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Be still, my beating heart: Deactivating cardiac electrical devices

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Abstract

This case study examines the circumstance of a patient who has clearly and repeatedly articulated non-treatment preferences for implantable cardiac devices who later becomes incapacitated. The patient's proxy consents to implantation during the patient's incapacity. The analysis of the patient's subsequent refusal and desire to terminate these devices results in distress by the cardiologist that is ultimately facilitated by the ethics consultation and palliative care teams. The analysis discusses the preventative and responsive aspects of the autonomy and beneficence considerations as why the treatment team should obey the patient's and family's request.

Keywords: Informed refusal; Proxy consent; Implantable cardiac devices; Medical ethics; Palliative care.

Introduction

Despite a 65-year history in medical treatment, cardiac pacing can still prove to be problematic. The illustrated case has less to do with the techniques used but does give one pause regarding how to better follow the values and preferences of patients, even when they lose decisional capacity. We will discuss advance care planning in the setting of cardiac device usage, consider how policies in place can instruct providers about treatment offered and withdrawn, and better enable readers to consider when and how to discontinue active medical treatment.

Case Study

Mr. R was an 84-year-old male with a history of coronary artery disease, congestive heart failure, chronic kidney disease, hypertension, diabetes, and a mixed Alzheimer's/vascular dementia. He also had known atrial fibrillation and first offered a pacemaker/Automatic Implantable Cardioverter Defibrillator, or AICD 13 months prior to his admission at Hospital Clinic A, with his physician noting, "we discussed

both issues extensively today and he still does not want to be considered for those [cardiac devices]." Nine months before admission, his cardiologist made the same offer of cardiac device intervention and he said he "does not wish to have that considered." Also, in early 2022, the patient had executed an advance directive with both living will and Durable Power of Attorney (DPA) components. Seven months prior to admission, his wife of 57 years was hospitalized at a local community hospital for a complicated UTI. During that same time, his son took the patient to lunch when the patient was noted to exhibit "stroke-like symptoms" of weakness, fatigue, blurred vision, and having bradycardia to the 30's. The patient was first seen at Hospital A's Emergency Department but transferred to Hospital B that had dialysis facilities due to concerns of acute kidney injury and hyperkalemia with possible emergent dialysis being required. He was admitted to Hospital B with bradycardia, atrial fibrillation, and hematemesis. Emergency room staff noted that the patient "has previously refused pacemaker as outpatient most recently in December when he saw his cardiologist." Urgent endoscopy revealed gastritis and multiple arteriovenous malformations. He was volume resuscitated and his symptoms resolved. Two days later, the patient's son was asked to consent telephonically for implantation of a pacemaker/AICD. The patient received the device, recovered and was discharged home.

Seven months after Hospital B's events, the patient was seen by his own cardiologist at Hospital Clinic A, and the patient and his wife voiced their preference that the pacemaker/AICD be removed. The cardiologist told the wife that the AICD was not firing, so could be inactivated. He stated that the pacemaker was intermittently pacing. The cardiologist stated that the removal of the pacemaker could result in syncope with resultant hip fracture and chronic pain.

Five months later after AICD inactivation, the patient and wife asked his PCP to turn off the pacemaker. The patient's dementia was now intrusive to his decision making. The patient was very upset regarding the presence of the pacemaker and inactivated AICD. His wife conveyed that the patient's mother had dementia with cardiac issues and that the patient had previously stated "I don't ever want that to happen to me." She added, "He'd be beside himself if he knew the situation." His wife believed the pacemaker now was prolonging the patient's life even as his dementia was advancing, and his quality of life was diminishing. Additionally, the patient completed an advance directive in 2010, updated his preference to include a Do Not Resuscitate order in 2014, and his wife reaffirmed the Do Not Resuscitate order in late 2022, with a Life-Sustaining Treatment Order in the medical record. Cardiology was made aware of this visit. His Cardiology clinic physician's response to this request was.

"He has a high level of pacing from his device. Please advise turning off the pacing function may well be equivalent to euthenasia [sic] on the spot. Right then. He might struggle along without pacemaker but that is unknown. We will not be comfortable with dc'ing his pacing function in clinic. Will ask for higher level input on that." This sentiment was mirrored by other health care staff.

The Chief of Medicine of the Hospital A responded:

"While the discontinuation of pacing may be an appropriate request, given the potential consequences of this I agree that this is not something that should be done in the Cardiology clinic. I would recommend

that this decision come with involvement of the primary care provider. It may be appropriate to involve ethics with the question: Is the pacemaker now no longer supporting the patient's well-being but rather prolonging the dying process? If that is the case, then allowing for the removal of a therapy that no longer serves the patient and is no longer desired by the patient (or surrogate) is not considered euthanasia, and its carefully considered withdrawal has been supported by both the Heart Rhythm Society and the European Heart Rhythm Association. I agree however that this should not be undertaken without a larger discussion [1,2]."

