Implantable cardioverter defibrillator devices - when, how, and who should discuss deactivation with patients: a systematic literature review

Authors

Megan Freemantle
Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, UK
hymf8@hyms.ac.uk

Fliss E.M. Murtagh*
Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, UK
fliss.murtagh@hyms.ac.uk

Abstract

Background:

Implantable cardioverter defibrillators (ICDs) are used to treat life-threatening cardiac arrhythmias and prevent sudden cardiac arrest. As recipients age they may develop a greater risk of dying as a result of progressive multimorbidity rather than sudden cardiac death. Defibrillation shocks may prolong an uncomfortable dying process. Deactivation of the defibrillator would prevent this, yet is not always discussed and planned.

Aim:

To systematically review published evidence on ICD deactivation discussions, and make recommendations on when, how and who should facilitate effective and patient-centred deactivation discussions.

Method:

Using standard systematic review methods, MEDLINE, EMBASE, CINAHL and PsycInfo were searched for studies published in the English language between 2010 and March 2021. Inclusion criteria: studies of adults (≥18 years) and including discussions on ICD deactivation and/or related communication. Included studies were independently reviewed, data extracted, quality assessed, and data were synthesised using a deductive approach.

Results:

Of the 8893 articles identified, 22 papers met inclusion criteria. Deductive approach led to the identification of five main themes: (1) timing of ICD deactivation discussions, (2) initiation of deactivation discussions, (3) advance directives, (4) barriers to discussions, and (5) facilitators to discussions.

Conclusions:

Despite available guidelines, conversations on device deactivation are not being undertaken consistently. Evidence suggests lack of professional awareness of guidelines and limited training in communication skills. To prevent distress and promote comfortable dying, there needs to be proactive clinical and policy initiatives in the education of both professionals, patients and relatives, about device deactivation.

Key Messages

What is already known?

- Implantable cardioverter defibrillators treat arrhythmias and prevent cardiac arrest.
- Deactivation is needed to avoid protracted distressing death.

What are the new findings?

- Deactivation discussions are inconsistent, late or do not occur.
- Professionals are unaware of guidelines recommending early discussion.

What is the significance?

- Proactive clinical initiatives and training about device deactivation are needed.
- Research is needed on best timing for discussions.

Introduction

Implantable cardioverter defibrillators (ICD) are used to treat life threatening cardiac arrhythmias and prevent sudden cardiac arrest.[1] The device is surgically inserted to perform four key functions: automatic administration of defibrillation shocks to terminate ventricular fibrillation (VF) or fast ventricular tachycardia (VT), anti-bradycardia pacing often used after a defibrillation shock as the heart returns to normal sinus rhythm, anti-tachycardia pacing to terminate slower VT and cardioversion of VT.[2] ICD's should be considered as a secondary prevention for patients who have experienced one or more episodes of spontaneous, sustained VT or VF; it can also be recommended for prophylactic primary prevention for patients who have not had prior episodes of VT or VF, but are at high risk for arrhythmias, with the aim of improving symptoms ,quality of life and preventing sudden death.

However, despite initial benefit, as ICD recipients age they may develop a greater risk of dying as a result of progressive multimorbidity rather than sudden cardiac death. In these cases, defibrillation shocks may result in the prolongation of an uncomfortable dying process, with one in three ICD recipients experiencing multiple shocks in their last days of life which can be both painful and futile, preventing a dignified death.[3]

To ensure high-quality end-of-life care, it is recommended patients should have an understanding of the impact ICDs can have during the active process of dying and how these events could be avoided if deactivation of the defibrillator was initiated, whilst maintaining the pacemaker function. This should be done through open, sensitive and culturally relevant communications.[2]

