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COLUMNS: Pearls and Discourse

Discharge to Hospice: A Kennedy Terminal Ulcer Case Report

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Introduction

My brilliant, charming, and vibrant father died on Christmas night 2007. For many days during his dying process, I was fortunate to be at his side to help keep him comfortable and meet his wishes.[1] During this time, I also observed the death of his skin, the body's largest organ. My father was diagnosed with glioblastoma multiforme (GBM) in October of 2007. GBM is an insidious brain tumor, a serpentine harbinger of death. After his diagnosis, my father elected to return home to the love and support of his family, church, friends, and pets. He elected to forgo aggressive treatment and was immediately placed on hospice service for palliative care. My usually genial father was now angry, bitter about his impending death. His wish was to die as quickly as possible as he knew his intellect was rapidly deteriorating. Hospice services, my mother's care, and appropriate medications were able to keep him seizure free and relatively comfortable at home. Dad was able to complete his activities of daily living with assistance, continue his daily routines, and enjoy his meals and a nice glass of wine now and then.

The Beginning of the End

Diagnosis to death was 7 weeks. I visited as often as I could and, being a nurse, performed head-to-toe assessments and offered instruction to my mom on nutrition, hydration, seizure precautions, safety, mobility, pain control, skin care, and pressure ulcer formation.

Four days prior to his death, my father wanted to have his regular Friday luncheon with friends and members of his church. It was a ritual he enjoyed, and although he was now frail and cognitively altered, it was not an unreasonable request. I decided to shower my dad, to perform the special "puff and polish" only a nurse can do. I soaped him from head to toe, washed his hair, brushed his teeth, and, of course, applied a good emollient. I made a mental note of numerous seborrheaic keratoses, senile purpura, actinic changes, and a herpetic lesion on his upper lip that I had watched for months. I checked all his primary pressure areas, sacrum, heels, trochanters, ischium, and spine; skin was dry, intact, and free from any pressure-related breakdown. I noted that his pressure redistribution surfaces, his ability to reposition himself, and good nutrition were working. Dad enjoyed his meal, the company of good friends, and his trip into town. This was his last full meal, his last car ride, and the end of his skin integrity.

The next day I left for my home. My dad was in good spirits, sitting at the kitchen table singing the melody of Christmas carols with words only he knew. He was ambulatory, toileting, and reasonably pain free with intermittent doses of morphine sulfate.

When I returned on Christmas eve, less than 48 hours later, it was evident my father was actively dying. The

Editor's Note: Welcome to our new column where clinicians are invited to share interesting cases, techniques, and experiences with the readership.

Submissions must contain a discussion section and at least three current and/or historical references. After review, the most interesting and thought provoking will be printed.

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hospice nurse was present and at our request inserted a Foley catheter to keep my dad dry and comfortable. Positioning was painful and difficult. The slightest touch caused him pain. He exhibited nonverbal pain cues: grimacing, moaning, and head holding. His breathing was labored, his color ashen, his mucous membranes dry. Early skin changes were already manifesting: reticular patterning to his legs, arms, and chest; cold and clammy extremities; cyanosis to his lips and nose; but no visible skin breakdown was noted. Because of his extreme anxiety and restlessness, we allowed him to return to his favorite recliner in the family room. We knew positioning would be difficult there, but this was where *he* was most comfortable.

I watched and ministered to my father throughout the night and into Christmas day. We attempted all our traditional holiday festivities, Christmas breakfast, gift opening, caroling, and prime rib. It was during our dinner that I noticed sudden and frank changes in his skin integrity. His heels and calves became turgid, showing a darkened, almost black discoloration and the evidence of a very thin layer of epidermal separation. It was clear that my father was dying, but, remarkable to me, his skin was *actively* dying as well. Noting his position in the chair, I knew with certainty that his sacrum was showing similar changes. These ominous findings were consistent with a Kennedy terminal ulcer (KTU). My sister looked at me and said, "What is happening to Dad's skin?" and my response to her was, "His skin is dying." At that moment I knew I was observing the development a KTU first-hand.

The KTU

As a Certified Wound Care Nurse, I have treated numerous patients with wounds or skin manifestations. I have worked as a hospice nurse and also directed hospice care in patients with difficult-to-manage wounds. I have observed the progression of KTUs and have instructed families and caregivers regarding the signs and symptoms. A KTU is a pressure-related wound with sudden onset. These wounds usually occur on the sacrum, typically present in a pear shape, and progress rapidly from intact-skin to full-thickness wounds. These ulcers are often an indicator of imminent death and can appear as blackened areas, small spots or "smudges" that may look like dirt or dried stool.[2]

While I was directing wound care in the hospice population, observing these skin changes was a sign that my patients were actively dying and that it was time to reinforce my education to the staff nurses and families of my patients in the progression of a KTU.

According to an article in the *Remington Report*,[3] KTUs have the following characteristics:

They start out larger than other types of ulcers.
They are initially superficial.
They increase rapidly in size and depth.
They are related to multiorgan failure toward the end of life.

Conclusion

The moment my knowledge of a KTU became reality, I stopped being a nurse so that I could be his daughter. I still administered my dad's pain medication, carefully following the doctor's orders. I sat at his side to hold his hand and gently rub lotion into his paper-thin and dry skin. I repositioned him to relieve his pressure points, but it caused him unbearable pain, so I stopped. My mother sang his favorite hymns. He was surrounded by his family and love.

My father died at home at 9:58 on Christmas night with his wife, two daughters, four grandchildren, two sons-in-law, a great-grandson, two poodles, and what I believe were KTUs to his heels and calves. After his death, I was not emotionally able to confirm my suspicions, to observe his sacrum. I did not need to confirm my suspicions. It was Christmas Day, after all, and he was my precious dad.

References

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