# Patients' Perspectives on End-of-Life Issues and Implantable Cardioverter Defibrillators

**Patricia H. Strachan**,
McMaster University, School of Nursing, HSC 2J20D, 1200 Main Street West, Hamilton, Ontario, Canada, L8N 3Z5

**Sandra L. Carroll**,
School of Nursing, McMaster University, Hamilton, Ontario, Canada

**Sonya de Laat**,
School of Nursing, McMaster University, Hamilton, Ontario, Canada

**Lisa Schwartz**, and
Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario, Canada

**Heather M. Arthur**
School of Nursing, McMaster University, Hamilton, Ontario, Canada, and Heart and Stroke Foundation of Ontario, Ottawa, Ontario, Canada

## Abstract

Increasing numbers of cardiovascular patients are receiving implantable cardioverter defibrillators (ICDs) for primary prevention of sudden cardiac death (SCD). This report examines patients' perspectives on related end-of-life issues. Using a grounded theory approach, audiotaped, semi-structured interviews were undertaken with 30 participants from two ICD referral centres in southwestern Ontario (24 who accepted an ICD and 6 who declined). Interview transcripts, researcher memos, member checks, published literature, and participant demographics were analyzed using NVivo7. Most participants were male, had comorbidities and an ejection fraction of less than 30 percent, and ranged in age from 26 to 87. Consensus was reached by three research team members on three main themes: quality versus quantity of life, preferred mode of death, and the technical realities of the ICD. The ICD was considered in relation to both quantity and quality of life. Most participants focused on the prevention of SCD, not the implications of the ICD for death by any other cause. Participants advocated for incorporating the ICD into advance care planning. Our findings have implications for the development of advance care plans and education of health professionals.

## INTRODUCTION

Implantable cardioverter defibrillators (ICDs) are being offered to an increasing number of cardiovascular patients for primary prevention of sudden cardiac death (SCD) (1, 2), an

Correspondence to: Patricia H. Strachan.

unexpected death that results from life-threatening cardiac problems — usually sustained ventricular tachycardia or ventricular fibrillation. The ICD offers an individual, internally placed alternative to the automatic external defibrillators that are frequently found in public places. The ICD contains a computer, a capacitor that holds the charge, a battery, and one or more leads that connect the ICD to the heart muscle (3).

The ICD is used to treat potentially life-threatening ventricular arrhythmias. In the absence of these rhythms, even as death approaches, the ICD will not deploy a shock; but if the ICD has not been deactivated and arrhythmias are detected, shocks will occur. A shock from an ICD has been described as a tingle, a lightning bolt, and a blow to the chest (4, 5). Appropriate and inappropriate shocks have been associated with decreased quality of life and psychologic sequelae such as anxiety and post-traumatic stress disorder (6). Although ICDs for primary prevention are known to decrease mortality related to SCD (7), ICD recipients remain vulnerable to death by other causes.

At the time of implantation, it is not possible to predict how a patient who receives an ICD for primary prevention will eventually die. However, failure to consider the implications of ICDs for the care of dying patients has resulted in unnecessary suffering at the end of life (EOL) for patients and their families. Single or repeated ICD shocks delivered to dying patients in the last days and minutes of life have prevented a peaceful death (8–10). Interestingly, when asked to anticipate their preferences should they become terminally ill, the majority of patients with heart failure who received an ICD for primary prevention said they would not deactivate it, even if they were receiving daily shocks (11). These patients also tended to overestimate the survival benefits of ICDs. This and other accumulating evidence has led those in the cardiovascular and palliative care communities to advocate for pre-implant discussions with patients about the implications of the ICD for possible EOL scenarios (11–16).

To our knowledge, little is known about how patients perceive the ICD in relation to EOL issues as they contemplate an ICD for primary prevention, yet this could have significant implications for the planning and future provision of EOL care. This paper reports on patients' perspectives on EOL issues in relation to the ICD at the time of their decision to accept or decline the intervention. The study sample is a subset of data extracted from an ongoing larger study exploring patients' decisions regarding ICDs in primary prevention of SCD.

