

Patient perceptions of implantable cardioverter-defibrillator deactivation discussions: A qualitative study

SAGE Open Medicine
Volume 4: 1–8
© The Author(s) 2016
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/2050312116642693
smo.sagepub.com


Jane MacIver, Alana Tibbles, Filio Billia and Heather Ross

Abstract

Background: There is a class I recommendation for implantable cardioverter-defibrillator deactivation discussions to occur between physicians and heart failure patients. Few studies have reported the patient's perspective on the timing of implantable cardioverter-defibrillator deactivation discussions.

Aim: To determine patient awareness, preferences and timing of implantable cardioverter-defibrillator deactivation discussions.

Design: Grounded theory was used to collect and analyze interview data from 25 heart failure patients with an implantable cardioverter-defibrillator.

Setting and participants: Patients with an implantable cardioverter-defibrillator, from the Heart Function Clinic at University Health Network (Toronto, Canada).

Results: The sample ($n = 25$) was predominately male (76%) with an average age of 62 years. Patients identified three stages where they felt implantable cardioverter-defibrillator deactivation should be discussed: (1) prior to implantation, (2) with any significant deterioration but while they were of sound mind to engage in and communicate their preferences and (3) at end of life, where patients wished further review of their previously established preferences and decisions about implantable cardioverter-defibrillator deactivation. Most patients ($n = 17$, 68%) said they would consider deactivation, six (24%) were undecided and two (8%) were adamant they would never turn it off.

Conclusion: The patient preferences identified in this study support the need to include information on implantable cardioverter-defibrillator deactivation at implant, with change in clinical status and within broader discussions about end-of-life treatment preferences. Using this process to help patients determine and communicate their implantable cardioverter-defibrillator deactivation preferences may reduce the number of patients experiencing distressing implantable cardioverter-defibrillator shocks at end of life.

Keywords

Implantable cardioverter-defibrillator, heart failure, advance care planning, palliative care

Date received: 29 September 2015; accepted: 10 March 2016

Introduction

Implantable cardioverter-defibrillators (ICDs) are recommended for use in select patients to lower the risk of sudden cardiac death.¹ ICDs prevent sudden death either by anti-tachycardia pacing or through delivery of one or more defibrillator shocks. ICDs do not improve cardiac function nor delay heart failure progression.² As heart failure progresses and patients become more symptomatic, the associated hypoxia and electrolyte imbalance might potentiate arrhythmias. Patients with ICDs may experience an increase in shock frequency during their last days and hours of life which is often distressing for them and their family.^{3,4}

Deactivation of the ICD is legal and morally acceptable when it is consistent with patient goals.⁵ An ICD can be easily deactivated by programming the device with a telemetry

Peter Munk Cardiac Centre, Toronto General Hospital, University Health Network, Toronto, ON, Canada

Corresponding author:

Jane MacIver, Peter Munk Cardiac Centre, Toronto General Hospital, University Health Network, 4N-437, 200 Elizabeth St, Toronto, ON M5G 2N2, Canada.
Email: jane.maciver@uhn.ca



computer or using an external magnet to disable the defibrillator. Turning off the defibrillator will avoid unnecessary and painful shocks at end of life. Moreover, the option to turn off the defibrillator in patients with severe advanced heart failure presents the possibility that their mode of death may change from progressive heart failure to sudden death, which may be a preferable and less traumatic death for patients.

Recommendations from the European Society of Cardiology, Canadian Cardiovascular Society, American College of Cardiology, American Heart Association and the Heart Rhythm Societies in Europe and America endorse a proactive approach to ICD deactivation.^{2,6,7} Clinicians are advised to approach patients who are nearing end of life to discuss ICD deactivation because it promotes advance care planning and supports informed consent. While many clinicians may agree that deactivating the ICD at end of life is in the best interest of the patient, few actually engage in this practice.⁸ Physicians may be misinformed about the role and function of the ICD or the legal and ethical implications of device withdrawal.⁵ Additionally, there is a dearth of evidence about when and how heart failure patients want these discussions to occur. To address this issue, we conducted a qualitative study to determine patient awareness, preferences and timing of ICD deactivation discussions.

