

Deactivation of implantable cardioverter defibrillators towards the end of life: a survey of perceptions and practice among New Zealand clinicians

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ABSTRACT

BACKGROUND: Implantable cardioverter defibrillators (ICDs) have the potential to reduce the quality of life in patients with life-limiting illnesses. Despite this, the literature suggests deactivation of ICDs occurs infrequently, and there is a lack of guidance on this issue.

AIMS: This nationwide survey aimed to investigate perceptions and practices regarding deactivation of ICDs among New Zealand clinicians caring for patients with life-limiting illnesses, and to identify barriers to conversations about ICD deactivation.

METHODS: Cardiologists, general physicians and geriatricians across New Zealand were sent a survey that explored their views and practices regarding deactivation of defibrillators in terminally ill patients.

RESULTS: One hundred and forty-five out of 457 clinicians (32%) replied. Most (98%) of clinicians felt deactivation may be appropriate in this group. Key barriers to discussions were felt to include uncertainty over prognosis (77%), likelihood of causing anxiety in their patients (70%), lack of clarity of roles and inexperience in the field. Cardiologists were more likely than general physicians and geriatricians to start deactivation discussions in patients with terminal disease. Doctors with more years in practice felt more comfortable raising the topic of deactivation.

CONCLUSION: While most doctors were comfortable with the concept of device deactivation, issues such as uncertainty of prognosis, fear of causing anxiety, lack of role clarity and inexperience can be barriers to initiating conversations. Further guidance, education, support and shared care could benefit doctors caring for ICD recipients who have life-limiting illnesses.

Implantable cardioverter defibrillator devices (ICDs) have been shown to reduce the risk of sudden death from arrhythmia in primary and secondary prevention settings.¹ ICD implantation in New Zealand has been increasing over the past decade.^{2,3} However, preventing a premature arrhythmic death will not prolong life indefinitely, and as patients proceed through the trajectory of chronic illness, the balance of harm and benefit related to ICD therapy, as well as their goals of care, may change.

Patients with ICDs at the end of life are at risk of electrical cardioversion (shocks), which can be painful and distressing in the conscious patient and for their family members. As patients approach the end of life, the frequency of shocks may increase,⁴ which physicians acknowledge is disturbing to patients and their families.⁵ A study

of ICDs explanted post-mortem revealed that almost a third of patients experienced shocks in their last hour of life.⁶ A survey of hospices that have cared for patients with ICDs showed that 86% of those patients experienced unwanted treatment and their sequelae, most commonly in the form of shocks.⁷

Studies from Europe and the USA reveal that at the end of life, fewer than half of patients with an ICD are offered a discussion about deactivation.^{4,6,8} A retrospective review of Canadian ICD patients with terminal illnesses showed that deactivation was only included in the end of life care for a third of patients, and a majority of patients died with an active device.⁹ More recently, a Japanese study showed that ICDs were deactivated in less than a quarter of patients dying of end stage heart failure.¹⁰ When discussions happen,

they tend to occur in response to rapidly changing circumstances rather than a decision planned in advance.⁴ Even in those patients with a do not resuscitate (DNR) order, ICD deactivation occurs in fewer than half of patients.^{4,6,10}

The reasons why ICD deactivation is not discussed earlier in a patient's condition are complex. Earlier studies found that doctors feel uncomfortable discussing cessation of cardiac device therapy.^{11–13} Almost half report feeling uncomfortable while deactivating an ICD.^{14,15} Doctors may overestimate the patient's knowledge of their ICD, and assume deactivation discussions should be brought up by the patients themselves.^{13,16} Despite this, surveys consistently show that patients have misconceptions about the risks and benefits of their devices.^{17–20} This likely contributes to patients' unwillingness to initiate these conversations themselves. Further investigation is important to offer guidance for the medical profession on improving these discussions, and therefore unwanted ICD treatments.

There has not been any research performed evaluating the perceptions of New Zealand clinicians on deactivation of ICDs, or the barriers to discussion about this important issue. This study aims to survey the views of cardiologists, general physicians and geriatricians on these issues.

