

“That’s Like an Act of Suicide” Patients’ Attitudes Toward Deactivation of Implantable Defibrillators

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OBJECTIVE: To understand potential patient barriers to discussions about implantable cardioverter defibrillator (ICD) deactivation in patients with advanced illness.

DESIGN: Qualitative focus groups.

PARTICIPANTS: Fifteen community-dwelling, ambulatory patients with ICDs assigned to focus groups based on duration of time since implantation and whether they had ever received a shock from their device.

APPROACH: A physician and a social worker used a predetermined discussion guide to moderate the groups, and each session was audiotaped and subsequently transcribed. Transcripts were analyzed using the method of constant comparison.

RESULTS: No participant had ever discussed deactivation with their physician nor knew that deactivation was an option. Patients expressed a great deal of anxiety about receiving shocks from their device. Participants discussed why they needed the device and expressed desire for more information about the device; however, they would not engage in conversations about deactivating the ICD. One patient described deactivation “like an act of suicide” and all patients believed that the device was exclusively beneficial. Patients also expressed a desire to have their physician make the decision about deactivation.

CONCLUSIONS: None of the patients in our study knew that they might need to deactivate their ICD as their health worsens. These community-dwelling outpatients were not willing to discuss the issue of ICD deactivation

and their attitudes about deactivation might impede patients from engaging in these conversations. These findings are in contrast to findings in other advance care planning research and may be related to the unique nature of the ICD.

KEY WORDS: palliative care; advanced technology; communication; patient–physician relationship; implantable cardioverter defibrillator.

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INTRODUCTION

An implantable cardioverter defibrillator (ICD) is a device implanted in a patient’s chest to monitor the heart rhythm and deliver shocks to terminate potentially lethal arrhythmias. Although ICDs reduce sudden cardiac death,^{1–4} patients ultimately die from either heart failure or another disease. As a patient’s disease worsens, physiologic changes (intrinsic and extrinsic to the heart) may affect the cardiac conduction system, leading to more arrhythmias and increasing the frequency of shocks. Because ICD shocks can cause pain and anxiety and may not prolong a life of acceptable quality,^{5–7} it is appropriate to consider ICD deactivation as a patient’s clinical status worsens and death is near. Previous work has shown that clinicians and patients rarely engage in discussions about deactivating ICDs and most devices remain active until death.⁸ Because of this, many patients may receive shocks in the final hours to minutes of life, an unpleasant situation that causes suffering to both patients and their families.⁸

Patient-related barriers to ICD deactivation discussions have not been previously studied. Given the expanding indications for ICD implantation,^{1–4,9,10} the issue of device deactivation will become more relevant as the population ages. Under current Medicare criteria, approximately 3–4 million patients are currently eligible to receive this device.^{4,11–13} Ultimately, all patients with an ICD will die, and therefore, it seems prudent to better understand their wishes with respect to the role the device will play in their future lives.

The purpose of this study was to identify barriers that impede patients from discussing deactivation of their ICD near the end of life. Because a traditional, closed-ended survey instrument might miss the nuances and intricacies that are

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key to understanding these conversations, we chose a qualitative method of using open-ended questions to conduct initial explorations.¹⁴⁻¹⁶ This method is more suited for understanding the complexity of patients' experiences and the role of these devices in their lives.

METHODS

Study Design and Sample

We conducted a qualitative study using focus groups of patients with ICDs. Patients were drawn from an outpatient electrophysiology clinic at an academic medical center that implants over 100 ICDs every year. All patients with ICDs who came to the clinic between June and July 2005 were approached by a member of the research team during their regularly scheduled follow-up visit and asked if they would be willing to participate in a "project discussing patients' perceptions and attitudes about their ICD." Potential participants were told that this was a research project and was not meant to be a support or informational group.

Patients were eligible if they had an ICD, their primary language was English, were cognitively intact as determined by a score of 8 or greater on the short portable mental status questionnaire,¹⁷ and were able to return to the medical center at a later date to participate in the focus group. Participants were compensated for their time (\$20) and transportation costs to the medical center (round-trip bus/subway fare) and were provided refreshments during the course of the focus groups.

