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“Just Because We Can Doesn’t Mean We Should”: views of nurses on deactivation of pacemakers and implantable cardioverter-defibrillators

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Abstract

Purpose—This study aims to identify nurses’ concerns about the clinical, ethical, and legal aspects of deactivating cardiovascular implantable electronic devices (CIEDs).

Methods—We used focus groups to discuss decision making in CIED management.

Results—Fourteen nurses described the informed consent process as overly focused on procedures, with inadequate coverage of living with a device (e.g., infection risks and device shocks). Elderly patients were especially vulnerable to physician or family pressure about CIED implantation. Nurses believed that initial advance care planning discussions were infrequent and rarely revisited when health status changed. Many patients did not know that CIEDs could be deactivated; it was often addressed reactively (i.e., after multiple shocks) or when patients became too ill to participate in decision making. Nurses generally were supportive of CIED deactivation when it was requested by a well-informed patient. However, nurses distinguished between

withholding versus withdrawing treatment (i.e., turning off CIEDs vs. declining implantation). Although most patients viewed their device as lifesaving, others perceived them as a “ticking time bomb.”

Conclusions—Nurses identified concerns about CIED decision making from implantation through end-of-life care and device deactivation and suggested avenues for improving patient care including early and regular advance care planning.

Keywords

Device deactivation; Ethics; Implantable cardioverter-defibrillators; Nursing; Pacemakers

1 Introduction

Millions of patients have had their lives improved and prolonged by cardiovascular implantable electronic devices (CIEDs), including pacemakers and implantable cardioverter-defibrillators (ICDs), and thousands more undergo CIED implantations every month [1, 2]. However, patients with CIEDs inevitably experience worsening of their cardiovascular disease, acquire other illnesses, or reevaluate the benefits and burdens of CIED therapy for other reasons [3]. For these patients, CIED deactivation (i.e., reprogramming a CIED so that it no longer delivers effective therapies) may be considered [4].

CIED deactivation raises ethical, legal, and logistical questions. Several studies have explored the views of physicians and patients on different features of CIED deactivation [5–9]. Few studies, however, have evaluated the perspectives of nurses who care for patients considering or undergoing CIED deactivation. Nurses have crucial roles in the care of patients with CIEDs [4]. Nurses in fields such as oncology, intensive care medicine, and nephrology provide unique and critical support to patients and families involved in end-of-life decisions and withdrawal of life-sustaining treatments, such as artificial nutrition and hydration, mechanical ventilation, and hemodialysis [10–13]. The views of nurses who work in cardiology on withdrawal of CIED therapy, however, have not been explored.

In this multicenter study, we explored the experiences and perspectives of nurses who work in cardiology regarding CIEDs, including decision making and areas perceived as needing improvement in the care of patients living and dying with CIEDs. Given that previous exploration of these topics is lacking, we used qualitative methods in this study [14].

2 Methods

2.1 Recruitment

Registered nurses from the Division of Cardiovascular Diseases at Mayo Clinic in Rochester, MN, USA, and from the CardioVascular Institute at Beth Israel Deaconess Medical Center (Boston, MA, USA) were eligible to participate. Nurses were recruited by e-mail, and those who expressed interest were provided additional information about the study goals. Study subjects were provided a small honorarium (\$50) for participating in the study.

This study was approved by the institutional review boards of Mayo Clinic and Beth Israel Deaconess Medical Center in accordance with federal regulations.

2.2 Focus groups

Focus group sessions, each lasting 60 min, were held at each institution (total of three sessions). Focus groups were chosen to promote self-disclosure and to encourage discussion among members of the group [15]. Each focus group session was led by a trained,

nonphysician facilitator. A semistructured interview guide with discussion questions was used to standardize each group's experience (Table 1).

The focus group guide was structured to include general and specific questions. The discussion began with questions about how nurses viewed their role in caring for patients and helping patients with medical decision making. The participants were asked how, if at all, they broached the subject of CIED implantation with patients and how they answered patient questions about receiving a device. Other questions probed for the nurses' perspectives on who should bear the most responsibility for addressing device implantation with patients and on the factors (aside from medical indications) that should be considered when deciding whether a CIED was an appropriate treatment choice. The discussion for the remainder of the session focused on end-of-life issues pertaining to device deactivation and advance care planning (the process through which patients articulate their goals and preferences about future health care decisions). The participants were asked about their experiences with device deactivation and their perspectives on the moral, legal, and ethical permissibility of deactivation. The contents of discussions about device deactivation were also addressed, along with advance care planning practices. The focus group guide concluded with questions about the advice nurses would ideally provide to patients, families, and practicing clinicians about CIED implantation and CIED deactivation. Physicians were excluded from the discussions so that they could not influence the group.