## METHOD AND ANALYSIS

A grounded theory approach was used to guide the study. Participants were recruited from two ICD referral centres in southern western Ontario. Research ethics approval was obtained from the research ethics board at each site. Inclusion criteria were: being 18 years of age or older, being able to read and speak English, and having accepted or declined an ICD for primary prevention. Potential participants were only approached for an interview after the device had been implanted or after they had declined the ICD; interviews were conducted one to four weeks after implantation or two weeks to eight months after declining. Interviews were scheduled according to the availability of the participant.

A purposive sampling technique was used to identify potential participants who met the inclusion criteria. Particularly appropriate for qualitative research, this technique involves seeking participants with experiences and insights related to a particular topic. The interviews were audiotaped then transcribed verbatim and anonymized. Member checks were completed by sending participants a one-page summary of the interview along with one to four additional questions to clarify, probe, and/or confirm interview responses and the evolving analysis concepts.

Interviews were conducted over a period of 14 months by the same interviewer, who had training and experience in qualitative data collection. Data collection continued beyond the point of saturation to ensure that no new data emerged. Analysis was undertaken by three members of the research team. Data (including transcribed interviews, researcher memos, member checks [17], published literature, and participant demographics) were analyzed within NVivo7 qualitative data management software (18). Initial analysis codes were derived from the interview guide. In accordance with the constant comparative approach inherent in Strauss and Corbin's grounded theory methodology (19, 20), a more refined analysis was then conducted with additional or more detailed codes inductively derived during team meetings in which transcripts, coded text, and published literature were discussed in relation to each other. As qualitative research is by nature non-linear and iterative, the results of comparing different data types (interviews, literature, memos, and so on) and of comparing against deviant cases within the data were constantly tested against any new information. Interview guides, follow-up tools, and analysis codes were adapted and refined to reflect new findings as they emerged. Consensus was reached by the research team regarding three emergent themes.

## FINDINGS

This report is based on analysis of 30 participants: 24 who accepted and 6 who declined the ICD. Approximately half responded to the request for member checks. Follow-up of non-responders revealed that one participant had died prior to completing the requested member check. The description of the participants is presented in the following tables.

The majority of participants were male, had underlying coronary artery disease, more than one comorbidity, and an ejection fraction of less than 30 percent. Their age range was from 26 to 87 years, and most lived more than 25 kilometres from the implanting site. Most participants (n=18) had some form of post-secondary education.

As the interviews progressed, it struck us that most participants (whether they accepted or declined the ICD) focused on prevention of SCD and the dramatic life-saving potential of the ICD. We began to notice that participants who accepted an ICD seldom raised issues related to their eventual and certain death, and the implications that having an ICD might have on that. Consistent with the methodological approach, we included a more explicit focus in the interviews on how the ICD fit with participants' considerations of EOL issues in general.

Three dominant themes related to EOL issues and the ICD were identified: quality versus quantity of life, preferred mode of death, and the technical realities of the ICD.

## Quality versus Quantity of Life

Participants reflected on their preference for quality of life and their hope for quantity of life. All reported wanting to have a good quality of life for as long as they could, and all believed the ICD could extend their lives. Many described, in vague terms, a time when their overall health would be poor and said that at this point they would not want to continue living. Despite acknowledging this, most participants had not considered the potential significance of the ICD to a future deterioration in health.

> "It's your quality of life, though, no matter what. You know when you can't move, [and] then all they are doing is feeding you pills. I can't really imagine what that must be like, but if [the ICD] helps you and you can still live a fairly normal life as you get older, then this is great stuff, I guess." (male, 70, accepted the ICD)

A different line of reasoning was voiced by some who declined the ICD and imagined the device would be more likely to preserve a life when the quality was no longer good.