Patients were assigned to one of four groups grouped based on the length of time since implantation and whether they had received a shock as follows: patients who had their device for less than 1 year and who had not received a shock, patients who had their device for 1 year or more and who had not received a shock, patients who had their device for less than 1 year and who had received a shock, and patients who had their device for a year or more and had received a shock. We refer to those patients who had their device a year or more as "ICD > 1 year." The differentiation point for time since implant was 1 year, as this is the length of time that has been shown to be necessary for patients to adjust psychologically to these devices.^{7,18,19} Based on our clinical experience, we believed that having received shocks would affect how patients might make future decisions about their ICD; thus, we divided groups into those patients who had never received a shock and those patients who had.

Data Collection

The first author and a PhD-level social worker moderated all focus groups. The social worker has had additional specialized training in psychoanalysis, as well as experience in running focus groups for health research purposes. Neither moderator had direct patient care responsibilities for any of the patients who were enrolled in the groups and had never met any of them before enrolling them in the study. The moderators used a predetermined guide (Table 1), which had been created by the investigators based on their clinical experience with this issue and their expertise in qualitative analyses. The guide began by asking patients to explain their understanding of why they needed an ICD. Next, patients were asked what they

Table 1. Outline of Prompts for Facilitating Discussion for Focus Groups of Patients with ICDs

Prompts
Tell me about the circumstances under which you needed your ICD—why was device implanted? Did any patient have a history of sudden death/syncope, or were all devices implanted for prophylaxis?
Tell me what you understand about your ICD and its role in your health and medical care now. How will this role change in the future if/when your health worsens?
Sometimes when a patient's heart becomes very sick, the person can be shocked often. In this case, some people choose to consider having their ICD turned off. Tell me what you think about this.—Probe to see if patients knew this was an option, their reaction to this information, and if this has ever been discussed with them.
Would you ever consider having your ICD turned off? Tell me more about the circumstances under which you would consider having it turned off.—Probe to identify how patients consider benefits/burdens and how these considerations compare to other medical devices. If issue of quality vs quantity of life has not been raised yet, raise now.
Pretend that in the future you develop a very bad disease. In one scenario, your doctor would turn off your ICD and you would die and in the other scenario you would receive several shocks before you die. In either case, unfortunately, you would die. How would this change your thinking about your ICD?

understood about their ICD and its role in their health and medical care. In addition, participants were asked how this role might change in the future if/when their health worsened. Finally, the moderators described two hypothetical scenarios, both of which ended in the participant's death. In one scenario, participants would leave the device active and possibly receive shocks as they were dying. In the other, the device would be deactivated and the patient would not receive shocks. (Of note, many ICDs are multifunctional devices that may also perform a pacing or resynchronization function. For purposes of this discussion, the term deactivation only refers to turning off the shocking function of a defibrillator.) Subjects who came to the sessions spoke readily, and were neither angered nor concerned when the topic of their own mortality was discussed despite not having been told in advance that the group would focus on the potential for their health to worsen in the future.

Data Analysis

We used the constant comparative method^{20,21} of qualitative data analysis to develop and implement consistent and comprehensive coding of the open-ended data. This method employs a process in which quotations or observations are catalogued into iteratively developed themes. The first transcript is analyzed and divided into passages relating to individual concepts. Subsequent transcripts are then analyzed and portions of these are compared to the previously analyzed data to determine whether the same concepts are apparent. New codes are added as needed until no new concepts emerge with successive interviews (i.e., thematic saturation).

All focus groups were audiotaped and transcribed. The transcripts were independently reviewed and coded by two of the investigators (NG and JZ) who met to discuss the interviews and the coding structure. In the rare cases where there were discrepancies in the coding of a passage (which occurred fewer than five times in the analysis of the data), the two investigators brought in a third investigator (RSM) and the three came to a negotiated consensus through further discussion of the content and its overall context, as recommended by experts in qualitative

analysis.²² The group determined by consensus at which point thematic saturation had been reached.

After analyzing the patients' descriptions of why they needed an ICD, the two investigators categorized the indications for device implantation as either primary prevention (patients at risk for sudden cardiac death) or secondary prevention (patients with a history of sudden cardiac death). There were no discrepancies between the investigators in these determinations. The Institutional Review Board at Mount Sinai exempted this project from review because subjects did not identify themselves during the course of the focus groups and audiotapes and transcripts could not be linked to the individual subjects' identities.