Methods

Study design

Qualitative data provide a way of seeing, organizing and understanding ICD deactivation discussions from the heart failure patients' perspective within the context of an academic teaching center. We used a qualitative design inspired by the grounded theory methods described by Strauss and Corbin.⁹ This version was chosen because it fits within a post-positivistic paradigm of inquiry, is well suited to answer the research question and is congruent with the worldview of the majority of clinicians who may be using this study to change practice. We used many elements of the grounded theory method but made conscious decisions about the design based on our clinical background. We are researchers and clinicians working with this challenging patient population. Our experience is different from those who either do only research or only work with patients in a clinical setting. We believe this enhances our ability to ask stimulating questions and make sound assumptions based on the data. The final product provides a way of understanding the experience of the participants that can be discussed, challenged and refined by others.

Participants

We enrolled 25 patients with heart failure who had an ICD for primary or secondary prevention and were followed by the heart function team at the Toronto General Hospital. The

Toronto General Hospital is an academic teaching facility in a large urban area. The Heart Function Program is the only center in the Greater Toronto Area that provides advanced surgical therapies such as heart transplantation and mechanical circulatory support for patients with heart failure. At each clinic, the attending physician identified the patients who they believed were good candidates for this study. Eligible patients were then contacted by a heart failure team member and asked if they would be willing to meet with the researcher. They were informed that the decision to participate in the study was voluntary and their decision to participate or withdraw would not affect their current or future care. Patients >18 years with an ICD who spoke, read and comprehended English were eligible for enrollment. Each patient was informed that the interview would be audio-recorded prior to signing the consent.

We used purposive sampling to identify patients with a variety of experiences: time living with heart failure, occurrence of ICD shocks, gender and ages. Purposive sampling was chosen over theoretical sampling because we wanted to ensure that our data were applicable to our entire patient population. For example, we chose patients who had an ICD shock and those who did not have an ICD shock to determine whether this experience affected their ICD deactivation discussion preferences. As concepts emerged, we selected patients who might provide information within a certain dimension; for example, we chose patients who were living with advanced heart failure to explore whether disease severity affected their preferences for ICD deactivation discussions. This was a conscious decision made prior to data collection because we felt our clinical experience would help us identify patients with a variety of experiences who could articulate their thoughts and experiences to inform our analysis. Twenty-five patients met with the interviewer to discuss the study, and all agreed to participate. The study was approved by the research ethics board at the University Health Network (REB #09-0950), and all participants signed the consent form prior to the interview.

Data collection

Data were collected using semi-structured face-to-face interviews over 1 year. The interviewer (A.T.) was an undergraduate student with experience in qualitative methods and not a member of the clinical team. She had no preconceived notions regarding ICD deactivation discussions. We felt that the participants would be more genuine with an interviewer who was not part of the clinical team. A.T. was co-supervised by J.M. and H.R., both of whom have experience in qualitative methods. Patients were made aware of her status and informed that identifying information would not be shared with the larger research team. Interviews were conducted in a private meeting room in the outpatient clinic, following an appointment with the heart failure cardiologist. The interviews were conducted using an interview guide (see

Appendix Table 1). If patients were unaware about the fact that the ICD could be deactivated, the interviewer provided the following scenario:

If a patient with an ICD was dying and the heart went into an irregular rhythm, the ICD would fire and shock the heart until the irregular rhythm stopped. The only way to stop the ICD from shocking the heart is to turn it off. Turning off the ICD doesn't hurt. It is done either in the defibrillator clinic with the computer or with a large magnet placed over the ICD at the bedside. They can turn off the ICD but keep the pacemaker going.

The interviewer then discussed the scenario with the participant to ensure he or she had interpreted it correctly. As the study progressed, specific questions were changed within the interview guide to explore and probe emerging concepts. A single interview was deemed appropriate because patients with heart failure may experience dyspnea and fatigue as well as the potentially upsetting nature of some concepts that may be discussed.