Method

Study design and recruitment

Ethical approval was obtained from the University of Otago. We sent an online questionnaire to cardiologists, geriatricians and general physicians in August 2020, to explore their perceptions of deactivation and barriers to having these conversations. Cardiologists and geriatricians received this through their national societies (Cardiac Society of Australia and New Zealand, and the Australian & New Zealand Society for Geriatric Medicine). General physicians were contacted through the general medical departments in 19 hospitals around New Zealand. Responses were collected for two months, and the survey was closed in October 2020.

Survey

The survey collected information on basic demographic data and explored views on deactivation of defibrillators in patients, barriers to conversations about deactivation, and usual practice regarding conversations about deactivation. The questions were graded on a Likert scale with

five categories.²¹ Questions regarding perceptions and barriers to conversations had the categories: “strongly agree”, “somewhat agree”, “neutral”, “somewhat disagree”, and “strongly disagree”. Questions relating to clinical practice had the categories: “always”, “most of the time”, “sometimes”, “occasionally”, and “never”. In the absence of a known validated questionnaire, this questionnaire was developed specifically by the lead author, based on an extensive literature review of similar studies investigating this topic.^{5,12,15, 16, 22,23} A copy of the questionnaire is included in Appendix A.

Data analysis

When analysing results, scores were treated as categorical values and results were analysed using nonparametric methods. Scores from questions relating to perception on deactivation and barriers to having conversations were grouped into three categories: “strongly/somewhat agree”, “neutral”, or “strongly/somewhat disagree”. Scores from questions relating to clinical practice were also grouped into three categories: “always/most of the time”, “sometimes/occasionally”, or “never”. Differences between types of specialists were analysed using the Kruskal–Wallis test. Comparisons between gender were made using the Mann–Whitney test.

When analysing results against years of experience, scores were treated as a continuous variable to see if a trend was seen against increasing years of experience. P values were derived using the Mann–Kendall test for linear trend.

The survey included two free text boxes: one to identify further barriers to having conversations, and the other to provide additional comments. A qualitative approach was taken to analyse these results, with two authors (TB, AL) independently reviewing and coding the comments. When there were discrepancies found, the authors met and negotiated a consensus. Overarching themes were analysed with the same method.

Results

The survey was sent to 457 clinicians in total. One hundred and five cardiologists and 157 geriatricians received this through their national societies. General medical departments of 21 hospitals were contacted—of which 14 agreed to take part—and questionnaires were forwarded to 195 general physicians. In total, 145 of 457 clinicians completed the survey, resulting in an overall response rate of 32%. Response rates differed between specialty, with cardiologists, geriatricians,

and general physicians having response rates of 41%, 18%, and 38%, respectively. Of the completed surveys, 99.3% of the questions had been answered. Fifty-nine percent of respondents were male. Thirty-five percent had more than 20 years of experience in their specialty.

Quantitative results

A majority of clinicians (98%) agreed that it is ethically appropriate to deactivate a defibrillator on patient request, with 81% agreeing that deactivation is ethically similar to refusal of implantation. Similarly, the majority (92%) felt comfortable bringing up the option of deactivation with patients, with 93% feeling confident about their communication skills about end of life issues. Eighty-four percent of respondents felt they had received enough training and support to have these discussions.

Over three quarters (77%) of doctors felt that uncertainty over prognosis can make it difficult to have these deactivation conversations. A majority (69%) felt they had enough time to have conversations with patients when this was required. Seventy percent felt that having these conversations may cause anxiety in patients, although only 9% felt that these may negatively affect the doctor-patient relationship.

Seventy-nine percent of cardiologists responded to the question about implantation of ICDs. Half

of these reported mostly or always discussing deactivation at the time of implantation, with 14% never discussing the issue at this time. Over half of doctors always or mostly discuss deactivation in patients with either terminal disease or rapidly declining quality of life (57% and 51%, respectively), however, fewer do so in patients with increasing hospitalisation (27%). Fewer than half of doctors (46%) felt that their patients were aware that deactivation would be an option if treatment were to become burdensome. Most doctors (68%) would not, or only occasionally, be present for deactivation of an ICD. Eighty-four percent of doctors would always or mostly bring up advance care planning in those with a rapidly progressive disease, and 49% would involve palliative care to help with decision-making in complex cases involving ICDs.