RESULTS

A total of 34 patients with ICDs were approached to participate and 15 were enrolled. Of the 19 patients who were approached but not enrolled, three refused and 16 could not return to the medical center on the particular date specified for their focus group. Nonparticipants did not differ from those who participated by age, sex, education, or time since implant ($p>0.05$). The 15 participants were divided into three focus groups (ICD< 1 year, never shocked; ICD>1 year, never shocked; and ICD> 1 year, had received shock). We were unable to enroll any participants who had the device for less than 1 year and who had received a shock. The characteristics of these patients are shown in Table 2. Four patients had a history of sudden cardiac death. Patients in the group who had been shocked each recalled only having been shocked once. All groups lasted approximately 90 minutes.

None of the participants recalled ever having had a conversation with their physician about deactivation, and no patient knew that deactivation was an option. The moderators spent a large portion of each focus group explaining to patients that, as their health changed in the future, there might come a point at which they would want the device deactivated.

In the course of these explanations, it became clear that participants did not understand the role their ICD played in their health. For example, instead of understanding that the role of the device was to treat a potentially fatal arrhythmia, one participant described his ICD as having a role in pacing his heart, as follows:

I was given to understand that the defibrillator, one of the jobs it does if the pacemaker falls asleep it will wake it up, like a booster, you know what I mean? Like, 'hey go to work,' you know what I mean? That's what I was given to understand.

(male participant, ICD<1 year, never shocked)

A patient in the same group described the role of the ICD as only regulating rate and not the rhythm:

Well, I know that as my heart goes up to a certain level or down to a certain level, it will go off. That's all that I understand.

(male participant, ICD<1 year, never shocked)

Patients also did not seem to fully understand the reason they received their ICD. Instead of understanding the risk of

Table 2. Characteristics of Patients Enrolled in Focus Groups

Category	Characteristic	Value
Enrollment	>1 year, no shock	2
	>1 year, + shock	8
	<1 year, no shock	5
Age	Median (SD)	69 years (18.6)
	Range	30–90 years
Ethnicity	White, non-Hispanic	10
	Hispanic/Latino	3
	Asian	1
	African-American	1
Sex	Male	10
Education	Less than high school	2
	High school graduate	3
	Some college	1
	College graduate	4
	Advanced degree	5
Indication for ICD	At risk for sudden cardiac death (primary prevention)	11
	History of sudden cardiac death (secondary prevention)	4

sudden cardiac death as the indication for needing an ICD, one patient described the reason for implantation as related solely to a change in heart rate:

When I came for my annual physical recently, the heart rate had changed a little bit and they said, 'Now you're a candidate for a defibrillator' and they put the defibrillator in. (male participant, <1 year, never shocked)

Given the misinformation that most patients have about their device, it is perhaps not surprising that many patients came to the focus groups looking for more information, despite the fact that when they were asked to participate they were clearly told that it was neither a support or informational group but instead part of a research study. One patient described his desire to come to the group as:

This is the reason I'm here because I wanted to get other people's input...I want to know, 'Hey, what can we do to avoid that shock?' That's what I'm looking for. (ICD<1 year, never shocked)

Another participant described his desire as

That's what I really wanted to find out...what it feels like for the device to go off. How tolerable is it? (ICD>1 year, never shocked)

Similarly, patients who had been shocked were seeking more information about their device and what to do when they were shocked:

Right, more information as to what to do when you get hit, what you can expect – there should be a whole list – and what you do—that's the other part. You don't know what the hell to do. (ICD>1 year, received shock)

While explaining their (mis)understanding of their device, participants in all groups described a great deal of anxiety

when thinking about future shocks from their device, regardless of whether they had previously experienced a shock. This sense of anxiety is described in the following quotation from a woman when she described an experience as a tourist passing through a security screening:

I was in Pennsylvania, at the Liberty Bell, and the guys were like, 'Oh, just go through,' and I had to fight with them to be like, 'I am not walking through that thing. You've got to be crazy.' They're like, 'It's okay, it's just this and that' and I'm like, 'Do you understand what I'm telling you?' They don't understand, they're just like, 'It's not a big deal' and I'm like, 'You get a shock, then tell me it's not a big deal.'

(ICD<1 year, never shocked)

Another participant who had the device for a longer period of time describes a similar anxiety:

I'm very active and I'm concerned. Every time I drive to work in the morning I ask myself what would happen if I got a shock now, but thank God so far that hasn't happened.