Data analysis

Data collection and analysis were conducted simultaneously consistent with the constant comparative methods described by Strauss and Corbin.⁹ The recorded interviews were transcribed verbatim (AT). Each transcript was reviewed for completeness by simultaneously listening to the recording while reading the transcript. Transcriptions and audio recordings were imported into NVivo[®] version 9 software (QSR International, Cambridge, MA). The coding process described by Strauss and Corbin involves three levels of coding: open coding, axial coding and selective coding. Open coding entails breaking down the data into codes/concepts to begin examining, comparing and categorizing data.⁹ Open coding was conducted independently by two researchers (A.T. and J.M.). As codes were identified, they were labeled with the participant's words and filed in the NVivo program as "free nodes." When a subsequent participant identified the same code it would be imported into the appropriate file. Early codes tended to reflect what the patient was feeling or thinking as they described the decision-making process. As codes were agreed upon, they were labeled by what they had in common and filed in NVivo as tree nodes. Many of the tree nodes had daughter nodes which described dimensions, variations and conditions of that particular category. Axial coding involves determining the properties and dimensions of a category as well as identifying relationships among categories.⁹ As categories emerged, they were incorporated into the interview to facilitate data collection. We used an iterative process going back and forth between the interviews and transcripts to determine what was similar, what was different and why. Memos were used to record our train of thinking as they developed. For example, when we were examining the three stages for ICD deactivation discussions, we identified how participants used different verbs to describe their participation in the discussions. In the

pre-implant stage, they used "inform," "know" and "told." In the significant deterioration stage, they used "meet," "discuss" and "plan." These ideas were noted and developed in the memos we used during analysis. Selective coding was conducted as a group. Codes, categories and relationships were discussed, reconsidered and refined until agreement within the group was reached. We reached saturation when the interviews were providing no new data and the categories were well developed. At this point, we stopped data collection. One overarching category was not identified. Instead participants identified three distinct stages to raise the issue of ICD deactivation, and their preference for information or discussion differed depending on the stage. We feel the final model is a fair representation of heart failure patient perceptions of ICD deactivation discussions.

We have chosen to use some numerical data in the "Results" section to quantify responses to specific questions. This was a practical decision based on our knowledge of professional guidelines for ICD deactivation discussions. Guideline recommendations regarding ICD deactivation discussions are based on expert clinical opinion (Level C). Our study identifies when patients want to engage in ICD deactivation discussions and what content they want covered at various stages of their illness. The two perspectives may differ. We felt compelled to include simple counts in our "Results" section so that our clinical colleagues can judge the intensity of the patients' response and make decisions regarding the applicability of our results to their clinical practice.

Results

Overall, 25 heart failure patients who had an ICD were enrolled in the study (see Appendix Table 2). The sample was predominately male (76%) with an average age of 62 years. Nine patients (36%) said they had experienced at least one shock from their ICD. There was no difference in preferences between patients who had or had not experienced a shock or between patients implanted as primary versus secondary prevention. One patient had his ICD deactivated for multiple shocks. Text that is in *italics* identifies a patient's own words.

Awareness of ICD deactivation

Out of the 25 patients, 11 patients (44%) were aware the ICD could be deactivated. Seven patients had been told prior to implant, and 4 patients had read about it during their own information search. Eight (32%) of the patients who were aware the ICD could be deactivated understood it would need to be turned off at end of life to prevent unnecessary shocks. Patients who were unaware the ICD could be deactivated explained how they might have been told, but had forgotten:

Well, they probably inadvertently did ... sometimes when you're getting information, you're getting quite a bit of information and some of it is a little bit upsetting. (Patient 16, male, age 38)

Patient preferences for the timing of ICD deactivation discussions

Patients identified three stages when ICD deactivation should be addressed: prior to implant, with significant deterioration and at end of life. How the information is addressed differs between the stages. We have labeled the three stages as Describe (pre-implant), Discuss (with significant deterioration) and Decide (EOL). (Appendix Table 3).