> "If all this is going to give me [is a] five-year extension on my life [so] I can sit in a chair for five years and do nothing…quantity, I don't really care anymore. I mean, I care but I don't care as much as I do about having quality of life, right?" (male, 67, declined the ICD)

For others who accepted the ICD and who had considered that it could extend a life of poor quality, there was a relatively cheerful recognition of the paradox that confronted them. A 67-year-old male who had accepted the ICD said, "Nobody lives forever, that's for sure!" As one participant so eloquently put it, having an ICD could also present an unresolved and unexplored conflict related to resuscitation and the quality and quantity of life:

> "I guess I was faced with the possibility that my heart just may stop one day or may go into a fibrillation, because there is not much of it left. So it threw new light on my situation and I discussed it with my wife that I would definitely prolong this as long as I could, because the last thing I wanted is to die one piece at a time. So having said that now, I am going in the complete opposite direction — Oh yeah, put a defibrillator in and whatever happens to my heart it'll just keep me going till I get to the hospital, where I have given instructions 'Do not resuscitate'! [Laughter.] So I am at a crossroads." (male, 61, accepted the ICD)

No one discussed raising such dilemmas with a health care provider.

## Preferred Mode of Death

The aim of all those who accepted the ICD was to prevent SCD. The possibility of another mode of death was acknowledged fleetingly, if at all. Some participants were surprised to learn that they were at risk for SCD and viewed the ICD as a means to control this new and frightening risk and allay related fears of death. A 48-year-old man with heart failure who accepted the ICD said that the way SCD was presented to him by a physician caused him to consider alternative modes of death. The physician told him, "The worst that can happen to

you is sudden death." The patient reported, "Then I thought, you know, sudden death is not so bad — at least you are not bedridden for two or three years; it's probably a blessing. But then again, I thought I was still too young to die."

Many participants had vaguely considered a mode of death in which suffering was likely, but they did not relate this to the presence of the ICD. The majority of those who declined the ICD preferred SCD over other possibilities. One 82-year-old man who had declined an ICD said that although he would like to live longer, he would prefer sudden death or falling asleep and not waking up. He was one of the few participants who claimed to have written an advance directive stating "No heroics." Another participant who had declined an ICD was an 87-year-old man with coronary artery disease and heart failure who understood that the ICD would deny him "the luxury of a sudden death." His statement reflected his desire to avoid the suffering that could arise from resuscitation efforts or the prolongation of life that he associated with the ICD.

### Technical Realities of the ICD

To explore how participants understood the role and function of the ICD, the interviewer asked if they had considered that the time might come when they would want to have the device turned off or removed. Most said they had not considered this; they had only thought that it might be necessary to turn off or remove the ICD because the battery had to be changed, or because there was a technical malfunction or infection, or because magnetic resonance imaging (MRI) was required. Although a few participants noted that the device would have to be removed for cremation, most did not address the dying process that would lead to such a circumstance. Only four participants said that they understood that the device could be deactivated to allow death to occur. The only participant who reported that he'd had a comprehensive discussion about the ICD and dying was an 87-year-old man who had declined an ICD. He reasoned that the firing of the ICD could interfere with dying naturally.

Several participants said that it would be better to have a discussion about the ICD's function in relation to EOL sooner rather than later — while they were still cognitively intact, or "all there." Those who had already had what they referred to as "the talk" with their clinicians said that it was best to do so when they were at the decision-making stage because they were already engaged in discussing the other pros and cons of the ICD. Several stated that it was an important discussion to have and said they would bring it up next time they went to the ICD clinic. During their interviews, several participants began talking about the role an ICD might play in their eventual death. Those who made the connection between the ICD and their death responded similarly to this participant, a 68-year-old man who had accepted an ICD and who planned on following up with his clinician: "I never really thought about that; the time to have it, in my opinion, would be now so that we didn't wait too long to do whatever needed to be done."