2.3 Data analysis

All focus group sessions were audio recorded and transcribed, with the identities of the nurses removed. Standard qualitative techniques based in grounded theory [16, 17] were used to categorize data. Each transcript was reviewed independently by four study investigators (D.B.K., A.L.O., S.G., and L.A.M.), and the resulting codes were systematically analyzed to develop themes [18]. Instances of disagreement were discussed until a consensus was reached.

3 Results

A total of 14 nurses (two men and 12 women) participated in the three focus group sessions at the two institutions. Not all answered the questions about their experience levels, but among those who responded, the median duration of experience as a nurse in cardiology was 20 years (range, 2.5–27 years) and the median duration of employment at their current institution was 10 years (range, 7 months to 28 years).

3.1 Themes and concerns

The nurses in our study raised several concerns about the care of patients with CIEDs, including specific problems not previously identified in the literature. The nursing perspective on decision making in particular identified challenges from initial discussions of device implantation through end-of-life care and device deactivation. Analyses of the transcripts revealed 6 themes and areas of concern (Table 2). Representative quotations from the participants are included below.

3.1.1 Preimplantation discussions and informed consent—The nurses believed that, in general, physicians appropriately identified candidate patients for CIED implantation. The decisions were driven by evidence-based clinical guidelines, such as those for ICD placement for patients with congestive heart failure. However, the nurses also believed the informed consent process was often flawed. Specifically, the risks associated with living with a device (e.g., inappropriate shocks, lead failure, and infections requiring explantation), aside from the implantation-specific complications, were commonly described

only superficially, with inadequate steps to ensure that patients and families understood fully the information presented by physicians.

The nurses noted that conversations before device implantation were largely physician driven. Patients were told about the benefits of the device, but equal time was not given to discussing options such as forgoing a device or later deactivation.

For me, the majority...do it because their doctor told them to do it.

This pattern was considered to be particularly concerning for elderly patients because they were deemed more likely to defer decision making to their physicians or family members.

And, I find the older population doesn't question their physicians.

I think all of those patients trust what their doctors recommend... They just do what their doctor tells them and they trust that that is the right thing to do.

Indeed, nurses perceived that many patients felt they did not have a choice on whether to proceed with CIED implantation. Patients were often presented with the choice in stark and sometimes dramatic terms.

They [patients] get a lot of fear approach—"Do this or you'll die!"

In addition to this dramatic language, nurses identified additional informed consent process breaches that impeded shared decision making, including physicians' failure to consider the psychosocial, economic, and advance care planning aspects of living with a device. In particular, nurses said that physicians did not explain in sufficient detail the possibility of psychologic trauma from shocks.

I think we do a good job of "Don't lift your arm" and "Watch for infection" and "Call us if it fires," but that is sort of where it stays.

There is a sort of a fine balance, I guess, that physicians would have to go through, where—you don't want to terrify them, but you don't want to sugarcoat what this experience is if that thing fires. You know it is a lifesaving measure...but, I feel like they are not as truthful as they could be in explaining what the experience could be like.

Failure to coordinate care between multiple providers was common. The nurses felt that the brevity of informed consent discussions existed, in part, because cardiologists may have been overly focused on patients' dysrhythmias and did not appreciate the patients' overall clinical pictures.

Physicians think that if they fix the rhythm, then they fix the patient.

In contrast to this superficial approach, the nurses in our study perceived themselves as well positioned to improve the psychologic adjustment many patients go through upon hearing their device-specific diagnoses. Patients often experienced stress knowing that they had heart disease, an aspect of the experience that may have been lost on physicians, whose time at the bedside was increasingly scarce and pressured.

It really hits home...I have heart disease, I have this machine, I have...so it is just a lot, everything just starts hitting them all at once.