1. *Pre-implant—Describe*: Prior to implant, patients explained how they wanted to know the ICD could be deactivated but did not want to engage in lengthy discussions about their preferences. Patients used words such as “tell,” “know” and “inform.” Patients felt they had a right to the information in order to make an informed decision regarding ICD implantation. They suggested information be included in written patient education materials and addressed during the pre-operative visit:

I think when you're first going into it ... you should be informed. (Patient 17, male, age 74)

... when a patient is seeing a physician for the first time it's very stressful. They don't take away half of the conversation, frankly. If it's not in the documentation—and I don't recall that it is—the documentation that you receive about your ICD, if it's not in there it should be in there. (Patient 25, female, age 42)

In contrast, some patients expressed how engaging in an ICD deactivation discussion before ICD implant may increase emotional distress. One patient said,

There's a point somewhere in the whole treatment where the doctor should (discuss turning it off). But certainly not at the beginning. A bit overwhelming ... I think I would have just lost it. (Patient 18, male, age 55)

Another patient identified the irony in having ICD deactivation discussions prior to ICD implant:

... they put in a machine that can save me ... and now they are talking about turning it off already ... [laughing]. (Patient 9, male, age 71)

2. *With significant deterioration—Discuss*: One-third of patients said the best time to talk to them about ICD deactivation was when their condition *changed*. There were two key features associated with this discussion: (1) patients should be “of sound mind” and (2) they preferred this discussion when deterioration had progressed to end of life—when they had “x” months left to live. Patients believed physicians could predict when a change in health status would result in death. They described how the purpose of

the discussion was to *remind* them that the ICD could be deactivated and determine individual preferences for ICD deactivation at end of life. They felt that having the discussion when the patient was of *sound mind* and before he or she was at end of life would avoid *surprises* when the patient was dying:

If someone's status is changing, they need to be reminded so it's not a surprise because it's going to feel like “Oh you want to kill me,” you know? versus I'm dying now, shall I turn it off? (Patient 25, female, age 42)

3. *At end of life—Decide*: Patients did not feel it was appropriate to have the first discussion about ICD deactivation when death was imminent. They described how preferences should be discussed during the deterioration stage and inform the decision to deactivate the ICD at end of life. It was during this terminal deterioration that patients, who would consider ICD deactivation, wanted the ICD deactivated:

But for me, like I said, I wouldn't do it until there is absolutely no hope. (Patient 13, male, age 28)

Interviewer: So, you just prefer at the end, when you are very sick, the doctor to just tell you?

Patient: *Oh, no, not to tell me, but to do it.* (Patient 13, male, age 28)

Most patients would consider ICD deactivation when there was no hope of meaningful recovery (n = 17; 68%). No hope of meaningful recovery was described as being bedridden, in a coma or on life support. There was no difference in preference for ICD deactivation between patients who initially said they were aware (8/17) and patients who were unaware of the option of ICD deactivation (9/17). Two patients (8%) were adamant that they would not get their ICD deactivated:

... when I was really sick, I honestly think that that's what kept me alive, it was my ICD.

I would never deactivate my ICD. To me, that's kept me alive. (Patient 2, female, age 50)

Another patient equated ICD deactivation with assisted suicide and stated he would not deactivate it because suicide was against his faith. Six patients (24%) were undecided about their deactivation preferences. These patients stated that their decision to deactivate the ICD was situational:

If it saves my life ... I still have a quality of life that's worth living, right? At some point when my quality of life is negative ... then ... shut it off. (Patient 7, male, age 66)

Factors that would affect their decision to deactivate included frequency and pain of shocks, overall quality of life and the recommendation of the physician. This group of patients seemed to be struggling with their perception that the ICD was a benevolent device, but that it may cause pain or emotional distress.