Both the British Heart Foundation (BHF) 2013, and the European Heart Rhythm Association (EHRA) 2010, advises device deactivation discussions should be included as part of pre-implantation informed consent, raising the issue of a future time whereby the patient's general health may deteriorate to such an extent that device deactivation may be appropriate.[2 4] At the time of the guideline publication, results of the EHRA survey (2010) suggested that only 4% of implant centres were doing this.[5] Indeed, current literature shows a mixed response to this proactive approach with clinicians suggesting that raising issues related to ICD deactivation at the pre-implantation stage might be inappropriate, since implantation of the ICD felt like a 'second chance at life'.[6] Furthermore,

it has been reported that patients have expressed how engaging in an ICD deactivation discussion before implantation may increase emotional distress.[7]

The goals of this review are: to provide an overview of the evidence on the process of initiating ICD deactivation discussions; when they should occur; who should be involved; the use of advance directive and barriers to these conversations. From this to provide recommendations on how to engage in effective, patient-centred deactivation discussions.

Methods

Inherent within the aim of this systematic review is the exploration of the complexity of balancing the duty of care to consider ICD withdrawal, when the ICD is at risk of causing harm, with the potential distress of these conversations. As such, although systematic reviews traditionally focus on quantitative evidence, qualitative evidence with the potential for rich explanatory data was incorporated.

Criteria for consideration of studies for review.

Prior to searching databases an inclusion criteria was agreed by both authors; literature had to be published in the last 10 years in the English language and refer to an adult population (over the age of 18 years). This timeframe was chosen to reflect current practice following recommendations of national and international guidelines.[2 4] To answer the research question literature had to be on the communication around ICD deactivation.

Identification and selection of studies.

The aim of the search was to identify and select an inclusive list of all studies that met the inclusion criteria. MF searched the following databases from October 2019 to February 2020 with a further search in March 2021: MEDLINE, EMBASE, CINAHL and PsycInfo.

Consensus was reached between reviewers for the specific MeSH headings and key words used for the population: Implantable cardioverter defibrillator, ICD, automatic implantable cardioverter defibrillator, AICD, implantable defibrillator (in relation to both patients and professionals). Search words used for intervention: Communication, health communication, consult, inform, mention, discuss, verbalise, talk to, vocalise, converse, address, advance care planning, advance directive, end of life planning. Appropriate wildcards were inserted where necessary.

MF hand searched reference lists of relevant studies to identify further papers. Titles and abstracts were inspected by MF and clearly ineligible papers or duplicates were deleted. Full copies of

potentially eligible papers were retrieved, if full copy of the text could not be found authors were contacted via ResearchGate. Abstracts alone could not be used as they provided insufficient data. Unpublished articles were included if they met the criteria for inclusion and the full text was available. All identified full papers were independently screened by MF.

Data Extraction.

A standardised electronic checklist was agreed and created by both authors to extract data on: general information (author and year, type of publication, country of origin, source of funding, study characteristics, aim, study design, inclusion and exclusion criteria, recruitment procedures); participant characteristics (participants, age, gender, ethnicity, disease characteristics); number of participants included; and number and reason for withdrawal. Additionally, the extraction form included three key criteria: experience of, barriers to and facilitators for ICD deactivation communication. This was a deductive approach to answer the research question. MF extracted the data.

Data analysis.

Critical Appraisal Skills Program (CASP) checklists (according to study type) were used by MF to assess the quality of included papers. It was anticipated that the search strategy would produce a diverse set of papers using different research methods.

Results

Following de-duplication, n=8063 studies were identified. During title/abstract screening and full-text review, n=8041 studies were excluded. Primary reasons for exclusion were: unrelated to study aim, ICD referred to 'International Classification of Disease', or articles could not be accessed. Ten of the included studies were qualitative reviews,[7 9-17] eight used a survey to extract data,[18-25] three retrospectively reviewed data[26-28] and only one study was a randomised control trial.[29]

Figure 1 PRISMA flow chart showing literature selection

Five included cohort studies assessed for quality using the CASP cohort checklist scored highly. Most of the studies were robust, and generalisable, but it was difficult to identify how studies controlled confounding factors.[23-24 26-28] 15 studies were qualitative, and appraised using qualitative CASP

checklist. These qualitative studies rarely reflected on the interactions between participants and researcher and if all ethical considerations had been taken into account. However, for all the studies there was a clear statement of findings.[7 9-13 16-21 25] Only one randomised controlled trial was included, and appraised using RCT CASP checklist, the study scored highly in all criteria.[29] See online supplementary material for full details of the quality assessments.

