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Pediatric Kennedy Terminal Ulcer

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A Kennedy terminal ulcer (KTU) is the product of unavoidable skin breakdown that can occur during the dying process. A KTU is a separate entity from a pressure ulcer because it originates from skin failure rather than from pressure or shearing. A KTU is caused by intrinsic factors, including hypoperfusion and ischemia associated with multi-organ failure, whereas a pressure ulcer is caused by extrinsic factors, including unrelieved pressure or shearing (Yastrub, 2010). This unique type of ulcer most commonly presents as dark red and pear-shaped with irregular borders on the coccyx (Figure 1), although it may also be yellow or black and may be found in other locations (Brennan and Trombley, 2010, Kennedy-Evans, 2009 and Schank, 2009). Initially staged as a pressure ulcer, KTUs can progress dramatically within hours and can appear from 2 hours to 2 weeks preceding a patient's death (Brennan & Trombley, 2010).

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Figure 1. Kennedy terminal ulcer.

Used with permission from Karen Lou Kennedy-Evans, <u>www.kennedyterminalulcer.com</u>. This figure appears in color online at <u>www.jpedhc.org</u>.

The KTU was first defined in 1983 by Karen Kennedy-Evans, a family nurse practitioner who started one of the first skin care teams in a long-term care facility. Kennedy-Evans discovered the phenomenon after tracking pressure ulcer prevalence in a 500-bed long-term care facility (Kennedy, 1989). Her data demonstrated that 55.7% of people who had a pressure ulcer upon dying died within 6 weeks of its onset (Kennedy-Evans, 2009). This observation raised the question of whether these wounds were pressure ulcers or a different type of ulcer that represented organ dysfunction preceding death.

Traditionally, KTUs have been described in the geriatric population rather than the pediatric population. Risk factors for developing a KTU include multiple organ failure (e.g., renal failure and respiratory failure; <u>Curry et al., 2012</u>). Understanding and diagnosing KTUs can help the health care team address any modifiable risk factors and prepare the family for the option of palliative care. <u>Kennedy-Evans</u> (2009) asserts that the KTU is in fact distinct from pressure ulcers. Whereas pressure ulcers are traditionally believed to be associated

with failure of care, a KTU occurs when skin, like other organ systems, exhibits increasing signs of dysfunction. Identifying the difference between pressure ulcers and KTUs can also affect what is considered a "preventable outcome" by the Centers for Medicare and Medicaid Services (CMS) and can have a potential impact on reimbursement.

Case Presentation

A 5-month-old female patient who had a history of tetralogy of Fallot with an atrioventricular canal defect and pulmonary stenosis and had undergone central shunt placement was admitted directly to the pediatric intensive care unit (PICU) from the cardiology clinic with hypoxia. Upon admission, she was noted to have significant cardiac failure and decreased pulmonary blood flow and underwent complete repair of her cardiac lesion 3 days after arrival at the PICU. Her postoperative course was complicated by low cardiac output syndrome, necessitating extracorporeal membrane oxygenation support, and *Pseudomonas aeruginosa* sepsis with subsequent endocarditis. After her infection cleared, she was successfully weaned from extracorporeal membrane oxygenation but continued to have significant cardiac failure, requiring high-dose vasopressor support.

Further cardiac evaluation revealed right pulmonary artery stenosis, and she subsequently underwent balloon angioplasty. After cardiac catheterization, her clinical course was characterized by multisystem organ dysfunction, including her respiratory, cardiac, and renal systems. Ultimately, she was transitioned to high-frequency oscillatory ventilation and underwent continuous veno-venous hemofiltration. Throughout her hospitalization, she was positioned on an infant warmer with a specialty gel surface overlay with standard pressure ulcer prevention interventions, including frequent repositioning, gel pads to offload pressure over bony prominences, and daily application of a moisturizer. She did not experience any pressure ulcers or skin breakdown during her complicated course; however, 24 hours prior to her death, her nurse identified a 15 cm \times 4 cm pear-shaped maroon lesion on her coccyx consistent with the appearance of a KTU (Figure 2).



Figure 2. Pediatric Kennedy terminal ulcer.

This figure appears in color online at <u>www.jpedhc.org</u>.