Preference for who should initiate the discussion

The majority of patients (n = 17) felt the discussion should be initiated by a team member; 9 patients identified the cardiologist, 8 identified nurses and social workers. Patients described trusting the team to know not only when but also how to initiate the discussion. This group of patients was relatively comfortable talking about ICD deactivation and dying. The remaining 8 patients said they thought the patient should be the one responsible for initiating the discussion. They worried that if the physician initiated the discussion before the patient was ready, it would increase emotional distress for the patient. This group of patients used the third person when talking about ICD deactivation discussions:

maybe the patient ... because I think ... that if the doctor start talking to that ... maybe they are gonna put stress on the patient; make them worry about something. (Patient 1, male, age 51)

This patient then goes back to talking about himself in the first person:

I don't need to know. I know my condition, I try my best to keep in shape and that's it, I don't want people to talk to me about it. (Patient 1, male, age 51)

Discussion

The proportion of patients who report awareness of ICD deactivation ranges from 13%–73%.^{10–14} In our study, 44% of patients reported being aware of ICD deactivation. Patients identified how “a lot” of information is discussed before ICD implantation. The information they receive in our program consists of written information as well as discussion with doctors and nurses about the ICD and their decision to proceed. Some patients may feel overwhelmed with the quantity and complexity of information and may not remember all information included in pre-implant discussions.

Patients who were unaware the ICD could be deactivated were provided with an explanation of how ICDs were deactivated and a scenario about what may happen at end of life if it remained active. Following this scenario, 68% said they would consider ICD deactivation at end of life. The proportion of patients who stated they would consider ICD deactivation is similar to some studies,^{12–14} while other studies have reported much lower rates (15%–30%).^{11,12,15} All studies were single center analyses, and the difference in results may reflect practice patterns between institutions.

Patients from our sample felt it was their right to be informed prior to implant that the ICD can be deactivated, and this information was necessary for informed consent. They identified how information on ICD deactivation should be included in written patient education materials and addressed during pre-operative discussions. However, they did not feel this was an appropriate time for a comprehensive ICD deactivation discussion. Our finding that patients did not want to engage in discussions regarding ICD deactivation prior to implant seems to contradict previous findings in the literature. Raphael et al.¹¹ surveyed 54 heart failure patients with an ICD to assess their recollection of the consent procedure and preferences for ICD deactivation discussions. Overall, 52% felt ICD deactivation discussions should occur prior to implant. Pederson et al.¹⁴ reported that 49% of 294 patients felt ICD deactivation should be discussed prior to implantation with 62% responding that information should be done both verbally and in writing. In an analysis of 3067 ICD patients recruited from a national ICD and pacemaker registry, 50% stated they wanted to discuss ICD deactivation at the time of implant.¹⁶ The lower proportion of patients in our study (28%) who wanted to include ICD deactivation prior to implant could be explained by our methodology. The qualitative approach allowed us to explore the type and amount of ICD deactivation information that the patients wanted prior to implant. They described the irony of having discussions about deactivating a device that had not been implanted. They felt discussing about it may increase emotional distress. The meaning patients assigned to “discussion” is missing from the quantitative studies. Perhaps patients were trying to emphasize the need for information for informed consent and not their preference for ICD deactivation. Regardless, both verbal and written information regarding ICD deactivation discussions should be included prior to implant. Patients can be given the opportunity to explore their ICD deactivation preferences at that time.

The majority of patients expressed a preference for comprehensive ICD deactivation discussions when their condition deteriorated but while they remained of sound mind to engage in a discussion and communicate their preferences. Pederson et al.¹⁴ reported 55% of their sample identified decreased life expectancy as the trigger for ICD deactivation discussions. The Annual Heart Failure review¹⁷ is a proactive and iterative approach to address patient preferences that is initiated when a patient's condition progresses to Stage D heart failure. Any significant change in the patient's condition, such as hospital admission or ICD shock, triggers another discussion about preferences. It is reasonable to include ICD deactivation preferences in the discussion with other life-sustaining therapies such as resuscitation, intubation and hemodialysis.⁵ Elective ICD battery placement is another milestone where clinicians can raise the issue of ICD deactivation and encourage patients to consider and discuss their preferences.⁷ Currently, many patients feel the decision to replace the battery is not a deliberate choice.¹⁸ Many

agree to proceed with battery replacement even if they had never experienced an ICD shock (79%), reached an advanced age (63%) or were seriously ill (55%).¹⁶ Standardizing ICD deactivation discussions as part of a patient's routine care should also ameliorate concerns that these discussions signify bad news.¹⁷