14 of the studies focused on patient experience, six on the perspectives of healthcare professionals and two on family member experiences. There is a significant gender disparity with 93% of the studies on patient experience having a male predominance. 12 studies were conducted in United States of America and Canada, seven in Europe Union and three in the United Kingdom. See Table 1 for full details of included papers.

Table 1 Details of included papers

Author	Year Published	Country	Study Design	Participants	Sample Size	Age (mean)	Male (%)	Female (%)
Ali-Ahmed *et al*	2019	United States of America	Survey	Healthcare professionals	124	-	-	-
Buchhalter *et al*	2014	United States of America	Retrospective review of medical records	Patients	159	79	101 (67%)	58 (33%)
Conelius *et al*	2013	United States of America	Survey	Patients	200	75	152 (76%)	48 (24%)
Fluur *et al*	2013	Sweden	Qualitative Interviews	Patients	37	64	23 (62%)	14 (38%)
Fluur *et al*	2014	Sweden	Qualitative Interviews	Family member	18	61	7 (395)	11 (61%)
Goldstein *et al*	2019	United States of America	RCT	Healthcare professionals	525	60	367 (70%)	158 (30%)
Hill *et al*	2018	United Kingdom	Survey	Healthcare professionals	262	46	199 (76%)	63(24%)
Hill *et al*	2019	United Kingdom	Qualitative Interviews	Patients	16	69	11 (70%)	5(30%)
Kramer *et al*	2011	United States of America	Qualitative Interviews	Healthcare professionals	14	-	2 (14%)	12 (86%)
Kutcher *et al*	2020	United States of America	Qualitative Interviews	Family member	5	-	0 (0%)	5(100%)
Hjelmfors *et al*	2014	Sweden	Survey	Healthcare professionals	111	51	7(6%)	104 (94%)
MacIver *et al*	2016	Canada	Qualitative Interviews	Patients	25	72	19 (76%)	6(24%)
Lee *et al*	2017	United States of America	Qualitative Interviews	Patients	6	55	3 (50%)	3(50%)
Miller et al	2019	United States of America and Australia	Survey	Patients	240	62	175 (73%)	65 (27%)
Mooney *et al*	2019	Ireland	Survey	Patients	30	62	24(80%)	6(20%)
Mueller *et al*	2011	United States of America	Qualitative Interviews	Healthcare professionals	17	43	12 (71%)	5(29%)
Pasalic *et al*	2016	United States of America	Retrospective review of medical records	Patients	150	79	102 (68%)	48(32%)
Raphael *et al*	2011	United Kingdom	Qualitative Interviews	Patients	54	72	43 (80%)	11(20%)
Stoevelaar *et al*	2020	Netherlands	Qualitative Interviews	Patients	41	64	23 (56%)	18(44%)
Thompson *et al*	2019	Sweden	Survey	Patients	2403	65	1922 (80%)	481 (20%)
Thylén *et al*	2014	Sweden	Survey	Patients	109	67	87 (80%)	22(20%)
Trussler *et al*	2019	Canada	Retrospective review of medical records	Patients	49	78	43 (88%)	6(12%)

There was variation across the 22 included studies about when, where and who conducted ICD deactivation discussions. In terms of timing: four studies mentioned deactivation being discussed as part of the informed consent,[7 12 16 18] seven did not specify a time,[10 17 19 23 25 26 29] two during ICD replacement,[9 22] and eight as part of end-of-life care.[11 13-15 21 24 27 28] One study described how these conversations occurred across transitions including informed consent, after implantation and as part of end-of-life care.[20] The location of these discussions was not always recorded: ten were conducted in 'a clinical setting',[9 10 12 13 15 16 18-22 26 29] one stipulated a hospice[13] and three out-patient clinics.[15 16 29] There was a lack of clarity and consensus regarding the appropriate person to initiate these conversations. Some studies simply recorded 'healthcare professionals', and others clearly identified cardiologists, heart failure nurse specialists or palliative care consultants (further details in table 2).