Case Study Questions

- 1. What are the signs and symptoms of a KTU?
- 2. What does the evidence indicate regarding the epidemiology and pathophysiology of a KTU?
- 3. What is the role of the pediatric nurse practitioner (PNP) in the care of children with a KTU?
- 4. What are evidence-based practices for the treatment of a KTU?
- 5. How does the diagnosis of a KTU affect the CMS reimbursement policy for preventable outcomes?

Case Study Answers

Signs and Symptoms

1. What are the signs and symptoms of a KTU?

The diagnosis of a KTU relies on the child's medical, surgical, and social history, as well as an awareness that the child is nearing death. The diagnosis should start with a thorough assessment and a focused review of systems, medication regimen, and most recent laboratory tests (<u>Yastrub, 2010</u>). The CMS Long-Term Care Hospital Quality Reporting Program Manual specifically mentions coding for

KTUs in comparison with pressure ulcers and states that skin ulcers should continue to be staged as pressure ulcers until it is confirmed that they are part of the dying process (<u>CMS, 2013</u>). Physical characteristics of a KTU are a pear, butterfly, or horseshoe shape with an initial shallow depth and irregular borders. They may appear red, yellow, purple, or black. A KTU is most commonly found on the sacrococcygeal area, although it can be present in other locations as well (Graves & Sun, 2013). These ulcers usually develop rapidly in size and depth; they may appear as an abrasion or blister but can progress into a stage III or IV ulcer. The patient's death typically occurs from days to weeks-months after the initial appearance of the ulcer (Graves and Sun, 2013 and Kennedy, 1989). Distinguishing characteristics of a KTU versus a pressure ulcer are that the KTU appears to have been present days or weeks longer than it actually has and develops despite use of preventative measures (Kennedy-Evans, 2009).

Epidemiology and Pathophysiology

2. What does the evidence indicate regarding the epidemiology and pathophysiology of a KTU?

The skin requires 25% to 33% of cardiac output to remain viable; therefore, decreased circulation and increased shunting as a result of illness or vasopressor use can lead to skin death (Schank, 2009). One retrospective study hypothesized that skin failure was the result of a combination of immobility and multiple organ failure, or another form of physiological disease, which led to ulceration in patients for whom pressure ulcer prevention measures had been instituted (Levine, Humphrey, Lebovits, & Fogel, 2009). Patients at risk of experiencing a KTU include those with respiratory failure, diabetes mellitus, hypoalbuminemia, hypoxemia, renal disease, or failure of two or more organ systems besides the skin (Curry et al., 2012 and Levine et al., 2009). One study found a positive correlation between concurrent sepsis, renal failure, and skin failure and between concurrent use of various vasopressors and skin failure (Curry et al., 2012). A KTU is caused by intrinsic factors including hypoperfusion and ischemia associated with multi-organ failure, whereas a pressure ulcer is caused extrinsically by unrelieved pressure or shearing (Yastrub,

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<u>2010</u>). This difference in etiology is important when discussing potential care of a KTU.

Role of the PNP

3. What is the role of the PNP in the care of children with a KTU?

Even with consistent, ongoing assessment of stressed areas, skin and underlying tissue failure may develop, with the skin and underlying tissue dying as a result of hypoperfusion concurrent with a critical illness (Langemo & Brown, 2006). Factors that contribute to this process include the use of vasopressors, the use of cooling mattresses, anemia, malnutrition, and immobility, which each uniquely contribute to decreased perfusion to the skin (Langemo & Brown, 2006). This process can be unavoidable in critically ill individuals and can be associated with the development of KTUs (Lepak, 2012). When faced with acute skin failure, the role of the PNP is to optimize peripheral oxygen and substrate delivery, maintain the skin's acid mantle, and optimize the child's nutrition (Edsberg, Langemo, Baharestani, Posthauer, & Goldberg, 2014). Despite efforts to achieve these goals, KTUs may still develop because the magnitude of illness and the severity of risk are overwhelming (Lepak, 2012). Although healing is often the goal of the clinical team, the PNP may help to set more appropriate goals, including controlling pain associated with the wound, preventing infection, and managing any drainage to prevent maceration of the peri-wound skin (Sibbald et al., 2008). The PNP should meticulously document the risk factors for developing acute skin failure and the strategies employed to improve perfusion to the skin and perform a thorough daily skin assessment (Levine et al., <u>2009</u>). Management through early intervention of controllable factors is important for effective care of the critically ill patient at risk for skin failure (Curry et al., 2012).

