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“But I Have a Pacer...There Is No Point in Engaging in Hypothetical Scenarios”: A Non-Imminently Dying Patient’s Request for Pacemaker Deactivation

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Abstract

In this case report, we describe a woman with advancing dementia who still retained decisional capacity and was able to clearly articulate her request for deactivation of her implanted cardiac pacemaker—a scenario that would result in her death. In this case, the patient had the autonomy to make her decision, but clinicians at an outside hospital refused to deactivate her pacemaker even though they were in unanimous agreement that the patient had capacity to make this decision, citing personal discomfort and a belief that her decision seemed out of proportion to her suffering. We evaluated her at our hospital, found her to have decision-making capacity, and deactivated her pacer resulting in her death about 9 days later. While some clinicians may be comfortable discussing patient preferences for device deactivation in patients who are imminently dying, we can find no reports in the literature of requests for device deactivation from patients with terminal diagnoses who are not imminently dying.

Keywords: dementia; device deactivation; palliative care decision-making; pacemaker; patient autonomy

Case presentation

The patient is an 86-year-old woman who presented to our palliative care clinic with a request for pacemaker deactivation. She underwent pacemaker placement following several episodes of symptomatic atrial fibrillation 3 years prior. At that time, she continued to have symptomatic atrial fibrillation and heart failure and was advised to undergo atrioventricular nodal ablation, which would make her pacemaker dependent. The ablation successfully stabilized her symptoms, but several months later she developed signs of short-term memory loss. She was frustrated by these symptoms and recognized she could no longer live alone. She was diagnosed with Alzheimer’s dementia in the following months; her family noted in retrospect these symptoms had started several years prior. After reflecting on her new diagnosis and loss of independence, she asked her physicians to deactivate her pacemaker. She knew this would result in death, which she preferred rather than continuing to live with advancing dementia.

The team at an outside hospital who considered her request included her long-time primary care physician, her cardiologist, a palliative medicine physician, a neurologist, a geriatrician, a psychiatrist, and the hospital ethics committee. When assessing why she was choosing this option, the team asked her what she would do in a similar situation if she did not have a pacemaker. Her response was, “but I have the pacer and there is no point in engaging in hypothetical scenarios when you can just turn it off.” The team did not find her to be depressed and they unanimously acknowledged that she had decision-making capacity. Nevertheless, they refused to honor her request, citing personal discomfort and claiming that her decision seemed out of proportion to her suffering.

After her children conducted research to identify physicians with expertise in cardiac device deactivation, the patient presented to our palliative care clinic. She shared that she prized her independence and ability to care for herself. She had previously cared for her spouse who died of advanced dementia. The value she placed on independence was incompatible with being dependent on the care of others. Her wishes were reflected in her advance directive completed several years prior. She was aware that deactivation of her pacemaker would shorten her life, noting “Longevity is nothing without quality.” In fact, following the previous denial of her request, she began voluntary cessation of eating and drinking. This carried a significant symptom burden; she described taking sips of fluids when she could no longer bear her thirst to “cheating.”

Additionally, there was significant emotional burdens on her adult children. Their mother would frequently request food, because her dementia prevented her from remembering why she was choosing not to eat or drink. At each request, they reminded her, saying, “We’d be happy to bring you whatever you’d like, but you were choosing not to eat because the doctors wouldn’t turn off the pacemaker.” At that point, the patient would immediately withdraw her request for food, reiterate her position, and angrily complain that the doctors at the other hospital had no right to refuse her legitimate request. This pattern of first requesting food or liquids and then refusing was repeated multiple times a day.

At our hospital, our palliative care team determined the patient had capacity to understand the implications of her decision of pacemaker deactivation. We presented the case to our hospital’s ethics committee. A lengthy discussion ensued. One committee member asked, “Wouldn’t that be murder?” Another replied, “Our job is not to decide what to call it but to determine what is the right thing to do.” Ultimately, the committee chair called for a vote of the members. They voted unanimously to comply with the patient’s wishes. Subsequently, the situation was discussed with our electrophysiology colleagues who concurred with the decision of the ethics committee and agreed to participate in the device deactivation.

The patient was subsequently admitted to our inpatient palliative care unit. Our palliative care team, assisted by our electrophysiology colleagues, deactivated her pacemaker. Her heart rate immediately demonstrated bradycardia at 34 beats per minute with a junctional rhythm (see Figure 1). Despite this, she was comfortable and able to eat and ambulate. Over the next days, she suffered progressive shortness of breath with exertion and became less interactive but remained comfortable. She died 9 days after deactivation of her pacemaker, with her family at her bedside.

Commentary

Pacemakers have enhanced the lives of numerous patients, many of whom live for several years before succumbing to other diseases. While some clinicians may be comfortable discussing patient preferences for device deactivation in patients who are imminently dying, we found no reports in the literature of requests for device deactivation from patients with terminal diagnoses who are *not* imminently dying. The discomfort with this type of clinical scenario is illustrated in the fact that the ethics committee members at another hospital determined the patient had capacity to choose device deactivation but chose not to comply with her request.