The nurses expanded on these observations and noted that older patients with ICDs may be less afraid of receiving shocks than younger patients, in part because younger patients had greater activity levels and other quality-of-life variables that made inappropriate shocks more likely.

For younger people, I just know that they sometimes are afraid of the shocks, so they try to guide their life avoiding getting shocks. They are very paranoid about it. If they anticipate one, they have told me they just totally just stop doing things and activities because they are afraid of it.

This recognition of age-specific concerns and adjustments to lifestyle extended to nurses' views on device-related knowledge. Many patients did not understand the differences between pacemakers and ICDs, for example, and may have been reluctant—particularly elderly patients—to admit such misunderstandings to physicians.

Right, and [elderly patients] are just doing what the doctor says and they don't want to ask anything. They don't want to admit they don't know something.

In sum, these concerns about informed consent reflected what nurses experienced with patients and families after the physicians left the room. At that time, nurses noted, it became clear what was understood and whether the patient truly grasped what living with a CIED entailed.

3.1.2 Advance care planning—The nurses did not believe that advance care planning was sufficiently addressed for most patients. Planning may include, for example, identifying a health care proxy or completing an advance directive. The nurses perceived that too few patients who had CIEDs or were considering CIEDs had health care surrogate decision makers or advance directives. Furthermore, these matters were not commonly discussed when patients had important changes to their health status.

Ideally, when a patient is admitted, I think that everyone should have their code status reviewed, goals of care addressed, and if there is an ICD in place, if...you know that might be part of the conversation, just as kind of a matter-of-fact thing. This is what we do; you are admitted to the hospital, and we would like to know your thoughts on these things—ideally.

The nurses believed that lack of advance care planning may have led to reactive decision making and was an avoidable stress for patients, families, and healthcare professionals.

3.1.3 Roles of nurses—The nurses saw themselves as generally involved in patient care and decision making only after implantation. While providing instructions after implantation (e.g., wound care) and answering questions, they learned a great deal about their patients' goals and preferences—details that they believed would have been important to consider before device implantation.

So, occasionally, rarely, we may be asked to provide education about a device before it is implanted, but that doesn't happen very often. So, you know, our first contact with a patient would be in the room while it is being implanted, and then, of course, after that, quite a bit.

We give them, maybe, a little bit more of a realistic view of their day-to-day life and how this will affect them.

Indeed, nurses may offer, as part of their education role, more details for patients and families about what to expect when living with a device. They often had opportunities to listen to patients' and families' concerns and reinforce the lifesaving features of the device while also acknowledging the potential for anxiety and emotional distress.

3.1.4 Nurses' views of family roles—The nurses offered their views on the role of families, who often participated in decision making from before implantation to the end of

life. Families provided support for patients and reinforced the importance of the device. However, nurses observed that families sometimes also caused conflicts.

You have to get social work involved and nursing and family meetings to really sit down and allow the patient to say, “This is really what I want. Leave me alone, this is what I want.” But then, what happens is, we try to abide by what they want, and the family keeps coming around and around, “Don’t do that...we want this.”

The nurses perceived that when families were informed, conflicts over decision making were reduced.

And if the family is informed all along, and they are better informed, they can also help when difficult decisions have to be made if you are going to deactivate or why is it firing? At least the family will also be informed, so they are not, like, “What do you mean?”...They won’t be so adversarial.

The nurses noted that families sometimes put pressure on patients to get a device or to keep a device active.

It just sounds like maybe the patient was trying to please the son...and trying to stay alive just for the son.

Of note, the nurses thought that families may not have been adequately prepared for some aspects of their loved ones’ experiences with devices, particularly shocks.

I remember we had a code on our floor. This lady kept getting shocked by her ICD over and over and over again, and the family member was sitting outside the room just like looking at her like, “Oh, my God!”

Nurses believed that experiences such as this reinforced the need for more thorough discussions before implantation and that the discussion should include family members when possible.

3.1.5 Initiating discussions regarding CIED deactivation—The nurses in our study thought that CIED deactivations were usually carried out in a reactive fashion (e.g., after multiple ICD shocks). A majority of requests were introduced by healthcare professionals because many patients and their loved ones did not know that device deactivation was an option.

Echoing their perception of the informed consent process, the nurses believed that they might be better suited than physicians to initiate end-of-life discussions with patients and families.