It is important to discuss the presence of a KTU with the health care team. Because KTUs are an under-recognized phenomenon in children, the PNP can help educate the team about the pathophysiology of the KTU and lead discussions about the treatment plan. When skin changes occur at the end of life, as seen in a KTU, the health care team may need to shift the focus away from healing the skin to preventing further deterioration (<u>Sibbald et al., 2008</u>). PNPs

can use several strategies to optimize care of the patient with a KTU. One simple intervention is to keep the entire surface of the skin moisturized to prevent transepidermal water loss (Langemo & Black, 2010). If the KTU develops an exudate, meticulous care must be given to the peri-wound skin to prevent maceration and further skin breakdown of the area surrounding the KTU. Liberal use of barrier cream on the peri-wound skin can help to ameliorate the risks associated with an exudative process (Langemo & Black, 2010). The care team should also be sure to assess and treat any skin-related pain. The principles of treating skin-related pain include maintaining a moist wound bed, covering the wound with dressings that can be used for days rather than dressings that require replacement daily, repositioning the child frequently, and provision of appropriate analgesics (Langemo & Black, 2010). Hospital-acquired pressure ulcers are traditionally considered a failure in nursing care. Appropriately distinguishing between a KTU and a pressure ulcer may prevent the care team from being blamed inappropriately because the KTU is not due to a lack of care but instead is a result of the natural physiological dying process (Schank, 2009).

Because KTUs are an under-recognized phenomenon in children, the PNP can help educate the team about the pathophysiology of the KTU and lead discussions about the treatment plan.

Treatment

4. What are evidence-based practices for the treatment of a KTU?

There is paucity of evidence for the proper care of a KTU. However, some investigators hypothesize that treatment of intrinsic factors, rather than extrinsic ones, may play a larger role in the care of these wounds (<u>Kahn, 2014</u> and <u>Yastrub, 2010</u>). In one case report, treatment of the underlying cause of the organ failure resulted in successful healing of a KTU (<u>Kahn, 2014</u>). Although few evidencebased treatments of a KTU exist, children who experience a KTU have skin failure and are at very high risk for developing a pressure ulcer. Evidence-based strategies that can mitigate risks include optimizing nutritional support, using appropriate pressure redistribution surfaces, moisture management, and frequent repositioning to relieve pressure

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from pressure points (<u>Baharestani and Ratcliff, 2007</u> and <u>Schindler</u> et al., 2011).

CMS Reimbursement Policy

5. How does the diagnosis of a KTU affect the CMS reimbursement policy for preventable outcomes?

In 2013 the CMS specifically mentioned KTUs in the *Long-Term Care Hospital Quality Reporting Program Manual* in the pressure ulcer coding tips section. The CMS recognizes that the KTU is part of the dying process and therefore should not be coded as a pressure ulcer. Prior to this recognition, KTUs were not differentiated from pressure ulcers and therefore were considered a hospital-acquired condition for which CMS denied reimbursement. This updated CMS reimbursement policy provides a more accurate view of health care outcomes for critically ill patients.

Conclusion

A KTU is an ulcer that occurs as a part of the dying process, and its presence signifies skin failure. KTUs have some variance in presentation, but they are often abrasive-looking sores on the sacral area that rapidly (within hours to days) progress into a stage III or IV pressure ulcer. A KTU develops despite preventative measures, with patient death typically seen hours to weeks-months after the initial discovery of the KTU. The etiology of this ulcer is thought to be intrinsic and is attributed to poor perfusion as a result of a critical illness. Evidence for treatment options is limited; however, the underlying cause of organ failure should be treated rather than using pressure redistribution methods. The diagnosis of a KTU may help guide health care decision making because its presence typically heralds the end of life.

A KTU develops despite preventative measures, with patient death typically seen hours to weeks after the initial discovery of the KTU.