When comparing doctors by specialty, there was some variation in results. More geriatricians felt that conversations about deactivation have the potential to negatively affect their doctor-patient relationship (18%, as compared to 5% in cardiologists, and 8% in general physicians). Most cardiologists (90%) would discuss deactivation in patients with terminal disease, compared with general physicians (45%) and geriatricians (50%). Similarly, cardiologists were more likely to do so in those with declining quality of life and

Table 1: Characteristics of respondents.

| Characteristic | N | % |
|---|----|-----|
| Specialty | | |
| Cardiologist | 42 | 30% |
| Geriatrician | 28 | 19% |
| General Physician | 75 | 51% |
| Gender | | |
| Male | 85 | 59% |
| Female | 60 | 41% |
| Years of experience in Specialty | | |
| <10 | 47 | 32% |
| 10–19 | 47 | 32% |
| 20–29 | 32 | 22% |
| >30 | 19 | 13% |

increasing hospitalisations (79% and 48%), than general physicians (43% and 20%) or geriatricians (39% and 19%). There was no disparity between general physicians and geriatricians. Cardiologists were more certain that their patients understood they had the option of deactivation if treatment was becoming burdensome. They would also be more likely to attend the bedside of a patient during deactivation.

When gender was compared, male doctors reported discussing deactivation more frequently in those patients with a terminal disease (68% vs 45%). Males were twice as likely to believe their patients were aware that deactivation was an option (60% vs 30%).

When assessing differences according to length of experience, there was a positive relationship between experience and confidence with having conversations ($P=0.002$). Doctors with more experience felt more comfortable raising deactivation discussions. In addition, doctors with more experience were less likely to feel that having conversations would negatively affect the patient–doctor relationship ($P=0.003$).

Qualitative results

The results of the comments revealed four major themes.

1. Time

Some answers raised having inadequate time for discussions, and others mentioned getting the time “right”. There was variation in the comments as to what is the best time, with some comments recommending discussion at implantation, and others suggesting this is the wrong time.

“...being able to bring about all interested parties at the right time” (female geriatrician)

“Time. Implant is not the best time” (male cardiologist)

2. Lack of skills and resources

Inadequate knowledge and support was the most common theme raised. These included under-recognition of the ICD itself, as well as lack of experience or guidelines with how to conduct these discussions. The practical knowledge of how to achieve deactivation was also brought up by non-cardiologists:

“I don’t think I always know when patients have defibrillators and don’t think to ask” (female general physician)

“I don’t know how it is done clearly” (male general physician)

3. Collegial relationships and ownership

Lack of clarity of roles was frequently mentioned as a significant barrier. Responses from some general physicians suggested a reluctance to address it due to perceived ownership from cardiology.

“I’m unsure if cardiologists or physicians need to have this discussion” (female general physician)

“Team dynamics, prevalent power structures in the institutions and burden of responsibility. ‘Passing the buck’ strategy exercised very admirably” (male general physician)

The involvement of palliative care or additional services was mentioned as being a positive, helpful factor.

“We have excellent pall care service at [anonymous] Hospital and a combined cardiology/pall care clinic which provides great service to patients with chronic cardiac conditions” (female general physician)

4. Patient and family expectations

The most common theme within patient factors was unrealistic patient expectations, particularly with reference to information previously provided to patients.

“Patient expectations about what a defibrillator can or cannot achieve— influenced by prior information and education at time of implantation” (female general physician)

“Patients sometimes have very unrealistic expectations of their prognosis” (male general physician)

Table 2: Perceptions of physicians regarding ICD deactivation.