Table 2 Details of when, where and who conducted conversations

Author	Year published	When conversation happened	Where conversation happened	Who conducted conversation
Ali-Ahmed *et al*	2019	informed consent	clinical setting	electrophysiologists or cardiologists
Buchhalter *et al*	2014	Time not specified	clinical setting	palliative medicine consultants
Conelius *et al*	2013	Time not specified		
Fluur *et al*	2014	Time not specified	clinical setting	healthcare professionals
Goldstein *et al*	2019	Time not specified	inpatient or outpatient setting	physicians, heart failure specialist nurses
Hill *et al*	2018	informed consent or part of end-of-life care	-	healthcare professionals
Hill *et al*	2019	part of end-of-life care		healthcare professionals
Kramer *et al*	2011	informed consent	clinical setting	electrophysiologists or cardiologists
Kutcher *et al*	2020	part of end-of-life care	hospice	palliative medicine consultants
Hjelmfors *et al*	2014	part of end-of-life care	-	physicians, heart failure specialist nurses
MacIver *et al*	2016	informed consent	-	doctor
Lee *et al*	2017	part of end-of-life care	-	doctor
Miller *et al*	2019	ICD replacement	clinical setting	healthcare professionals
Mooney *et al*	2019	Time not specified	-	healthcare professionals
Mueller *et al*	2011	part of end-of-life care	inpatient or outpatient setting	doctor
Pasalic *et al*	2016	part of end-of-life care	-	physicians, heart failure specialist nurses
Raphael *et al*	2011	informed consent	outpatients	healthcare professionals
Stoevelaar *et al*	2020	Time not specified	-	doctor
Thompson *et al*	2019	Time not specified	-	
Thylén *et al*	2014	part of end-of-life care	-	healthcare professionals
Trussler *et al*	2019	part of end-of-life care	-	healthcare professionals

Main themes

Following data extraction on the experience, barriers and facilitators of communication five main themes were identified: (1) timing of ICD deactivation discussions, (2) initiation of deactivation discussions, (3) advance directives, (4) barriers to discussions, and (5) facilitators to discussions.

Timing of ICD deactivation discussions

Informed consent is the voluntary agreement given by a fully informed, competent person and is central to both ethical and legal aspects of care. Informed consent requires effective communication between the healthcare professional and the patient to explain the benefits, risks and alternative treatment options.[30] Therefore, prior to ICD implantation, as recommended by the BHF and EHRA, ICD deactivation should be discussed.[2 4] Raphael *et al* showed this recommendation is supported by patients, who when asked in an interview when they would want to discuss ICD deactivation 52% preferred discussion before implantation compared to just 22% who believed it should be delayed until they were terminally ill.[16]

Despite this recommendation some studies report that engaging in early discussions might increase emotional distress.[7 9 11 19] A qualitative study showed that patients found talking about death too difficult as it shifts the focus away from what they consider important which was living in the present.[9] In addition, MacIver *et a*l reported the irony in having deactivation discussions prior to ICD implantation: "they put in a machine that can save me … and now they are talking about turning it off already".[7] Further literature also suggested it might be inappropriate to discuss deactivation early since implantation felt like 'a second chance at life'.[17]