Patients seem to be receptive to ICD deactivation discussions when they know they are nearing end of life.¹⁸ In a study of 20 patients with an ICD and a terminal illness,¹⁹ diagnosis of the terminal illness triggered a comprehensive discussion regarding prognosis with the patient, primary care physician and appropriate sub-specialists. ICD deactivation was discussed with other life-sustaining therapies, and all 20 patients had their ICD deactivated. The average time from device deactivation to death was 49 days, and only 15% of patients experienced a shock within 1 month of death. These results are similar to those where patients with a terminal disease, counseled on ICD deactivation, were more likely to choose ICD deactivation at end of life.^{20,21} Dodson et al.¹³ used five scenarios to help patients determine their ICD deactivation preferences. The scenarios represented treatment outcomes known to influence treatment preferences: (1) bedbound, (2) memory problems, (3) burden to family, (4) prolonged mechanical ventilation and (5) advanced incurable disease. After being presented with each scenario, patients were asked if they would want their ICD deactivated on a scale from 1 (definitely no) to 5 (definitely yes). They were classified as wanting deactivation if they responded possibly yes or definitely yes. The sample consisted of 95 patients (66% male) with an average age of 71 years who had an ICD for an average of 4 years. No information was given on the New York Heart Association (NYHA) classification or illness severity. The majority of patients (71%) stated that they would want ICD deactivation in one or more scenario(s) with 24% wanting deactivation when bedbound to 61% wanting deactivation with advanced incurable disease. These scenarios may provide patients with a way to help them consider and clarify their preferences and make a thoughtful, reasoned decision.²¹ Conversational protocols using "a patient" instead of "you" may be useful strategies to help patients who are reluctant to discuss ICD deactivation. Understanding what a patient thinks someone else might choose in a particular situation may provide insight into their treatment preferences. Scenarios can be included as part of the protocol and clinicians directed to depersonalize the content for patients who are reluctant to engage in these discussions. Conversational protocols have been shown to increase the rate of ICD deactivation among patients admitted to hospice patients.²²

The majority of patients (68%) who participated in our study felt ICD deactivation discussions should be initiated by the clinical team. Patients trust the team to know when to raise the issue, and how the information should be presented. Cardiologists and nurse practitioners who care for heart failure patients are uniquely suited to accept responsibility for

initiating ICD deactivation discussions when discussing advance care directives or during end-of-life conversations.⁵

Limitations to the study

The results of this study must be interpreted within the context of the sample, an academic program providing advanced medical/surgical therapies for heart failure patients. The average age of our patient population was 60 years. These results may not reflect the preferences of older patients or those cared for by community cardiologists. The majority of patients who participated in this study were NYHA II–III. Hence, we cannot assume that these preferences reflect the actual choices patients would make at end of life. Further research is needed to describe actual ICD deactivation preferences at end of life. The use of a scenario for patients who were unaware the ICD could be deactivated may have affected our results. Our interviews were conducted by an undergraduate student associated with our program. While we have complete confidence in her abilities, we recognize that others might conduct the interview differently based on their level of training and experience. Finally, the results of this study are meant to provide a framework and language to stimulate discussion about how and when to engage patients in ICD deactivation discussions. It should be considered a starting point.

Conclusion

Few studies have examined the patient's perspective on the timing of ICD deactivation discussions. The patients who participated in our study identified three stages where they felt ICD deactivation should be discussed: prior to implant, a comprehensive discussion about ICD deactivation preferences when their condition deteriorated and review of decisions regarding ICD deactivation as patients near end of life. They identified the physician or a member of the clinical team as the most appropriate person to initiate the discussion and trusted them to know when and how the topic should be introduced. ICD deactivation should be included within the broader discussion of end-of-life preferences. The findings of this study support recommendations made to standardize ICD deactivation and end-of-life discussions within the patient's plan of care. Structuring ICD deactivation discussions in this way helps dissociate ICD deactivation or end-of-life planning with the delivery of bad news and promotes consistency between treatment goals and patient preferences.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethics approval

Ethical approval for this study was obtained from University Health Network Research Ethics Board (REB 09-0950).