The hospital ethics committee was consulted at this juncture, recommending a palliative care consultation to review prognosis, assess the status and resources available to caregivers, and to plan for pacemaker deactivation. The cardiologist noted that the family should be aware that the effect of pacemaker deactivation was uncertain with potentially diverse outcomes of rapid death, profoundly symptomatic bradycardia, or very little change in clinical status. The committee thought it would be appropriate for deactivation to occur in a setting that would be able to provide care and support to the patient and family in any of these circumstances. They also felt it important to understand the state of the patient's caregivers, understanding the impact of stress and evaluate for potential burnout, and find ways to assist them through this time.

While the patient's dementia resulted in his being deemed not having decisional capacity by the Hospitalist Attending, his wife and son agreed with the patient that the device should be either disabled or removed. The patient's wife and son were in the ethics committee meeting and shared aspects of the patient's life including his expressed goals of care. Family members expressed the patient's values that he would not choose life prolonging treatments such as the pacemaker if he were currently able to express his wishes. The team clarified that the current concern expressed by family was the function of the pacemaker rather than its presence and considered pacemaker discontinuation an appropriate request. This avoided the need to consider a potentially hazardous and difficult removal of a chronically implanted cardiac device. The team considered that having had the AICD already inactivated that pacemaker discontinuation should be considered a valid request by the team. The patient was admitted to Hospital A for monitoring while pacing was reduced in a stepwise fashion in 10 BPM increments from 70 BPM to 40 BPM. The patient had an intrinsic rate in the 50's and remained asymptomatic. The pacemaker was deactivated. The patient remained stable and discharged home with hospice care.

Analysis

The ethical analysis for this case can be broken down into two essential perspectives: Preventative and Responsive. In a Preventative Analysis, we would look at those things that could have been done in retrospect that would have been beneficial and respectful for this patient toward not having the cardiac device implanted, per prior statements, assessments, and documents. In this circumstance, Mr. R had rejected the intrusive intervention of an implanted pacemaker and cardiac defibrillator repeatedly prior to his admission in this case at Hospital A.

Informed consent/refusal in such a circumstance is assumed to be with capacity, unless there is

sufficient evidence to reason that there is an intrusion of his mental state causing incapacity, in this case, by progressive dementia. But no decisional incapacity had been noted by cardiologists at Hospital A. The patients' autonomous preferences were well-defined at Hospital A. He had made repeated clear statements to his physicians in the medical record indicating that he would not want an implantable defibrillator and pacemaker put in his body. He had repeatedly rendered an informed refusal regarding his perceived harm and benefits on the devices use given his many medical problems.

While we do not know his mental state/capacity on his admission to Hospital B, we can infer that he was deemed as lacking decisional capacity when cardiologists had proposed cardiac device implantation. As this occurred during the COVID-19 Pandemic, they turned to the son to consent to the informed consent process over the telephone (as the wife was herself hospitalized-though that does not necessarily preclude her ability to consent) for an implantable defibrillator and pacemaker. If a patient has been deemed as being without decisional capacity, knowing as they did in the ER that he did not want any cardiac devices, they should have communicated with his original PCP, Hospital A's cardiologists, and his health care agent, which in this case was his son and perhaps convened a family meeting (whether in person, by videoconference, or by phone), but there is no evidence that this was done. Instead, the patient had the pacemaker and defibrillator implanted after the son's telephonic consent.

If they had contacted the original PCP or cardiologist and had been told that the patient did not want the implantation of the two devices, his contemporaneous cognitive deterioration resulting in the hospitalization was not a sufficient reason to usurp his valid refusal and to then turn to his son to ask for the consent they desired. The best way of articulating what should have been done for this patient is that the cardiologist at Hospital B should have honored his previous autonomous preferences to serve as his current and future preferences regarding cardiac care. To substitute one's own beneficence-based intrusion of an invasive device is an example of strong paternalism at the most, and neglect in obtaining medical information at the least. The patient had made clear statements of refusal that had been documented, and the physicians who subsequently cared for him evidently did not try to ascertain the patient's prior clinical status and values and preferences regarding the treatment that was being offered.

On review, the patient likely had symptomatic hypovolemia on admission with chronic intermittent bradycardia. Were there any indications that the patient wanted this intervention? Quite the opposite. Does the patient at the point of cardiac device implantation have decisional capacity? Per the cardiologist's Informed consent form, it is inferred "no." If he had capacity, his consent (or assent, if full consent is impracticable) should have been obeyed. However, if he indeed lacked decisional capacity, then the DPA agent was asked to make the decision.

Given the son is the back-up agent of the patient's Durable Power of Attorney (with the wife appointed as primary), what is his responsibility? He is to carry out the patient's prior values and preferences. Did a thorough discussion of the patient's values and preferences regarding implantable cardiac devices take place? The patient had both an advance directive and a known "Do Not Resuscitate" order. So even without being privy to how the consent from the son was obtained (i.e., due to a reversal due to best interests –

a specious argument, or was possibly coerced by the cardiologist, which would constitute professional impropriety due to assault and battery), we are left with an implanted device that the patient never wanted. In which one may ask: Was there a thorough discussion regarding the implications of the use of these devices, the symptoms that would be caused, and the ethical implications of future discontinuation at Hospital B?.