Pacemakers and implantable cardiac defibrillators are viewed as life-sustaining treatments on par with artificial nutrition, dialysis, or mechanical ventilation.¹ As such, patients with decisional capacity should be allowed to refuse or discontinue life-sustaining treatments when they determine that continuing treatment amounts to a harm rather than a benefit. Respect for patient autonomy requires allowing the patient to determine when and whether a medical intervention is a benefit or a harm. That freedom to choose what to value and how to rank one’s own priorities is the most critical feature of liberty. That is what autonomous people treasure. Patients’ choices about refusing treatment and discontinuing treatment should be respected regardless of how close the patient is to death.² The fact that our patient was pacemaker dependent and that deactivating her pacer had the potential to immediately end her life does not change the ethical and legal arguments fundamentally supporting her autonomy and ability to make decisions about discontinuing her life-sustaining treatments.

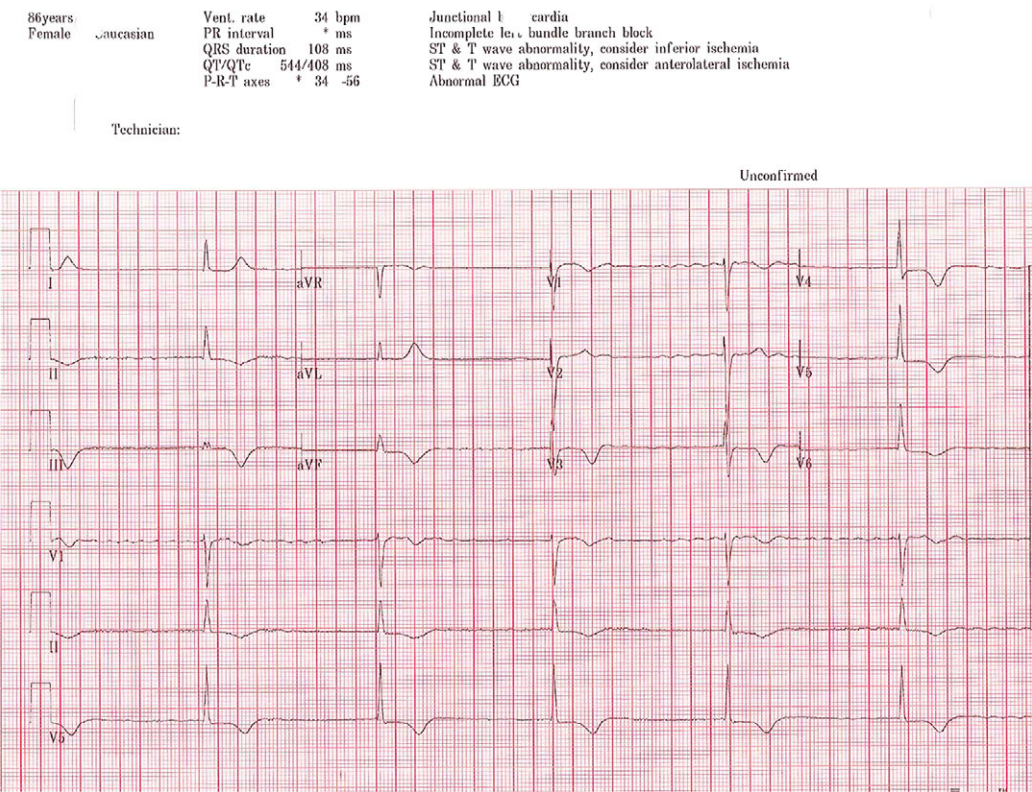


Figure 1. Patient electrocardiogram after deactivation of implanted pacemaker.

Ironically, had she waited several years until she had advanced dementia and had lost the capacity to make decisions, it is easy to imagine that many clinicians might have been comfortable in granting this same request from her surrogate decision makers.

Clinicians do not have a right to impose their own judgments about how burdensome a particular condition is for a patient. Allowing clinicians' own opinions and experience to trump a patient's assessment of the benefits and burdens of a therapy crosses a line and invades a domain that belongs to clinicians only in the rare circumstances of a patient without capacity refusing urgent treatment with likely significant and enduring benefit. For the most part, decisions to accept, refuse, or discontinue treatment belong to patients, not their clinicians.

As medical science and technology continues to advance and our society ages, questions about the ethics of discontinuing treatment and turning off machines will become more prevalent.^{3,4} To maintain the trust that patients' choices will continue to be respected, clinicians must assure society that the basic ethical principle of respect for patient autonomy will continue to be upheld.

Competing interest. The authors have no competing interests to disclose.

Notes

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