(male participant, ICD>1 year, never shocked)

One patient who had received a shock also described a similar sense of anxiety:

I was on my way to work and all of a sudden I got a blow into my back...It was like someone took a medicine ball and threw it with tremendous force into my back and I turned around and asked some young fellow standing there...'Did you see what hit me?'...On the plus side, I know it works. It saved my life. On the uh minus side, like everybody else I think...that it scared me...it scared me because it plays games with your head and you think about it.

(male participant, ICD>1 year, had received shock)

In contrast to their willingness to talk about other issues relating to their ICD, participants would not engage in conversations about device deactivation during the focus group, nor did they seem willing to have these conversations with the clinicians who cared for them. When asked how he would react to a physician raising the issue of device deactivation, one participant stated:

That's like an act of suicide. It's a threat to your life.

That's like cardiac arrest. That's insane.

(male participant, ICD>1 year, never shocked)

A subject in another group (ICD>1 year, had received shock) described deactivation as a "no-win situation," but she would not further characterize how she might consider turning off the ICD. In fact, many patients could not contemplate any situation in which death was a likely or probable outcome. As described by one man:

The only solution to [the] problem that you pose is probably a transplant...there has to be an alternate

solution—and I see transplant as being the only alternate solution...I would never consider just shutting it off.
(male participant ICD>1 year, never shocked)

Another participant in this same group stated:

I would keep the defibrillator forever.

(male participant, ICD>1 year, never shocked)

Regardless of whether or not a participant had received a shock from their device, all participants described the ICD as only beneficial, with no burdensome aspect associated. As one patient described:

For me, it's like getting an extra life.

(female participant, ICD<1 year, never shocked)

This theme is illustrated even more clearly in the group of patients who had been shocked. As one participant recounting his doctor's explanation at the time of implantation stated:

[My doctor said] you still have the [medical condition]... And if it comes back in the bottom chamber of your heart you just drop dead...We are going to suggest implanting a defibrillator on you strictly as an insurance policy basically. So that if it does come back you will be shocked and you will be fine.

(male participant, ICD>1 year, had received shock)

Another participant in this same group anthropomorphizes her ICD, almost describing the device as a trusted friend:

All I know is that it is there to help me and as long as I don't do wrong by it, it won't do wrong by shocking me.

(female participant, ICD>1 year, had received shock)

The closest any participant would come to discussing deactivation was describing their preferred role in decision making about ICD deactivation. When asked about how he might make a decision about deactivation, one participant refused to answer and instead described his physician as the one who should make such a decision:

That's for your doctor to be the judge of that. If you have something wrong with you, hey, you go right back to the source. If you got a problem, go back to your doctor. He's the one who'll tell you what to do and how to handle yourself. You can't do it on your own.

(ICD<1 year, never shocked)

As stated by a male patient in the same group,

I think that the doctor has to make that decision for you. We're all laymen, it isn't for us to do that, that's what we've got doctors for.

Another patient expressed this theme in a slightly different way, when he stated:

Do you always take your doctor's advice? I find I have no option [but to follow it].

(ICD>1 year, never shocked)

DISCUSSION

Patients with ICDs in this qualitative study were uniformly unaware that device deactivation was a decision that they might face in the future. Furthermore, and despite multiple prompts from the group facilitators, no participants were willing to engage in advance care planning discussions regarding deactivation—either during the focus group or with their own clinicians. These results have important implications for advance care planning as the number of people with ICDs is rapidly growing.

These results are markedly different from other research examining patients' willingness to engage in advance care planning. In the majority of other studies examining patients' wishes for care at the end of life, investigators have found that patients are quite open to discussing, and indeed want, to address treatment options and goals of care near the end of life.^{23,24}

There are several possible reasons for why our results differ from other studies of advance care planning. First, ICDs are fundamentally different from other interventions that patients might receive at the end of life and those that have previously been examined in other advance care planning studies. Unlike mechanical ventilators, feeding tubes, and dialysis, ICDs are typically implanted well before the patient perceives themselves to be seriously and terminally ill. That is, most patients who receive an ICD are at risk for a fatal arrhythmia but are not symptomatic from a serious illness that would place them at high risk for a noncardiac death. Given the tremendous fear of receiving a shock from the ICD expressed by patients in this study, the inherent "emergency rescue" nature of the ICD, and patients' faith in the ICD's life-restoring ability, it may be impossible for otherwise "healthy" patients to envision a situation when they would want this life-saving technology withdrawn like they would for a hypothetical mechanical ventilator or feeding tube.