One small survey recorded only 13% of patients (n=4) had spoken with their doctor or nurse, regarding deactivation. Nevertheless, many reported they would raise the question about end-of-life if they had multiple shocks (83%); repeated hospital admission with recurring heart problems (87%) or towards end-of-life (97%).[25]

However, it is important to acknowledge that some patients never want to discuss end-of-life issues.[7 17 22-24] Thompson *et al* found 40% of participants said they never wanted to have a conversation concerning end-of-life care; 55% of the cohort said they would want to have their ICD battery replaced even if they were seriously ill and suffering from a terminal disease.[23] This has been supported by Miller *et al* who found that patients who had already experienced a shock were more likely to maintain defibrillation therapy "it saved my life, and I don't want to live without it" and would choose to avoid ICD deactivation discussions.[22] One study uncovered reasons for this

reluctance experienced by patients including that information may be confusing, the decision is best left to the doctor and switching off may prematurely shorten life.[16]

Initiation of deactivation discussions

The British Heart Foundation guideline advices ICD deactivation discussions should occur, ideally between the heart failure nurse, the patient and their chosen representative.[2]

However, literature suggests that many patients would prefer to leave the decision to engage in deactivation discussions solely in the hands of clinicians.[9 16 24] Fluur *et al* found that this was because patients felt clinicians knew best and trusted their judgment to decide whether or not the ICD should remain activated.[9] Miller *et al* reported that patients trusted clinicians so much that if they did not bring up discussion about end-of-life choices they inferred it was not important.[22]

In terms of which specific member of the clinical team should be involved in these discussions, Maclver's *et al* study of 17 patients reported that nine suggested a cardiologist and eight suggested nurses.[7] Similar results were supported by Hill *et al* with healthcare professionals recommending a cardiologist (97%) or specialist heart failure nurse (82%).[20]

Despite the general consensus that specialist nurses have the necessary attributes to initiate a discussion about deactivation, overall data shows a lack of nursing contribution to the final decision. Kramer *et al* interviewed nurses who described how pre-implantation discussions were largely physician driven. These physicians placed a strong emphasis on the benefits of the device and less attention on future deactivation.[12] The nurses in this study reported they would be better suited than physicians to initiate end-of-life discussions, largely because they are generally more involved with patient care and decision making after implantation. Through this greater level of interaction, the nurses learned a great deal about their patient's goals and preferences; these factors are important in influencing end-of-life decisions. The current lack of nurses' involvement was explained by one study as a result of the structure of healthcare systems and the traditional role of physicians to diagnose and make treatment decisions.[20] Hjelmfors *et al* reported there may be an issue with the lack of education and training nurses receive to have these conversations.[21] The study showed that despite most nurses thinking it appropriate for them to talk about prognosis and end-of-life decisions with the patient, 58% were hesitant due to uncertainty of knowing how to approach the topic or answer patient questions.[21]

The evidence suggests that perhaps clinicians should not be the only ones to initiate deactivation discussions.[7 11 20 21 24] Maclver *et al* reported that some patients would prefer that patients themselves were the ones to start the conversation.[7] They felt that if the physician initiated the discussion before

they were ready, this could increase emotional distress. Further literature also supported this approach stating the choice to deactivate was best left to the patient because 'no time is really the right time'.[11]

Advance Directives

To facilitate the topic of deactivation an AD, a process of formal decision making that aims to help patients establish decisions about future care that take effect when they lose capacity, can be used.[31] However, literature has shown that in the case of ICD deactivation ADs are either not being used or their purpose is not being explained fully.[9 12 14 17 19 21 23 26 27 28] In addition, Conelius et al suggested some healthcare professionals either do not understand the ADs themselves or do not believe they are useful.[19] Buchhlater *et al* found 57% of participants had ADs of these 48% were executed before implantation.[26] Worryingly, only one advance directive addressed ICD deactivation. Interestingly, this patient executed his AD four months after implantation and died 10 years later, two days after deactivation for end stage heart failure.

