retrospective chart audit of patients with skin	Median time from admission to death was 11 days. 98.8% of patient wounds were superficial and remained intact at the time of death;

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<i>or practice failure?</i>			patients.			changes at	not progressing to stageable wounds.
<i>Trombley-Brennan terminal tissue injuries</i>			Determine the relationship between skin changes and patients' death			life's end (Jan 2009 - June 2011), Sample $n = 80$	Rather than a KTU, authors suggest new observed phenomena: Trombley-Brennan Terminal Tissue Injuries (TB-TTI). Despite aggressive repositioning and wound prevention care, TB-TTI are unavoidable and appear on body locations absent of any pressure/trauma.
31 Vera (2014). <i>Literature Review of Kennedy terminal ulcers:</i>	USA	Nurse	KTU literature review: Assessment,	Grey literature, Dissertation	Palliative care unit	Literature review	KTU, a sub-set of PI, develop in some dying patients. Accurate assessment of KTU needs to be conducted by an expert wound consultant

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<i>Identification, diagnosis, nursing goals, and interventions</i>			diagnosis and treatment				(nurse or doctor). Interdisciplinary approach to KTU management advised. Early patient and family involvement in care decisions, and education of impending death KTU management includes adequate analgesia, effective wound care (exudate, odour), infection and prophylaxis. More KTU research needed to raise awareness and treatment. Patient's quality of life may be impacted if KTU is misclassified as a PI.

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							KTU deemed unavoidable in 2008. Prior to this, these tissue injuries were subject to financial penalties and litigation.
32 Yastrub (2010). <i>Pressure or pathology: Distinguishing pressure ulcers from the Kennedy terminal ulcer.</i>	USA	Nurse	KTU overview and management	Journal, Clinical update	Acute care hospital	N/A	Author is an “expert in defense cases for unavoidable wounds.” Documented KTU provides a feasible defence for clinicians facing negligence charges. Often clinicians assess KTU as PI; significant implications for wound healing. Accurate KTU diagnosis relies on

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							<p>specialist clinician knowledge, full patient medical history and an awareness of impending death.</p> <p>Following KTU diagnosis, appropriate treatment goals are established. Patient, family and clinicians should be educated regarding treatment (comfort and quality of life).</p> <p>KTU are not a sign of poor care or abuse.</p>

N/A: not applicable; N/S: not stated; UK: United Kingdom; USA: United States of America