Second, the participants in our study did not appear to fully comprehend the nuances and intricacies of these devices. This lack of knowledge may also inhibit their ability to engage in conversations, as they may not have the knowledge necessary to adequately weigh the option of deactivating the device. In addition, the internalized and unseen nature of the device makes it easier for patients to avoid conversations about them.

Third, patients appear to develop a complex psychological relationship with their ICD in a way unlike other interventions. The devices provide a sense of security ("like an insurance policy" or like a trusted friend) and the very notion of removing them is "like an act of suicide." ICD discharges seem to be psychologically destabilizing, as a shock "plays games" with the patient's emotional well being. It is somewhat paradoxical that, in the same focus group, patients can acknowledge the anxiety of getting shocked but nevertheless continued to speak of the device as only beneficial. Participants seem to have developed a symbiotic relationship with the device. If the ICD is seen as a friend, then it is difficult for a patient to believe that the device could actually do them any harm. The interplay of these psychological factors results in a state of perceived immortality for these participants—they will either get a new heart or just keep their ICD "forever."

Many of the participants in our study wanted their physician to make a decision about deactivation for them, and this may be a phenomenon related to the fact that the participants were all at a similar point in their overall state of health. The

research literature on decision making demonstrates that patients' desired role in decision making may change over the course of their illness. For patients who are relatively healthy, for whom the medical decisions are relatively simple, patients want to either make the decisions themselves or share decision making with their families.²⁵ As a patient's illness progresses, however, they go through a period of more complex decision making where they desire less autonomy and want their physician to make the decision for them.^{25,26} Participants in this study might be included in this category—the decision about whether to deactivate the ICD is complex (both medically and psychologically) given their current state of health, so at the time of the interviews, patients ceded decision making to their physician. As illness severity worsens and patients approach the end of life, there are fewer options available, and thus, decisions are simpler; the literature supports that patients near the end of life desire to be more autonomous and make decisions for themselves.^{27,28} There are no data from this study to show that these participants' desired roles in decision making will necessarily change as their health worsens, so future work will need to examine this issue.

This study had several limitations that should be noted. First, although all of the patients in this study had a serious cardiac condition that required an ICD, they had an excellent performance status and did not have other major comorbid illnesses. It is possible that this might have created a selection bias against patients who were more debilitated and may have been more likely to contemplate their own mortality and the changing role of the device. The participants in this study were all drawn from a single academic medical center and may not be representative of the larger population of patients with ICDs. The majority of the patients included in this study were male and white, which may limit the generalizability of these findings. It should be noted, however, that disparities in implantation have shown that women and minorities receive these devices with less frequency than other groups.^{29,30} Another potential limitation is that patients may either not comprehend or not remember information that their physician had told them,^{31,32} so it is possible that some of the patients included in this study may have previously been told that they could have their ICD deactivated. Finally, a relatively small number of patients were enrolled. The investigators chose not to continue to enroll patients because it became apparent near the end of the data analysis that no new concepts were emerging from the data (i.e., thematic saturation had been reached), but these finding will need to be further explored in future larger, quantitative studies.

In this study of community-dwelling, ambulatory individuals with ICDs, we found that patients were either unwilling or unable to engage in conversations about deactivation. While the goal of the study was to identify barriers that could be overcome, what we found was that patients' perceptions and understandings of their device may be the most significant difficulty that impedes them from engaging in discussions about the management of the ICD. For clinicians who wish to have conversations about these devices with patients near the end of life, one approach might be to first elicit larger goals of care, and then assist patients and families with a benefit/burden analysis to determine how each specific treatment decision should be made in the context of their desires. Discussions about deactivating ICDs can then be seen in the context of other goals of health

care, thus helping patients understand that the decision to deactivate the ICD may be a decision in-line with their overall wishes as their illness progresses. Future work that involves both qualitative and quantitative analyses is needed to create communication interventions that will help physicians elicit these larger goals of care and make ICD deactivation decisions within this framework.

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