| Questions | Response | Cardiologist (n=42) | General Physician (n=75) | Geriatrician (n=28) | P-value |
|--|----------|---------------------|--------------------------|---------------------|-------------------|
| In a competent patient with a terminal illness, I feel it is ethically appropriate to deactivate a defibrillator if they request this. | Agree | 42 (100%) | 74 (100%) | 27 (96%) | 0.19 ^Y |
| | Neutral | 0 (0%) | 0 (0%) | 0 (0%) | |
| | Disagree | 0 (0%) | 0 (0%) | 1 (4%) | |
| I feel that deactivation of defibrillators at the request of a patient is ethically similar to refusal of implantation. | Agree | 32 (78%) | 62 (82%) | 25 (89%) | 0.65 ^Y |
| | Neutral | 3 (7%) | 5 (7%) | 0 (0%) | |
| | Disagree | 6 (15%) | 8 (11%) | 3 (11%) | |
| I feel that family should all agree to the decision of deactivation before it is performed. | Agree | 9 (21%) | 12 (16%) | 2 (7%) | 0.43 ^Y |
| | Neutral | 4 (10%) | 12 (16%) | 3 (11%) | |
| | Disagree | 29 (69%) | 50 (68%) | 23 (82%) | |
| I feel that active defibrillators have the potential to worsen quality of life at the end of a terminal illness. | Agree | 41 (98%) | 74 (99%) | 25 (89%) | 0.07 ^Y |
| | Neutral | 1 (2%) | 1 (1%) | 3 (11%) | |
| | Disagree | 0 (0%) | 0 (0%) | 0 (0%) | |
| I think all patients with defibrillators should have timely discussions about deactivation. | Agree | 42 (100%) | 72 (96%) | 28 (100%) | 0.07 ^Y |
| | Neutral | 0 (0%) | 0 (0%) | 0 (0%) | |
| | Disagree | 0 (0%) | 3 (4%) | 0 (0%) | |

Table 3: Perceptions of physicians regarding communication about ICD deactivation.

| Questions | Response | Cardiologist | General Physician | Geriatrician | P-value |
|--|----------|--------------|-------------------|--------------|-------------------|
| I feel comfortable bringing up the option of deactivation with my patients. | Agree | 42 (100%) | 68 (91%) | 25 (89%) | 0.06 ^y |
| | Neutral | 0 (0%) | 6 (8%) | 1 (4%) | |
| | Disagree | 0 (0%) | 1 (1%) | 2 (7%) | |
| I feel confident in my communication skills about end of life issues. | Agree | 39 (93%) | 70 (93%) | 28 (100%) | 0.39 ^y |
| | Neutral | 3 (7%) | 3 (4%) | 0 (0%) | |
| | Disagree | 0 (0%) | 2 (3%) | 0 (0%) | |
| I feel I have had enough training and support to have these discussions. | Agree | 35 (83%) | 63 (85%) | 25 (89%) | 0.76 ^y |
| | Neutral | 3 (7%) | 4 (5%) | 0 (0%) | |
| | Disagree | 4 (10%) | 7 (10%) | 3 (11%) | |
| I have enough time with my patients to have conversations about deactivation when I need to. | Agree | 30 (71%) | 51 (68%) | 20 (72%) | 0.86 ^y |
| | Neutral | 6 (14%) | 8 (11%) | 4 (14%) | |
| | Disagree | 6 (14%) | 16 (21%) | 4 (14%) | |
| I feel conversations about deactivation might cause anxiety in my patients. | Agree | 29 (69%) | 54 (72%) | 21 (75%) | 0.32 ^y |
| | Neutral | 7 (17%) | 13 (17%) | 1 (4%) | |
| | Disagree | 6 (14%) | 8 (11%) | 6 (21%) | |
| I feel conversations about deactivation may negatively affect my patient-doctor relationship. | Agree | 2 (5%) | 6 (8%) | 5 (18%) | 0.03 ^y |
| | Neutral | 1 (2%) | 13 (17%) | 2 (7%) | |
| | Disagree | 39 (93%) | 56 (75%) | 21 (75%) | |
| I feel that uncertainty over prognosis can make it difficult to have deactivation conversations. | Agree | 34 (81%) | 59 (79%) | 22 (79%) | 1.00 ^y |
| | Neutral | 3 (7%) | 6 (8%) | 2 (7%) | |
| | Disagree | 5 (12%) | 10 (13%) | 4 (14%) | |

Table 4: Usual practice of physicians regarding ICD decision making.