## DISCUSSION

SCD is responsible for 35,000 to 40,000 deaths a year in Canada; thus, the potential is great for increased numbers of patients with ICDs for whom EOL care is relevant (21, 22). While patients who accept an ICD for primary prevention are choosing to avoid SCD, at some

point all of them will die from one cause or another. The numbers of ICD recipients who are dying of non-cardiac-related illness is increasing, and this raises questions about the impact of the ICD on this process and the ethics of withdrawing this potentially life-sustaining treatment (23). Patients, their family caregivers, and/or substitute decision-makers may require assistance in making decisions about EOL care, including whether or not to deactivate an ICD (13). This has significance for the health professionals who provide EOL care in all practice settings in urban, rural, and remote communities. Many of our participants lived at a distance from the implanting site. Those providing such patients with EOL care in their home communities need to gain a greater understanding of the implications of the ICD. There is a need, therefore, for emergency personnel, nurses, and physicians, in communities and in hospitals, to receive continuing education about ICDs in EOL care provision. Our findings indicate that ICD-related issues reported by participants that may prove to be problematic at the EOL could be managed proactively if discussed much earlier in the life of the patient. Creating the opportunities and fostering the skills for all stakeholders to have conversations about resuscitation, ICDs, and EOL issues is a necessary part of a comprehensive advance planning strategy (24). It has been suggested that the onus for considering ICDs in relation to EOL planning and issues surrounding resuscitation must also be shared by those involved in implanting the devices (6, 23, 25). Hospice care providers (13) have advocated for a coordinated, system-wide approach that includes device manufacturers to assist in the development of education related to such an effort.

The majority of study participants focused on ICDs as a way to avoid SCD and did not consider death by other causes at the time we interviewed them. When patients focus solely on ICDs as a way to avoid SCD, the stage is set for human suffering and dilemmas in care provision when the EOL approaches. Why don't patients think about their eventual death or consider what it means that ICDs will prevent SCD? It may be that this issue is discussed but patients do not hear or retain what is said, or they do not want to know about it. Alternatively, death due to a cause other than SCD may not be discussed prior to implantation of the device. Whatever the explanation, this gap needs to be understood. This could be examined in greater detail in future studies.

While the ICD may be a compelling technical means of prolonging life, it may also serve to mitigate consideration and discussion of other death-related issues. While the fact that the ICD recipient is protected against SCD may bring all stakeholders peace of mind, it seems paradoxical that the ICD's promise of resuscitation from arrhythmia does not prompt consideration of death by other causes. The difficulties that physicians may have in communicating with patients about the potential for ICD deactivation at the EOL would suggest that health professionals need help to engage in these discussions much earlier in the illness trajectory (23). Stevenson and Desai (12) have outlined an approach by which practitioners could introduce the issue as part of the conversation when offering the ICD for primary prevention.

End-of-life planning should not begin at the EOL. An extensive ethical and legal approach has been advocated for the process of ICD deactivation that includes evaluation of the patient's mental status, documentation of informed decision making, coordination of care

between implanting and community care centres, and consideration of the conscientious objection of health providers to the withdrawal of treatment. Some have suggested that prior to implantation, candidates for ICD therapy participate in the development of an advance care plan that includes a directive related to possible deactivation of the device (14). It is therefore logical that ICD implantation trigger the integration of cardiac care services into a patient-centred, community-based EOL strategy that informs those who will be providing care to patients with ICDs during the dying process.

## CONCLUSION

While increasing numbers of people choose to have an ICD implanted to prevent SCD, they may not have considered the implications of the device if they should die by any other cause. This lack of consideration of ICDs in relation to EOL may have significant consequences for health practitioners required to provide care for these individuals. There is an urgent need for health practitioners in all practice areas to understand the function of ICDs and their impact on patients who require emergency or palliative care. Ideally, those who are engaged building comprehensive EOL strategies should consider issues related to ICDs at the stage when the initial decision is made to implant the device and throughout the individual's lifespan.