How many times did these situations occur in which a patient has been [given comfort measures only] and has a device and...the nurses are upset, feeling as if it is the device that is prolonging...the end of life, and they want it shut off? A lot of times, the nurses will actually bring up the conversation with the family when they start saying, “Why is it taking so long?”

The nurses thought physicians may have been uncomfortable addressing end-of-life issues that involved CIEDs.

And I think physicians have a very difficult time to have that end-of-life discussion with patients and patients’ families because they are trained to what is the next step to make you better, to improve your quality of life, to improve longevity, you know, mortality. So, I think it is very difficult for physicians to have that discussion.

As noted previously, nurses believed many patients did not understand basic features of their devices and may not have been aware that CIEDs could be deactivated at all, let alone noninvasively. Patients varied widely in their perception of their device's functions and its relation to their health care goals, yet understanding patients' views of their device was essential to initiating useful discussions about deactivation. Although most patients viewed their device as lifesaving, others perceived it as a "ticking time bomb."

There are people that look at their device like it is their guardian angel; they are fortunate to have it because you or I could be out walking the street and have that happen and we would probably die. But they have their device that could save their life built right in. And then there are other people who walk around with it like it is a time bomb ticking in them—waiting to get shocked. They are mentally really upset about the thought of this happening.

The nurses thought that most of their patients were grateful to have their devices—even those who had been shocked with an ICD.

You know, I hear that a lot from patients....They say, "This is really a simple thing that I have and it is saving my life."

In contrast, for many—even if they were grateful for having the device—the experience of being shocked was deeply troubling and may have led to substantial anxiety.

They really...they start to, even the slightest little thing, you can see them...They start perspiring, they start getting anxious, you know...just the talking about it, the memory of it, they really fall right back into it. They do go through little posttraumatic episodes.

3.1.6 Ethical problems in CIED deactivation—The nurses generally supported the concept of CIED deactivation for a well-informed patient.

If everything is on the table, you know the risks and benefits...How can you tell someone what to do with their life then?

The nurses perceived a difference, however, between deactivating a device and not implanting a device in the first place; that is, they saw a moral distinction between withholding treatment and withdrawing treatment (despite ethical analyses and laws that make no such distinction). Nurses described a sense of actively participating in a patient's demise with device deactivations, rather than deciding against an initial implantation and letting an underlying disease run its natural, life-limiting course.

I think maybe it feels more active. You know, you can say, "We are not going to do anything more, add anything more," but to go and turn something off feels a little bit...even more active in a way.

The nurses thought that CIEDs were usually deactivated when patients were undergoing withdrawal of other life-sustaining treatments (e.g., mechanical ventilation or feeding tubes). Under these circumstances, care was refocused on patient comfort.

Generally speaking, those people have a lot of comorbidities going on, so they also have just other stuff going on. So, the ICD [deactivation] part was just, you know, an extra thing. They all had something else going on—another disease process that was taking them.

The nurses in our study also made a distinction between pacemaker deactivation and ICD deactivation and perceived that other members of the care team (such as physicians) held similar views. Specifically, requests for pacemaker deactivation were considered more morally complex (both for nurses and for physicians) and far less common than those for

ICD deactivation. Nurses expressed reticence regarding deactivating pacemakers in pacemaker-dependent patients and noted that some of their physician colleagues would not perform deactivations under those circumstances.

Now, it is different if a patient is dependent on their pacemaker, meaning that if you turn that pacemaker off, that is it for them. I don't feel comfortable doing that, and that is something that a physician needs to do. And you will get varying answers from the physicians...in who is comfortable doing that.

At least some of that reluctance and moral uncertainty seemed to arise from feeling like an "active" participant in a patient's demise, particularly in cases in which death would be expected to occur shortly after cessation of therapy.

I hardly ever see us turn off a pacemaker because usually at that point a patient is paced, and that feels a little bit like very active, where the patient is probably just going to die from a respiratory standpoint and then lose their pulse...In turning off the pacemaker, it feels like I have just turned your heart off...We usually don't turn off pacemakers in dying patients. They keep going.

This situation contrasts with typical ICD deactivations, in which it would be unusual (although possible) for a lethal tachyarrhythmia to arise immediately after CIED therapies have been deactivated. This creates a "distance" between the caregiver's act and the patient's death that is absent in pacemaker deactivations in pacemaker-dependent patients.