In addition to advance directives, palliative care medicine consultations (PCMC) also provide a suitable opportunity for discussing and recording ICD deactivation wishes alongside all life-prolonging treatments as an integral component to holistic assessment of physical, psychological, spiritual and social care. However, reporting on a retrospective review of the medical records of 150 patients who had undergone deactivation Buchhalter *et al* and Pasalic *et al* found only two-thirds of PCMC's specifically addressed this aspect of care.[26 27] They acknowledge this may reflect a lack of awareness that the patient had an ICD. It is noteworthy that PCMC's occurred significantly more frequently in patients who requested deactivation themselves suggesting decision making capacity.

Stoevelaar *et al* established that not everyone was in favour of recording their preferences in a document.[17] This was due to a range of reasons including not knowing choices available or personal preferences for end-of-life care, knowing what they wanted but worrying that their decision would change when actually in that situation, or being doubtful that even if they expressed their choices, they would be respected.

Barriers to discussions

Literature suggests making advance decisions about deactivation can be difficult for the patient and their family due to lack of information or understanding. Two studies reported how family members felt 'left out' from the lack of information.[10 13] Fluur *et al* described how spouses were rarely offered verbal or written information and had to rely on second-hand recollections following the consultation.[10] Kutcher *et al* reported that spouses recalled how the medical team showed great

enthusiasm for implantation but great reluctance to consider deactivation.[13] Without this support caregivers felt lost and hopeless. In both cases caregivers were forced to turn to their own network and educate themselves about the possibility and benefits of deactivation.

However, there is debate on whether family members should be involved in advance decision making.[9-13 17 19 20] Fluur *et al* revealed that spouses were often over protective which could have a negative impact on the patient, leading to reduced social interaction and impaired communication when it came to making advance decisions.[10] One study reported nurses' observation of family pressure to encourage patients to keep their device, with one nurse quoting how the patient felt the need to avoided deactivation and stay alive just for their son.[12]

Evidence suggests it is not family members alone who may lack an understanding on device deactivation. Conelius *et al* reported patients had a lack of understanding of their medical condition and treatment options and limited confidence in healthcare providers to decide their treatments.[19]Mooney *et al* highlighted that patient information in respect of device management and deactivation during serious illness or at end-of-life is limited. In their study, 17% and 20% of patients were unable to offer an opinion when asked if they would deactivate their ICD if receiving shocks daily, or if they had serious illness.[25]. Miller *et al* showed that understanding of the device is crucial and that when patients had increased knowledge they were more likely to consider deactivation. [22]

Furthermore, although patients and family members may lack knowledge, clinicians can also feel underprepared to have these conversations. Hjelmfors *et al* reported that more than half the nurses surveyed hesitated when it came to initiating end-of-life discussions; in practice they lacked confidence in answering patient questions and 91% reported a need for further training in advanced communication skills.[21]

Facilitators to discussions

A key facilitator as reported by Goldstein *et al* is the training of physicians.[29] This RCT explored the impact of an interactive 90 minute communication skills training session on advance care planning conversations and ICD deactivation. The single RCT involved six hospitals with heart failure programs and an absence of protocols addressing ICD deactivation. These were randomised in a single-blinded cluster to reduce cross contamination at the level of clinician and patient.[29] The study found that patients were more likely to have goals of care conversations, if the physicians had undertaken the training, compared with those cared for by clinicians in the control group, (47% intervention vs. 38% control; odds ratio: 1.53; p = 0.04).