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

Informed consent

Written informed consent was obtained from all subjects before the study.

References

1. Epstein AE, DiMarco JP, Ellenbogen KA, et al. ACC/AHA/HRS 2008 guidelines for device-based therapy of cardiac rhythm abnormalities. *Heart Rhythm* 2008; 5: 934–955.
2. Jessup M, Abraham WT, Casey DE, et al. 2009 focused update: ACCF/AHA guidelines for the diagnosis and management of heart failure in adults: a report of the American College of Cardiology Foundation/American Heart Association task force on practice guidelines: developed in collaboration with the International Society for Heart and Lung Transplantation. *Circulation* 2009; 119: 1977–2016.
3. Goldstein NE, Lampert R, Bradley E, et al. Management of implantable cardioverter defibrillators in end-of-life care. *Ann Intern Med* 2004; 141: 835–838.
4. Westerdahl AK, Sjoblom J, Mattiasson A, et al. Implantable cardioverter-defibrillator therapy before death: high risk for painful shocks at end of life. *Circulation* 2014; 129: 422–429.
5. Mitar M, Alba AC, MacIver J, et al. Lost in translation: examining patient and physician perceptions of implantable cardioverter-defibrillator deactivation discussions. *Circ Heart Fail* 2012; 5: 660–666.
6. Arnold J, Parker J, Liu P, et al. Canadian Cardiovascular Society consensus conference recommendations on heart failure 2006: diagnosis and management. *Can J Cardiol* 2006; 22: 23–45.
7. Lampert R, Hayes DL, Annas GJ, et al. HRS expert consensus statement on the management of cardiovascular implantable electronic devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm* 2010; 7: 1009–1026.
8. Goldstein N, Bradley E, Zeidman J, et al. Barriers to conversations about deactivation of implantable defibrillators in seriously ill patients. *J Am Coll Cardiol* 2009; 54: 371–373.
9. Strauss A and Corbin J. *Basics of qualitative research*. 2nd ed. Thousand Oaks, CA: SAGE, 1998.
10. Strachan PH, Carroll SL, de Laat S, et al. Patients' perspectives on end-of-life issues and implantable cardioverter defibrillators. *J Palliat Care* 2011; 27: 6–11.
11. Raphael CE, Koa-Wing M, Stain N, et al. Implantable cardioverter-defibrillator recipient attitudes towards device deactivation: how much do patients want to know? *Pacing Clin Electrophysiol* 2011; 34: 1628–1633.
12. Stewart GC, Weintraub JR, Pratibhu PP, et al. Patient expectations from implantable defibrillators to prevent death in heart failure. *J Card Fail* 2010; 16: 106–113.
13. Dodson J, Fried T, Van Ness P, et al. Patient preferences for deactivation of implantable cardioverter-defibrillators. *JAMA Intern Med* 2013; 173: 377–379.
14. Pederson SS, Chaitsing R, Szili-Torok T, et al. Patient's perspective on deactivation of the implantable cardioverter- near the end of life. *Am J Cardiol* 2013; 111: 1443–1447.
15. Sherazi S, McNitt S, Aktas MK, et al. End-of-life care in patients with implantable cardioverter defibrillators: a MADIT-II substudy. *Pacing Clin Electrophysiol* 2013; 36: 1273–1279.
16. Thylen I and Moser DK. Are ICD recipients able to foresee if they want to withdraw therapy or deactivate defibrillator shocks? *IJC Heart Vessel* 2013; 1: 22–31.
17. Allen LA, Stevenson LW, Grady KL, et al. Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation* 2012; 125: 1928–1952.
18. Fluor C, Bolse K, Stromberg A, et al. Patients' experiences of the implantable cardioverter defibrillator (ICD); with a focus on battery replacement and end-of-life issues. *Heart Lung* 2013; 42: 202–297.
19. Lewis WR, Luebke DL, Johnson NJ, et al. Withdrawing implantable defibrillator shock therapy in terminally ill patients. *Am J Med* 2006; 119: 892–896.
20. Goldstein N, Mehta D, Siddiqui S, et al. "That's like an act of suicide" patients' attitudes towards deactivation of implantable defibrillators. *J Gen Intern Med* 2008; 23: 7–12.
21. Matlock D and Allen L. Defibrillators, deactivation, decisions, and dying: comment on "patient preferences for deactivation of implantable cardioverter-defibrillators." *JAMA Intern Med* 2013; 173: 379–380.
22. Goldstein N, Carlson M, Livote E, et al. Brief communication: management of implantable cardioverter-defibrillators in hospice: a nationwide survey. *Ann Intern Med* 2010; 152: 296–299.