| Questions | Response | Cardiologist | General Physician | Geriatrician | P-value |
|---|-------------------------|--------------|-------------------|--------------|---------------------|
| I discuss the possibility of future deactivation of ICDs at the time of implantation. | Most of the time/always | 18 (60%) § | § | § | |
| | Occasionally/sometimes | 10 (33%) § | § | § | |
| | Never | 2 (7%) § | § | § | |
| I discuss the possibility of deactivation of ICDs with patients who have developed a terminal or rapidly progressive disease. | Most of the time/always | 38 (90%) | 33 (45%) | 14 (50%) | <0.001 ^y |
| | Occasionally/sometimes | 4 (10%) | 34 (46%) | 12 (43%) | |
| | Never | 0 (0%) | 7 (9%) | 2 (7%) | |
| I discuss the possibility of deactivation of ICDs with patients who I feel have a rapidly declining quality of life. | Most of the time/always | 33 (79%) | 32 (43%) | 11 (39%) | <0.001 ^y |
| | Occasionally/sometimes | 9 (21%) | 32 (43%) | 15 (54%) | |
| | Never | 0 (0%) | 10 (14%) | 2 (7%) | |
| I discuss the possibility of deactivation of ICDs with patients who have had increasing numbers of hospital admissions. | Most of the time/always | 20 (48%) | 15 (20%) | 6 (22%) | 0.005 ^y |
| | Occasionally/sometimes | 20 (48%) | 41 (55%) | 16 (59%) | |
| | Never | 2 (5%) | 18 (24%) | 5 (19%) | |
| My patients are aware that if treatment with an ICD were becoming burdensome, they would have the option of deactivation. | Most of the time/always | 35 (83%) | 27 (37%) | 6 (23%) | <0.001 ^y |
| | Occasionally/sometimes | 7 (17%) | 38 (53%) | 17 (65%) | |
| | Never | 0 (0%) | 7 (10%) | 3 (12%) | |
| If I made a decision to deactivate an ICD, I would attend the bedside of a patient during the deactivation. | Most of the time/always | 8 (19%) | 11 (15%) | 1 (3%) | 0.003 ^y |
| | Occasionally/sometimes | 28 (67%) | 30 (41%) | 12 (43%) | |
| | Never | 6 (14%) | 32 (44%) | 15 (54%) | |

Table 4 (continued): Usual practice of physicians regarding ICD decision making.

| Questions | Response | Cardiologist | General Physician | Geriatrician | P-value |
|--|-------------------------|--------------|-------------------|--------------|--------------------|
| I bring up advance care planning with patients with terminal or rapidly progressive disease. | Most of the time/always | 33 (79%) | 65 (88%) | 27 (96%) | 0.152 [‡] |
| | Occasionally/sometimes | 9 (21%) | 8 (11%) | 1 (4%) | |
| | Never | 0 (0%) | 1 (1%) | 0 (0%) | |
| I involve palliative care to help with decision making in complex cases involving ICDs. | Most of the time/always | 15 (36%) | 44 (56%) | 13 (46%) | 0.059 [‡] |
| | Occasionally/sometimes | 26 (62%) | 26 (35%) | 12 (43%) | |
| | Never | 1 (2%) | 4 (5%) | 3 (11%) | |

† P-value is derived using Kruskal–Wallis .

‡ P-value is derived using Fisher's exact test.

§ This question only relates to practice from relevant cardiologists. 71% of responding cardiologists answered this question

Discussion

We surveyed cardiologists, general physicians and geriatricians around New Zealand regarding the deactivation of ICDs as patients enter a more terminal phase of chronic illness. A majority of responding clinicians agreed that it was ethical and necessary that timely discussions should be undertaken with patients in this situation to help prevent unwanted and distressing ICD treatments. This is concordant with other research showing similar beliefs.^{12,15,22}

In our survey, most cardiologists stated that they discussed deactivation at the time of implantation. This contrasts with other literature suggesting this is done rarely.^{8,12} There is little data in the literature looking at the true frequency of discussions held at this time. Most clinicians agree that initiating discussions about device deactivation should start at the time of implantation,⁵ although one survey revealed conflicting results, showing some cardiologists felt that the focus at implantation should remain solely on prolongation of life.²⁴ This variation of opinion over the right timing was also reflected in our qualitative results. Future discussions on deactivation, and deactivation itself, are more likely if they are initiated at the time of implantation.²⁵

Perceived “ownership” or responsibility of the device may play an important role, with cardiologists potentially feeling a greater sense of responsibility for management of the device. This concept was reflected in both our quantitative and qualitative results, with non-cardiologists feeling more hesitant about approaching this issue. A Swedish study looking at deactivation rates in patients with a DNR order showed that those in a cardiology ward had higher rates of deactivation than those in a non-cardiology ward.²⁶ This could also reflect education and guidelines, as this study observed an increase in deactivation following publication of European guidelines on ICD management.²⁷ As these guidelines are directed at cardiologists, they may be more likely to read and benefit from this guidance. Lack of physician knowledge can therefore be a barrier to deactivation. Our study revealed uncertainty over the practical knowledge of deactivation. Inadequate knowledge, or awareness of guidelines has been found to be a significant barrier to deactivation.^{28,29}

