LETTER TO THE EDITOR

The Kennedy Terminal Ulcer – Alive and Well

Plaintiff attorneys may wish for the death of the Kennedy Terminal Ulcer, but this has actually been in the medical literature since 1877. Dr. Jean Martin Charcot (same physician known for his work with patients with Charcot foot) first described this phenomenon as Decubitus Ominosus.¹

Fast forward approximately 112 years to Byron Health Center in Fort Wayne, Indiana. Karen Lou Kennedy, now Karen Lou Kennedy-Evans, (NOT Mary Lou as Dr Miller cited) and the Byron staff also noticed this phenomenon. The facility's medical director, Dr. Stephen Glassley, coined the term Kennedy Terminal Lesion, which later became known as the Kennedy Terminal Ulcer. Their research was presented by Kennedy at the first National Pressure Ulcer Advisory Panel in Washington, DC, in 1989.²

It is important to note Kennedy was not aware of Dr. Charcot's work as it was lost to the healthcare community. It was not discovered until years AFTER Kennedy had published her research observations. Dr. Charcot's work surfaced because Dr. Jeffrey M. Levine discovered a long-lost medical textbook and shared Dr. Charcot's research with all of us. It is interesting to compare Dr. Charcot's findings with those of Karen Lou Kennedy-Evans. It is uncanny how some of her photographs mirror Dr. Charcot's drawings.

The Kennedy Terminal Ulcer (KTU) is an unavoidable skin breakdown which occurs in some patients as part of the dying process. It often appears on the sacrum or coccyx, but can appear elsewhere. Kennedy described two presentations affecting the buttocks. The first describes a bilateral presentation with the onset of death within 2 weeks to several months.^{2,3} Dr. Miller specifically mentioned the 3:30 Syndrome in his article. Kennedy describes this presentation as a unilateral ulcer on the buttock, which has a shorter onset to death of 24–48 hours. With this presentation, the skin damage often remains a closed ulcer.³

The etiology of the Kennedy Terminal Ulcer is still unknown. Some have suggested there may be an element of pressure, that in healthy people would not cause any repercussion; whereas with the dying patient, the least amount of pressure might result in a major ulceration. Dr. Charcot attributed it to a neuropathic origin.¹ Others have theorized it is a perfusion issue and noted that pressure is not the primary causative factor; instead determined it was skin failure. The concept of skin failure was reported by Langemo and Brown in 2006.^{3,4} In 2008 an expert panel convened to discuss the concept of end of life skin failure. The panel's work is known as SCALE (Skin Changes at Life's End).^{3,5} The KTU appears to be a part of multiorgan system failure and end-stage disease. More research is definitely warranted to determine the physiological changes of this skin failure at life's end.

There have been many medical advances since Kennedy's original research. Clinicians have reported anecdotal accounts of patients living longer than several months with Kennedy Terminal Ulcers.⁶ They have surmised this might be due to the patient receiving advanced medical treatments, which were not available at the time of Kennedy's original research.

It is unclear what motivated Dr. Miller to proclaim the death of the Kennedy Terminal Ulcer. If the Centers for Medicare and Medicaid Services (CMS) recognize the KTU, what influenced Dr. Miller to believe otherwise? The recent guidance from CMS to Surveyors for Long Term Care Facilities is Kennedy Terminal Ulcers are considered to be pressure ulcers that generally occur at the end of life.⁷ Dr. Miller's theory appears to be all pressure ulcers, including the Kennedy Terminal Ulcer, Skin Changes at Life's End (SCALE) and other manifestations of skin failure are avoidable. This is contrary to medical literature and CMS guidelines. So, despite Dr. Miller's decree, the Kennedy Terminal Ulcer is alive and well, so to speak.

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The Death of the Kennedy Terminal Ulcer, Michael S. Miller, DO, FACOS

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