Appendix

Appendix Table 1. ICD interview guide.

I will ask you a number of questions and you just answer to them to the best of your ability. Remember I will be recording this interview, but no one outside of the study team will have access to the tapes. If you get uncomfortable and want to stop the interview, let me know, and we will stop immediately. So, let's get started.

1. Tell me about living with heart failure.
2. When did you get your ICD?
3. Can you tell me why you have the ICD?
4. Can you tell me how it works?
5. Have you ever had an issue with the ICD—that is, replacement, recalls, position?
 - Has it ever gone off?
 - What was it like?
 - Do you worry about it going off?
6. If a patient with an ICD was dying and the heart went into an irregular rhythm, the ICD would fire and shock the heart until the irregular rhythm stopped. The only way to stop the ICD from shocking the heart is to turn it off. Turning off the ICD doesn't hurt. It is done either in the defibrillator clinic with the computer or with a large magnet placed over the ICD at the bedside. They can turn off the ICD but keep the pacemaker going.
 1. Do you remember talking to anyone about deactivating the ICD?
 - Can you tell me about that discussion (When, Why?)
 2. When would you like to discuss the possibility of turning off the ICD?
 3. Who do you think should start these discussions?
 - a. Would you want the doctor to wait until you asked about it or would you want the doctor to start the discussion?
 4. Describe these discussions for me—how would they work, what would you talk about?
 - a. What issues do you think should be discussed?
 - b. What information would you need to decide if turning off the ICD is the right thing to do?
 5. Have you ever thought about turning off the ICD?
 6. Would you consider turning off the ICD?

Appendix Table 2. Sample characteristics.

Characteristic	n = 25
Age, years (mean ± SD)	62 ± 14
(Range)	(28–78)
Male, n (%)	19 (76)
Etiology, n (%)	
Dilated	11 (44)
Ischemic	12 (48)
Other	2 (8)
NYHA classification, n (%)	
I	3 (11)
II	10 (40)
III	12 (48)
IV	0
Years living with HF (mean ± SD)	7.8 ± 3.3
LVEF% (mean ± SD)	25.6 ± 9.6
Serum sodium, mmol/L (mean ± SD)	138.8 ± 3.0
Serum creatinine, μmol/L (mean ± SD)	120.9 ± 42.7
Serum BNP, pg/L (mean ± SD)	487.6 ± 712.7
ICD + CRT, n (%)	15 (60)
Experienced at least one shock	9 (36)

NYHA: New York Heart Association; HF: heart failure; LVEF: left ventricular ejection fraction; BNP: brain natriuretic peptide; ICD: implantable cardioverter-defibrillator; CRT: cardiac resynchronization therapy.

Appendix Table 3. Format for ICD deactivation discussions.

	Describe	Discuss	Decide
When	Pre-implant	Transition to Stage D heart failure	End of life
Purpose	Information	Discussion and communication of patients preferences	Preferences from last review are used to inform discussion
Format	Include in pre-implant discussions and patient education materials	Formal meeting with clinical team, patient and family	Formal or informal meeting
Outcome	Awareness that ICD can be deactivated Patients should be given the opportunity to discuss ICD deactivation if they so desire	ICD deactivation preferences are documented in clinical record Provides a record of how preferences have changed over time	Decision regarding ICD deactivation