Further support and resources directed at these clinicians would be vital, given many patients with ICDs may be managed by general physicians and geriatricians at the end of life. An audit in

the UK showed that using interventions such as grand rounds, posters, and teaching on this issue reduced the number of patients who died with an active ICD in place.³⁰ Similarly in the USA, teaching in addition to the use of an electronic decision-making tool improved both the rates of discussion, and the rates of deactivation.³¹ Further research focussing on improving the rates of discussion and deactivation in New Zealand, using similar interventions, would be useful to identify the most effective method of further supporting doctors here. Clinicians may feel uncomfortable discussing deactivation. Several surveys have shown that physicians were consistently less comfortable discussing deactivation of cardiac devices compared with other life-sustaining therapies such as ventilation or dialysis.^{11,12} We found over 90% of the doctors in our survey felt comfortable bringing up deactivation, although there was a significant difference seen between cardiologists and general physicians/geriatricians, with the former feeling more confident.

Accurate prediction of prognosis has previously been identified as an issue.²⁸ In our study, three quarters of doctors felt that unclear prognosis was a barrier for them. Other studies have shown that this may be more significant in patients with advanced heart failure who have been identified as being more challenging to predict disease trajectory for.^{23, 32–34}

Lack of clarity of clinician roles emerged as a factor in our study. As patients may be involved with many different specialists during their illness, this “fragmentation of care” may lead to uncertainty of who is responsible for these discussions, or whether they have already occurred.^{23,28,29,35} Shared care approaches have been suggested as a positive path through this uncertainty.³³

Other research has revealed several other barriers, such as taking away hope, fear of frightening the patient, and a lack of rapport or time.^{12,28} Our survey showed that one fifth of doctors did not feel they had enough time to have these discussions, and this issue was brought up frequently in the comments. Almost three quarters of doctors in our study felt that discussing deactivation may cause anxiety in patients. A UK survey of patients about ICDs at the end of life showed that none of those patients found deactivation discussions distressing to experience.³⁶

Clinicians may assume their patients are aware that deactivation is an option and tend to overestimate their patient’s understanding of their device.¹² In our survey, most cardiologists believed

their patients knew of the potential for deactivation, though fewer than half of general physicians and geriatricians believed the same. Doctors may also assume that patients have a good understanding of their devices; however, studies have shown that the opposite is true. Patients often have poor understandings of the role of their devices, and are rarely aware that deactivation is an option.¹⁷⁻¹⁹ An Irish survey of ICD recipients showed that over half of patients felt that ICDs reduced the risk of heart attack, and improved the pumping function of the heart.³⁷ Some patients view deactivation to be akin to immediate suicide or euthanasia.^{17,20,22,38} Insufficient knowledge of ICDs in patients correlates with unwillingness to discuss deactivation with clinicians.²⁰ This only increases the need for doctors to be able to initiate conversations and provide adequate information themselves. We did not survey patients to confirm similar patient views in this New Zealand population.

Impact of palliative care and advance care planning

Palliative care involvement in end of life care of patients with ICDs is rare; however, when patients are referred the rates of ICD deactivation increase.²⁵ Doctors in our study tended to involve palliative care in complex cases around half the time. Involvement of palliative care services at the time of deactivation also results in increased attention toward symptom management and clarification of goals of care.³⁹ Sharing the load of decision-making and goals of care can be enormously helpful for these complex decisions.

Limitations

This study had some limitations. The response rate to our questionnaire was 32%, which is typical of similar questionnaires in other research, but may result in reporter bias.^{11,40} In addition, the method of sending out surveys differed for general physicians compared with cardiologists and geriatricians. This was due to privacy restrictions of the national society for general physicians. Despite this, we were able to reach a majority of general physicians, and had a high response rate. There was the potential to have overestimated the

denominator of total doctors being sent surveys, as some general physicians may have also been members of specialty colleges from cardiology or geriatric medicine. Response rates were not compared between hospitals, as the location of the respondents were anonymised. With this, it is possible that there was a difference in response rates for certain hospitals, resulting in underrepresentation of some centres. We only surveyed general physicians, cardiologists and geriatricians, and have not included perspectives from primary care. Given the involvement of primary care in these patients, further research in this area could add to our understanding of their practice and needs. Cardiac physiologists were not formally surveyed but play a central role in patient care and education, and should be involved in education and policy and development related to this topic. There are also inherent limitations in the self-reporting of confidence in the absence of objective measures.