Shared decision making as described by Ali-Ahmed *et al* and Hill *et al,* incorporating relevant facts about risks and benefits, facilitating accurate and timely information to inform treatment choices.[18 20] In addition, Miller *et al* found that increasing patient knowledge decreased unnecessary procedures including shocks in the active dying phase.[22]

Building supporting relationships with healthcare professionals over time allows a process rather than one-off conversations to occur. Hjelmfors *et al* reported nurses were in 100% agreement on two main facilitators for end-of-life discussions: a good relationship with the patient and repeated opportunities.[21] Moreover, Maclaver *et al* promoted the recognition of the palliative phase of illness, identifying the best time to talk about deactivation being when the patient's condition changes with these transitions providing opportunity for conversations.[7]

Discussion

Alongside developments in healthcare there has been an increase in the use of ICDs to treat life threatening cardiac arrhythmias and cardiac arrest. However, with increasing age, disease burden and co-morbidities, these devices have the potential to cause harm with many patients experiencing shocks as they approach death. The associated pain, distress and anxiety with possible prolongation of the dying experience could be avoided. This review suggests that despite guidelines[2 4] recommending conversations about deactivation of the defibrillator element of the device to prevent this, these recommendations are not always translated into clinical practice. Furthermore, these conversations are fraught with difficulties for healthcare professionals, patients and families.

To answer the research question of when, how and who should have deactivation discussions a deductive approach was constructed which yielded both quantitative and qualitative cross-national studies. Of the included studies there was only one randomised control trial, the rest were observational or qualitative. Due to the diverse nature of selected articles it was not appropriate to use traditional synthesis methods instead results were reported under pre-determined themes. Consideration needs to be taken of the diverse healthcare systems, practices and policies when applying the relevance of this review to practice. Overall, there is little strong evidence to support practice when faced with the complexity of these conversations. Nevertheless, this review identifies significant issues that deserve further discussion.

Current guidelines recommend that device deactivation discussions should be included as part of pre-implantation informed consent.[2,4] The review suggests a variety of preferences when ICD deactivation conversations should occur and there is no overall defining answer from literature. It is clear that as part of the informed consent process, where patients should receive a full explanation,

of the benefits and risks of their defibrillator, ICD deactivation should be mentioned. In general, patients concur that they want to be 'informed' about device deactivation prior to implantation but lengthy discussions should be avoided until more appropriate times.

It is the role of clinicians to provide guidance and support about appropriate treatments and options at each phase of the disease trajectory. The review suggests there are some patients who are not aware that deactivation is available to them. To address this, experienced, competent clinicians could take opportunities to introduce conversations during elective ICD battery replacement, when there is functional decline, frequent hospital admissions, on referral to palliative care and as a component of resuscitation conversations. Crucial to discussions is the sensitive exploration of the patient's readiness to talk about deactivation and tailor information and delivery to their expressed preference.

The British Heart Foundation recommend heart failure nurse specialists, who know the patient and have had advance communication training, should be the ones to initiate and revisit deactivation discussions.[2] These guidelines concur with general recommendations from most of the studies reviewed. Although some studies suggest deactivation discussions are not welcomed by patients[7 17 22-24] this should not deter healthcare professionals from seeking to engage in these conversations in order to prevent distressing shocks at end-of-life. Indeed, healthcare professionals have a duty of care to consider withdrawal of non-contributory therapies and prevent the distress caused by resuscitation measures in those with a progressive and irreversible decline in their condition.[32] Conversations should reassure the patient that device deactivation is painless, only discontinues the shock component and does not hasten death.[2]

Palliative care is an approach to improve the quality of life of patients and their families facing problems associated with life-threatening illness, offering a support system to help the patient live as actively as possible until the end of life, and can be applicable in the early course of illness in conjunction with other life-sustaining therapies.[34] Indeed, in the UK this phased transition of including palliative care alongside disease modifying treatments has been suggested as particularly relevant for those with slowly progressive or fluctuating trajectories as with cardiovascular disease.[8] Joint working between cardiology and palliative care could be a conduit for advance care planning conversations including deactivation. However, this contrasts with US models which are defined by a sharper transition to palliative care accompanied by a cessation of curative care and is illustrated by the 63 patients who received late referrals to palliative care, who all had a poor or terminal prognosis, and for whom median survival after deactivation was just 2 days.[27]

