

# Communication Barriers Concerning Implantable Cardioverter Defibrillator Deactivation Near End of Life

Matthew Robinson, DO<sup>1</sup> • William Clay Jackson, MD, DipTh<sup>2</sup>

A 62-year-old White woman presented to our palliative care clinic for follow-up of symptom management. Her history was significant for stage 3A squamous cell carcinoma of the lung, stage 2 supra-glottic squamous cell carcinoma, and ischemic cardiomyopathy with implantable cardioverter-defibrillator (ICD). She reported a recent fall after unexpectedly being shocked by her ICD. Unaware of the force of an ICD, her fall resulted in a left hip fracture, which caused her pain and restricted ambulation.

In addition to stopping her current antineoplastic therapy, she informed the palliative team that she no longer wanted to experience any further shocks stating, "I could have already died by now if it was not for this device." The patient was informed of the risks of deactivating the ICD, and she agreed to deactivate it to avoid any further discomfort. The ICD representative and her cardiologist were notified of her decision.

## Discussion

An ICD is a device used to treat advanced heart failure (HF) in patients who are receiving guideline-directed medical therapy, have an ejection fraction (EF) of 35% or less, and have New York Heart Association (NYHA) functional class 2 or 3 symptoms. The overall goal of an ICD is to prevent sudden death secondary to lethal arrhythmias. Although placement of an ICD device reduces the risk of sudden death and may improve quality of life, recommendations on how to manage these devices at the end of life (EOL) are an ongoing challenge for clinicians.<sup>1</sup> Goldstein and colleagues noted that conversations involving deactivation tend to be complicated, and patients may not fully comprehend the role or consequences that an ICD plays near EOL.<sup>2-4</sup> There are guidelines that instruct clinicians on how to approach conversations about device deactivation at particular times: prior to implantation, after an episode of increased or

repeated shocks, progression of cardiac disease, code status changed to do-not-resuscitate (DNR), and near EOL.<sup>1</sup> Regardless of these established guidelines, there remains a high degree of uncertainty and a paucity of conversation throughout the patient's disease trajectory. Our case highlights the need for improvement in discussions among patients, care partners, and clinicians with continued efforts to reassess patients' goals as their condition advances.

Discussing ICD management near EOL can be challenging for patients, care partners, and multidisciplinary teams. Roughly 45% of patients with an ICD and a DNR have not discussed ICD deactivation.<sup>5</sup> Currently, a combination of conversation pitfalls exists, including the fear of moral consequences, fear of legal consequences with the belief it may be like assisted suicide or passive euthanasia, clinician discomfort, and failure to reassess goals of care.<sup>1,5</sup> Many physicians find it difficult to properly broach the topic of ICD management near EOL. It is thought that many believe that ICD deactivation is ethically unique compared with deactivation of other support devices (eg, ventilators, dialysis, artificial nutrition/hydration, etc.).<sup>6-8</sup> However, according to current guidelines, there is no legal or ethical difference if the patient or surrogate decision-maker has the capacity to make decisions.

Additionally, advance directives are widely variable, vague, and fail to adequately address expectations or consequences of deactivation at EOL. Failure

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## AFFILIATIONS:

<sup>1</sup>Hospice and Palliative Fellow, University of Tennessee Health Science Center, Memphis, TN

<sup>2</sup>Clinical Assistant Professor of Family Medicine and Psychiatry, University of Tennessee College of Medicine, Memphis, TN

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## CORRESPONDENCE:

W. Clay Jackson, MD, DipTh, University of Tennessee College of Medicine, 910 Madison Ave #1002, Memphis, TN 38103 (mydocjackson@live.com)

to continually reassess the need for deactivation at EOL can have significantly negative consequences, such as those that befell our patient. Many patients are unaware of the painful and often-times repeated shocks delivered by the ICD, causing significant discomfort for the patient, as well as distress for care partners.<sup>1,8</sup> Studies have shown that most patients do not consider, nor are given the opportunity to consider, how to manage their ICD at EOL.<sup>9-11</sup> There is evidence to suggest that having patients more involved in their care can result in care decisions more in line with their values and wishes while improving patient and family satisfaction near EOL.<sup>12</sup> Continuing to reassess and engage in conversations about ICD deactivation increases patient awareness, improves overall quality of life, reduces unnecessary variation in care delivery, and facilitates alignment of care with patients' values.<sup>13</sup>

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