Some nurses, however, described important similarities between pacemaker deactivation and withdrawal of other essential, life-sustaining treatments such as mechanical ventilation. These similarities lent support for deactivation, at least for patients who are terminally ill.

To me, turning off a pacemaker or taking away someone's ability to breathe is the same thing...If a doctor asked me to turn a pacemaker off, that would not bother me to do that. Because to me, if we deactivated those patients, you could stand there and watch them fade away.

Notably, the nurses in our study described cases in which pacemakers were "turned down" rather than "turned off": bradycardia parameters might be changed to decrease the rate of backup pacing (e.g., from 60 to 30 beats per minute) but the pacemaker would not be deactivated. The genesis and rationale for these decisions were not totally clear but seemed to emerge as a compromise between "actively" causing a patient's demise and unnecessarily prolonging suffering. It was not stated whether this solution was proposed by physicians, patients, or the nurses themselves.

3.2 Recommendations for improving patient care

On the basis of their clinical experiences and ethical views, the nurses in our study made concrete suggestions for improving patient care. Indeed, one case recounted by a study participant illustrated many specific opportunities for improvement with initial decision making, informed consent, patient education, and eventual discussion of deactivation of an ICD:

[T]he patient was ambivalent but was pressured by the son, and then [after getting an ICD] he got two shocks and he was done—he didn't want it anymore. And I think the nurses sort of felt like... had he been given an opportunity, like, it sounded—it seemed like the physician had his idea of what should happen, the son agreed and wanted to press the father to go on with it, and once the father really realized what was going on, what this meant to him now that he had this ICD in, he wanted no part of it. But it was already done and it was how many thousands of dollars, and it was turned off in 3 days.

Although this example is extreme, it emphasizes the challenges and opportunities to improve management of patients eligible for and living with CIEDs. The nurses in our study had specific suggestions for improving the process of caring for patients considering or living with CIEDs (Table 3).

3.2.1 Empower patients by improving the quality of discussions—Nurses felt strongly that preimplantation discussions needed to be more thorough, thoughtful, and detailed, and, in particular, the discussions should be structured so that patients felt more comfortable asking questions. A crucial component would be making patients aware of the elective nature of CIED implantation, particularly for ICDs. Nurses felt that the informed consent process generally needed to capture more details of the adverse potential consequences of living with a device, apart from the specific procedural risks. At a minimum, these should include the possibility of inappropriate shocks and psychologic distress, as well as the resources available to manage these, should the need arise. They thought it was critical for many patients to include family or other caregivers in these discussions and suggested that physicians should work closely with nurses and social workers to proactively identify those patients.

3.2.2 Frequently revisit advance care planning—Nurses found that advance care planning was often hamstrung by the poor initial discussions, particularly for elderly patients, who might be vulnerable to influence from family members and less likely to either question their physicians or independently explore the possibility of device deactivation without being prompted. Although improvement in the informed consent process may be expected to resolve some of these challenges, nurses clearly noted that advance care planning was an ongoing, longitudinal process that required attention as patients' healthcare status and goals evolved.

Patients with progressive heart failure, who have an increased possibility of dying of pump failure or pulseless electrical activity, were noted as examples of patients with whom the treating physician needed to proactively discuss the possibility of deactivating the device in an overall goals-of-care discussion.

[B]ut I think it needs to be out there on the table, that we know you have a progressive disease, and if things change and your status changes, there are things we can do to keep you comfortable. You don't have to worry about [your ICD firing]. I think that needs to be known, too.

Again, nurses clearly felt that physicians bore the burden of making patients feel comfortable regarding asking questions about their device as it related to health care goals, while being mindful of the need to keep key family members involved in decision making for specific cases.

3.2.3 Build support for patients in the outpatient environment—The previous suggestions for improvement emerged, in part, from nurses' perspective on the shortcomings of a cardiovascular care system focused largely on acute care rather than chronic, outpatient management. For example, survivors of cardiac arrest were seen to be forced to make decisions about ICD implantation during that same hospitalization instead of at a future outpatient appointment. In general, patients may not appreciate that even their heightened risk for sudden death likely still translates to a very low day-to-day risk, and the timing of ICD implantation for primary prevention remains controversial [19]. Similarly, advance care planning discussions often occurred during dramatic shifts in health status, such as at an intensive care unit admission, while opportunities to address many of the same questions and concerns were missed in less-pressured and less-emotional situations. Thus, nurses felt

that outpatient care of patients with CIEDs needed to be dramatically expanded beyond simple checks of device function.