In a Responsive Analysis, we look at the ethical response once the device has been implanted, and then decipher what happened when the patient and family requested its removal. Seven months after his discharge, Mr. R returned to his cardiologist at Hospital A, and he and the family voiced their desire that both the AICD and pacemaker be removed. The pacemaker was intermittently pacing and might be preventing symptoms of dizziness or syncope. The AICD had not fired and was not playing a role in symptom management. However, the patient and his wife voiced their desire to remove/discontinue the pacemaker and ICD at the same time. It has been noted in the past that some clinicians look upon a discharging ICD as more burdensome, and therefore more defensible in its discontinuation, when compared with the low burden of a pacemaker [3]. A pacemaker is a medical treatment, and as such can be stopped (just as easily as it could have been withheld), even when considered a "low-burden" intervention [4-7]. Here the cardiologist opted for stopping only the ICD-stopping the potential, grave discomfort of a future shock but retaining the pacemaker's presence and function. Importantly, this physician's personal bias is seen subsequently when opining the moral impropriety of the cessation of the pacemaker. This decision still violates the patient's values and preferences regarding this medical treatment. Five months later, the patient implored his PCP to have his cardiologist turn off the pacemaker. The cardiologist voiced his concerns of actively causing the patient's death.

The concern voiced by his cardiologist was that there could be a sudden cessation of cardiac function with termination of the pacemaker. He is making both a beneficence claim (preventing harm to the patient), as well as a professional autonomy claim (the physician maintaining a right of conscience to not be co-opted into stopping the device). The cardiologist does not wish to inflict sudden death upon the patient as that this would be violative of his own perception of his responsibility to avoid causing harm to the patient. It is heartening that Hospital A's Chief of Medicine assuaged the cardiologist that the Heart Rhythm Society and the European Heart Rhythm Association concurred with the right of the patient to discontinue this form of intrusive therapy [8,9]. Here the standard of care by professional societies in cardiology stand firmly on the side of patient autonomy regarding consent and refusal to cardiac devices. Standards of care are meant to be ethical and medical guideposts of professionalism on how individual clinicians are to behave in similar circumstances. This clinician was to respect the patient's preference regarding cessation of cardiac devices. The clinician was concerned he was violating his ethical duty by causing harm to the point of patient death, which was equated as active euthanasia and is not the case [10,11]. Objections grounded in pacemakers serving a "substitutive intrinsic function" also fails as the pacemaker is an electric device, powered only by a battery that must be changed and is incapable of self-repair [12]. Additionally, comparisons to a not removing a kidney transplant fails as a patient is free to stop taking anti-rejection medications (thereby causing organ rejection) when medical co-morbidities compel the patient to stop treatment. Also, cardiac device implantation cannot be equated to an irrevocable Ulysses Contract, even

though physical removal of a device may be difficult or impossible, the ongoing functionality is consent driven by the patient or proxy [13]. The withdrawal of consent by patients or proxy may be addressed by allowing the pacemaker battery to become depleted, but should equally apply to patients who believe the burden of treatment from the technology exceeds its benefits. Physician hesitation is likely more grounded in their inexperience in receiving these requests, and reveal that proactive discussions on patient experiences, values, and preferences regarding their cardiac device must be part of the clinician's care in advance care planning [14,15]. Hesitation by physicians in stopping a cardiac device therapy defended on conscientious objection grounds can be addressed through transfer of care to another provider or facility [16,17]. This professionalism issue would best be handled first by educating the clinician on their responsibility within the profession's standard of care, and their duty to respect treatment refusal. If unable to participate in the discontinuation, then care could be transferred to another facility cardiologist who would participate in the discontinuation.

The reluctant response by the cardiologist is why the assessment and eventual admission to palliative care was undertaken. The patient's values in this regard were clear: He did not wish to be kept alive using an artificial cardiac treatment, particularly considering the diminution of his quality of life based on his suffering from an assortment of medical infirmities. He recognized the magnitude of his medical circumstances to the degree that he had an advance directive completed eight years prior to this event.

Conclusion

This patient provided repeated evidence refusing implantable cardiac devices. These values and preferences were conveyed consistently, and with capacity. Even when the patient's decision-making capacity lapsed, there were means by which to confirm his prior refusal, and that did not occur. After implantation, the patient had the right to discontinue the function on both implantable cardiac devices, as his refusal should have been respected as soon as it was voiced. When a patient regards a treatment as burdensome, as non-beneficial, and has capacity to evidence the desire for discontinuation, physicians have a responsibility to both acknowledge and abide by the patient's preferences.

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