Conclusions

This nationwide survey of New Zealand cardiologists, general physicians and geriatricians showed that most doctors agreed that there should be advanced planning of ICD deactivation in patients with life limiting illnesses. Most doctors were comfortable discussing deactivation of ICDs, but identified barriers including unclear prognosis, varying patient and physician understanding and fear of patients' emotional reactions. Geriatricians and general physicians felt less equipped to have these conversations compared with cardiologists. Future interventions, involving training and support, could be useful to reduce disparities in practice between specialties and prevent potential harm. Further education and guidelines are likely to be helpful in supporting doctors providing care to these patients as they approach the end of life. Shared care between specialties such as cardiology, general medicine, geriatrics and palliative care would help clarify complex issues such as prognosis and decisions on appropriate withdrawal of treatment.

COMPETING INTERESTS

Nil.

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Appendix A: Survey Questions.**SECTION ONE: Demographics**

What is your role (select more than one if applicable)?

a) Cardiologist b) Geriatrician c) General Physician

What is your Gender?

a) Male b) Female

What is your age?

<40 b) 40–49 c) 50–59 d) >60

How many years have you been qualified as an SMO in your specialty?

<10 b) 10–19 c) 20–29 d) >30

SECTION TWO: Perceptions

This section aims to explore your views on deactivation of defibrillators.

These questions are on a Likert scale as follows:

1 2 3 4 5 N/A
(strongly agree) (somewhat agree) (neutral) (somewhat disagree) (strongly disagree)

In a competent patient with a terminal illness, I feel it is ethically appropriate to deactivate a defibrillator if they request this.

I feel that deactivation of defibrillators at the request of a patient is ethically similar to refusal of implantation.

I feel that family should all agree to the decision of deactivation before it is performed.

I feel that active defibrillators have the potential to worsen quality of life at the end of a terminal illness.

I think all patients with defibrillators should have timely discussions about deactivation.

SECTION THREE: Conversations

This section aims to explore your level of comfort and training in regard to conversations, as well as barriers to communication.

These questions are on a Likert scale as follows:

1 2 3 4 5 N/A
(strongly agree) (somewhat agree) (neutral) (somewhat disagree) (strongly disagree)

I feel comfortable bringing up the option of deactivation with my patients.

I feel confident in my communication skills about end of life issues.

I feel I have had enough training and support to have these discussions.

I have enough time with my patients to have conversations about deactivation when I need to.

I feel conversations about deactivation might cause anxiety in my patients.

I feel conversations about deactivation may negatively affect my patient-doctor relationship.

I feel that uncertainty over prognosis can make it difficult to have deactivation conversations.

What other barriers prevent you from discussing deactivation of ICDs? [free text].

SECTION FOUR: Practice

This section aims to explore your usual practice of communication with patients

Note that the Likert scale is slightly different to the previous questions.

These questions should be answered with a Likert scale as follows:

| | | | | | |
|-----------------|---------------------------|--------------------|-----------------------|----------------|-----|
| 1 | 2 | 3 | 4 | 5 | N/A |
| <i>(always)</i> | <i>(most of the time)</i> | <i>(sometimes)</i> | <i>(occasionally)</i> | <i>(never)</i> | |

I discuss the possibility of future deactivation of ICDs at the time of implantation.

I discuss the possibility of deactivation of ICDs with patients who have developed a terminal or rapidly progressive disease.

I discuss the possibility of deactivation of ICDs with patients who I feel have a rapidly declining quality of life.

I discuss the possibility of deactivation of ICDs with patients who have had increasing numbers of hospital admissions.

My patients are aware that if treatment with an ICD were becoming burdensome, they would have the option of deactivation.

If I made a decision to deactivate an ICD, I would attend the bedside of a patient during the deactivation.

I bring up advance care planning with patients with terminal or rapidly progressive disease.

I involve palliative care to help with decision making in complex cases involving ICDs.

Do you have any other comments on this topic?