## Acknowledgments

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**Table 1**

Details of participants who accepted a primary-prevention ICD

| Age | Sex | Diagnosis | Comorbidities | Ejection Fraction (%) | Discharge (Yes/No) | Education | Distance (km/2-way) |
|---|---|---|---|---|---|---|---|
| 71 | M | CAD | Hypertension; Peripheral Vascular Disease; TIA | 29 | No | Elementary | > 100 |
| 82 | M | CAD | Diabetes; CABG | 23 | No | Some high school (HS) | 25–50 |
| 46 | M | Cardiomyopathy | Stroke | N/A | Yes | HS | <25 |
| 70 | M | HF | | 23 | No | University | 25–50 |
| 76 | M | CAD | Arthritis; Renal Insufficiency | 30 | No | Some college/trade | <25 |
| 26 | F | Cardiomyopathy | | 21 | No | University | 50–100 |
| 55 | M | HF | Diabetes; Smoker; Hypertension; Sleep Apnea; GERD; Arthritis | 22 | No | Some HS | 50–100 |
| 61 | M | CAD | Diabetes; CABG; Cirrhosis | 25 | No | Some U | 25–50 |
| 58 | M | CAD | Smoker | 27 | No | Some college/trade | 50–100 |
| 70 | M | CAD | CABG | 25 | No | HS | 50–100 |
| 48 | M | HF | Smoker | 16 | No | HS | 50–100 |
| 69 | F | CAD | Lupus | 20 | No | HS | 50–100 |
| 58 | F | CAD | | 32 | No | HS | <25 |
| 67 | M | CAD | Hypertension | 25 | No | Post Graduate | <25 |
| 66 | M | CAD | Hypertension | 28 | No | Post Graduate | > 100 |
| 50 | M | CAD | Smoker | 25 | No | Diploma | 25–50 |
| 67 | M | CAD | Diabetes | 18 | No | Diploma | 25–50 |
| 44 | F | Brugata Syndrome | Fibromyalgia; Depression; GERD | N/A | No | Diploma | 50–100 |
| 55 | M | CAD | Smoker; hypertension | 28 | No | Some HS | 25–50 |
| 69 | M | CAD | Diabetes; Hypertension; Sleep Apnea; Morbid Obesity; Smoke | 29 | No | Some Elementary | <25 |
| 55 | M | CAD | Diabetes; Stroke; Hypertension; | 28 | No | University | 50–100 |
| 67 | M | CAD | COPD; bladder cancer 2007 | 25 | No | Diploma | > 100 |
| 76 | M | Possible Long QT Syndrome | Smoker; Arthritis; Hypothyroidism | 33 | No | Some college/trade | <25 |
| 68 | M | Cardiomyopathy | Arthritis | 38 | No | Some college/trade | 50–100 |

**Table 2**

Details of participants who declined a primary-prevention ICD:

| Age | Sex | Diagnosis | Comorbidities | Ejection Fraction (%) | Education | Distance (km/2-way) |
|---|---|---|---|---|---|---|
| 67 | M | CAD | Chronic Bronchitis | 29 | Some University | > 100 |
| 64 | F | Possible ARVD | COPD; Smoker | N/A | Some HS | 25–50 |
| 82 | M | CAD | Stroke; COPD | 25 | Some College/Trade | 25–50 |
| 73 | M | CAD | Obesity; Diabetes; Smoker | 27 | Elementary | 25–50 |
| 53 | F | ARVD | | N/A | University | <25 |
| 87 | M | CAD | Hypertension; Hyperthyroidism; | 30 | Post Graduate | <25 |

ARVD- Arrhythmogenic Right Ventricular Dysplasia

CABG- Coronary Artery Bypass Graft

CAD- Coronary Artery Disease

COPD – Chronic Obstructive Pulmonary Disease

GERD- Gastroesophageal Reflux Disease

HF- Heart Failure

TIA- Transient Ischemic Attack