I also think maybe it should be treated a little bit like they do cardiac rehab...After they go home and after they settle in...they have some counseling sessions.

Nurses felt that patients' understanding of device functions was markedly overestimated at hospital discharge. Patients may think that at discharge, the opportunity to ask questions has passed, and indeed they may feel embarrassed to ask questions about, for example, the differences between pacemakers and ICDs. Thus, they suggested that outpatient device clinics should include dedicated time for patients and families to ask additional questions about advance care planning and the experience of living with a CIED.

4 Discussion

This research study adds the unique perspective of nurses working in cardiology to the current understanding of the care of patients with CIEDs. A number of themes were identified by this qualitative study, including nurses' perceptions of shortcomings in the process of decision making, starting with informed consent and insufficient consideration of the psychosocial elements of living with a permanent cardiac device. Nurses further identified deficiencies in advance care planning (both initial and ongoing) and substantial tensions related to deactivation of CIEDs. The nurses distinguished between withdrawing therapy and withholding therapy, and they considered pacemaker deactivation in particular to be problematic. To address these challenges, nurses called for efforts to empower patients by facilitating individualized discussions throughout the experience of living with a device. Frequent revisiting of advance care planning, particularly as part of a strengthened outpatient care practice, would further support efforts to better match patients' goals with the functions of their CIEDs. A team-based approach involving nursing, social work, psychiatry, and other healthcare professionals could enhance the conversation before implantation by informing patients in a comprehensive fashion about the risks and benefits of receiving a CIED.

This study builds on prior work evaluating aspects of provider views on CIED deactivation [3, 6, 8, 9, 20]. These studies have illustrated variable understanding of the laws and ethics surrounding cessation of therapy, and they underscore the many barriers to delivering optimal care to patients. Our study offers additional evidence that health professionals view pacemakers and ICDs differently (from each other and from other life-sustaining therapies). Nurses described this difference starkly—"turning off the pacemaker feels like I have just turned your heart off"—and noted that CIED deactivation (particularly for pacemakers) typically arises as a choice only after other life-sustaining therapies have been discontinued. This narrative view of CIED deactivation as an "active" role in a patient's demise contrasts with recent Heart Rhythm Society and European Heart Rhythm Association consensus statements that distinguish CIED deactivation from physician-assisted suicide or euthanasia [4, 21]. The uncertainty around CIED deactivation was captured well by the practice of turning down the pacing rate of pacemakers rather than turning off therapy for pacemaker-dependent patients. There is no clear correlate to this for other life-sustaining therapies, such as breathing more slowly with a ventilator or undergoing incomplete dialysis. Indeed, because the flexibility of CIED programming may make it possible for caregivers to avoid directly confronting the moral questions raised by device deactivation, more work is required to precisely characterize the distinctions drawn between various life-sustaining therapies [22].

A related problem is the implicit bias toward considering CIED deactivation only when patients have become seriously or terminally ill. Patients without terminal diagnoses may

reasonably prefer to have an ICD deactivated (or decide to decline a generator change), but making these choices depends on caregivers understanding the available options and communicating proactively with patients. Nurses identified multiple barriers to this ideal, including fragmentation of care among providers and reluctance of patients to ask questions. Nurses in our study focused specifically on the outpatient setting as the avenue through which deficiencies in knowledge and advance care planning should be addressed. In addition, nurses viewed elderly patients as vulnerable to coercion by family members or, more simply, were considered less likely to ask questions or to opt for treatment against a physician's recommendation.

Previous studies identified concerns with informed consent in a general way [6], but our study pairs those concerns with specific criticisms and suggestions for improvement. Nurses argued for a team-based approach to patient care, starting before implantation, when nurses can have a vital role in understanding patient values and preferences and encouraging questions. Continuity should be established with outpatient assessments of patients as their clinical conditions evolve.