References

- Baharestani and Ratcliff, 2007. M.M. Baharestani, C.R. Ratcliff. Pressure ulcers in neonates and children: An NPUAP white paper. *Advances in Skin & Wound Care*, 20 (4) (2007), pp. 208–220
- <u>Brennan and Trombley, 2010.</u> M.R. Brennan, K. Trombley. Kennedy terminal ulcers—a palliative care unit's experience over a 12-month period of time. *World Council of Enterostomal Therapists Journal*, 30 (3) (2010), pp. 20–22
- <u>Centers for Medicare and Medicaid Services, 2013.</u> Centers for Medicare and Medicaid Services. (2013). Skin conditions. In *The CMS Long-Term Care Hospital Quality Reporting Program Manual* (Chapter 3: Section M). Retrieved from <u>https://www.cms.gov/medicare/quality-initiativespatient-assessment-instruments/ltch-quality-reporting/</u>
- <u>Curry et al., 2012.</u> K. Curry, M. Kutash, T. Chambers, A. Evans, M. Holt, S. Purcell. A prospective, descriptive study of characteristics associated with skin failure in critically III adults. *Ostomy Wound Management*, 58 (5) (2012), pp. 36–43
- Edsberg et al., 2014. L.E. Edsberg, D. Langemo, M.M. Baharestani, M.E. Posthauer, M. Goldberg. Unavoidable pressure injury: State of the science and consensus outcomes. *Journal of Wound Ostomy and Continence Nursing*, 41 (4) (2014), pp. 313–334
- <u>Graves and Sun, 2013.</u> M.L. Graves, V. Sun. Providing quality wound care at the end of life. *Journal of Hospice & Palliative Nursing*, 15 (2) (2013), pp. 66–74
- Kahn, 2014. R. Kahn. Healing a Kennedy terminal ulcer: A case study. Journal of Wound Ostomy and Continence Nursing, 41 (2014), p. S33
- Kennedy, 1989. K.L. Kennedy. The prevalence of pressure ulcers in an intermediate care facility. *Advances in Skin and Wound*, 2 (2) (1989), pp. 44–45
- Kennedy-Evans, 2009. K. Kennedy-Evans. Understanding the Kennedy terminal ulcer. *Ostomy Wound Management*, 55 (9) (2009), p. 6
- Langemo and Black, 2010. D.K. Langemo, J. Black. Pressure ulcers in individuals receiving palliative care: A National Pressure Ulcer Advisory Panel White Paper. *Advances in Skin & Wound Care*, 23 (2) (2010), pp. 59–72
- Langemo and Brown, 2006. D.K. Langemo, G. Brown. Skin fails too: Acute, chronic, and end-stage skin failure. *Advances in Skin & Wound Care*, 19 (4) (2006), pp. 206–211
- Lepak, 2012. V. Lepak. Avoidable & inevitable? Skin failure: The Kennedy terminal lesion. *Journal of Legal Nurse Consulting*, 23 (1) (2012), pp. 24–27

- Levine et al., 2009. J.M. Levine, S. Humphrey, S. Lebovits, J. Fogel. The unavoidable pressure ulcer: A retrospective case series. *Journal of Clinical Outcomes Management*, 16 (8) (2009), pp. 1–5
- <u>Schank, 2009.</u> J.E. Schank. Kennedy terminal ulcer: The "ah-ha!" moment and diagnosis. [corrected] [published erratum appears in *Ostomy Wound Management* 2009, *55*(11), 5] Ostomy Wound Management, 55 (9) (2009), pp. 40–44
- <u>Schindler et al., 2011.</u> C.A. Schindler, T.A. Mikhailov, E.M. Kuhn, J.
 Christopher, P. Conway, D. Ridling, V.A. Simpson. Protecting fragile skin: Nursing interventions to decrease development of pressure ulcers in pediatric intensive care. *American Journal of Critical Care*, 20 (1) (2011), pp. 26–35
- <u>Sibbald et al., 2008.</u> R.G. Sibbald, D.L. Krasner, J.B. Lutz, O. Alvarex, E.A. Ayello, S. Baranoski, D. Weir, *et al.* Skin changes at life's end (SCALE): A preliminary consensus statement. *World Council of Enterostomal Therapists Journal*, 28 (4) (2008), pp. 15–22
- <u>Yastrub, 2010.</u> D.J. Yastrub. Pressure or pathology: Distinguishing pressure ulcers from the Kennedy terminal ulcer. *Journal of Wound, Ostomy & Continence Nursing*, 37 (3) (2010), pp. 249–250

Conflicts of interest: None to report.

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