Our study has several limitations. We spoke with nurses in the Midwest and Northeast USA only, and therefore we were not able to assess whether regional differences existed in the perspectives or practices of nursing. Our findings may not be generalizable to the experience of nurses in community clinics or nonacademic medical centers, and the qualitative nature of this study does not allow for quantitative estimates of the views expressed by nurses.

5 Conclusion

This qualitative study of nurses who work in cardiology identified important concerns about decision making with CIEDs, from implantation through end-of-life planning and care. Many avenues were suggested for improving patient care. Nurses provided insight's into patient preferences and offered psychosocial considerations for care. Specifically, nurses appeared particularly well suited to encourage patients and families to engage in advance care planning early and with regularity. A team approach should be adopted when caring for patients with CIEDs to improve the quality of discussions and enhance patient care. Finally, the results of this study provide themes for future research.

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Abbreviations

CIED	Cardiovascular implantable electronic device
ICD	Implantable cardioverter-defibrillator

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Table 1**Interview guide used to facilitate focus group discussion**

1	[Opening question/demographic information] Please tell me a little bit about your professional background. How long have you been practicing nursing? Why did you choose a career in nursing in cardiology? How long have you been at _____?
2	Explain to me how you see your role as a clinician in terms of the overall health of the patient. <i>Probe:</i> Determine how they see their role in terms of guiding medical care/patient decision making. ^a
3	What criteria do you use to evaluate if a patient needs a cardiac device? Do you take a patient's cognitive or emotional state into account in your decision? How about their social situation? Or their economic status? How much of a role do you think the preceding factors should play in the decision as to whether or not to recommend implantation of a device? Do you think that certain patients (eg, terminally ill patients) should be ineligible for devices?
4	If you believe a given patient should undergo device implantation, how do you broach the subject with the patient? How do patients typically respond? If patients ask questions, what are typical questions? How do you respond to those questions? How do you think families play a role, if any, in this decision-making process?
5	Who do you think should bear the most responsibility for addressing the issue of device implantation with patients? Why?
6	Do you think a patient's quality of life changes after implantation? Why or why not? What sort of feedback do you get from patients about their life after implantation? <i>Probe:</i> Ask about different devices.
7	Who do you think should bear the most responsibility for addressing the issue of device deactivation with patients? Why?
8	Have you ever discussed device deactivation with a patient? If so, what is your typical approach? Do you feel comfortable doing so? If not, what would make you more comfortable? When do you think this conversation should take place?
9	Prior research has shown that conversations about deactivating devices in patients with advanced illness rarely happen. Why do you think this might be? <i>Probes:</i> Ask if these conversations are different than others at the end of life. Ask about different devices. ^a
10	Have you ever performed a device deactivation? If so, how did that make you feel? If not, why not? <i>Probe:</i> Ask about different devices (eg, implantable cardioverter- defibrillators vs pacemakers).
11	Do you have any moral concerns about device deactivations? Does this affect your willingness to carry out deactivations? <i>Probe:</i> Ask about different devices.
12	Do you have any legal concerns about device deactivations? Does this affect your willingness to carry out deactivations? <i>Probe:</i> Ask about different devices.
13	Do you typically seek ethical or legal counsel prior to proceeding with a deactivation? <i>Probe:</i> Ask about different devices.
14	Do you see a difference between a patient refusing device implantation or pack change and a patient request for device deactivation? If so, why? <i>Probe:</i> Ask about different devices.
15	Do you typically engage in advance care planning with your patients? <i>Probes:</i> How do you discuss advance directives with patients? Do you encourage patients to include provisions for their devices in their advance care planning?
16	What advice would you give to patients and families contemplating device implantation or deactivation? What advice would you give clinicians or others who are having these discussions with patients? Is there anything you would change about the consultation process as it currently stands?

^aQuestion was adapted from Goldstein et al. [8]. Used with permission.

Table 2

Themes from focus groups on the care of patients with CIEDs

1	Preimplantation discussions and informed consent
2	Advance care planning
3	Roles of nurses
4	Nurses' views of family roles
5	Initiating discussions regarding CIED deactivation
6	Ethical problems in CIED deactivation

CIED cardiovascular implantable electronic device

Table 3

Recommendations for improving the care of patients with cardiovascular implantable electronic devices

1	Empower patients by improving the quality of discussions.
2	Frequently revisit advance care planning.
3	Build support for patients in the outpatient environment.