The main issue, that many studies in the review support, is deactivation discussions are being left until the impending death of the patient. A study by Kim et al suggests one possible reason is that ICD is primarily considered a life-saving therapy, for many patients and healthcare professionals' deactivation is considered a controversial issue leading to a delay in discussion.[35]

The inclusion of cross-national literature means the review is subjected to impact of variations in healthcare systems around the world. The American College of Cardiology/American Heart Association and Heart Rhythm Society advises patients with an ICD to make a device specific advance directive when nearing end-of-life.[36] This approach appears to differ from that in Europe as illustrated by a 6-country, cluster-randomised European advance care planning study where only 10% of patients who received the intervention had an advance directive in their hospital files. Although not specifically related to ICD deactivation, this illustrates the differences in cross-national approaches to advance directives.[37]

Reported barriers suggested from this literature review and supported by other studies[38] include: lack of professional teaching and a knowledge deficit of patients regarding deactivation. To improve professional training a quality improvement project by Javid et al found targeted teaching, compared to posters or emails, had the biggest improvement in the occurrence of deactivation discussions.[39] Goldstein et al randomised control trial found the intervention group that received communication training were more likely to discuss goals of care than the control.[29] This suggests education and targeted workshops can help increase professional's awareness and confidence. To support patient and relative knowledge verbal information should be supplemented by written education materials. Establishing early conversations and having a process of continued dialogue with experienced health care professionals can help with the processing of information resulting in appropriate timing of deactivation. This in turn may help decrease unnecessary harm and distress and promote comfortable dying.

The review highlights that despite guidelines,[2 4] which provide advice on how and who should be having device deactivation discussions, the opportunity for these conversations are not offered or undertaken on a consistent basis. Reasons could include a lack of professional awareness of guidelines or that current teaching practice commonly includes the reasons for implanting life sustaining devices, but fails to acknowledge deactivation. Literature suggests without education and training in communication skills to explain these complex issues with clarity, and where possible, encourage advance care planning discussions, these conversations remain limited. One option could be to include ICD deactivation education alongside teaching on do-not-attempt-resuscitation.

A strength of this review is that only one author was involved in selecting, extracting and evaluating the available evidence, providing internal consistency. However, this increases the risk of bias by having only one reviewer. In hindsight if MF had conducted a pilot search this would have illustrated the issue of the abbreviation ICD also referring to International Classification of Disease and would have better limited the number of studies to be filtered. Furthermore, the lack of response from authors to requests full text articles meant that potential studies were excluded.

In summary, this review shows that there needs to be a proactive clinical and policy initiative in the education of both professionals, and patients and relatives about device deactivation. Moreover, healthcare professionals should be taught how to communicate these complex issues in a clear and compassionate manner to ensure timely deactivation of the shock element of the ICD to facilitate a comfortable, natural death. Further research could be conducted on the most effective way for this to be implemented.

Contributors: MF participated in all aspects of the review: data searching, study selection, data extraction, quality appraisal, manuscript writing and edits. FM coordinated all aspects of the review and assisted in manuscript writing and editing.

Funding: This review was completed as part of a research module towards a primary medical degree and received no external funding. Professor Murtagh is a National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.

REFERENCES:

1. Matchett M, Sears SF, Hazelton G, *et al.* The implantable cardioverter defibrillator: its history, current psychological impact and future. *Expert Rev Med Devices*. 2009;6(1):43-50.
2. British Heart Foundation. ICD deactivation at the end of life: Principles and practice, 2013. Avaliable at: https://www.bhf.org.uk/informationsupport/publications/living-with-a-heart-condition/icd-deactivation-at-the-end-life [Accessed 13 December 2020]
3. Kinch Westerdahl A, Sjoblom J, Mattiasson AC, *et al.* Implantable cardioverter-defibrillator therapy before death: high risk for painful shocks at end of life. *Circulation.* 2014;129(4):422-9.
4. Padeletti L, Arnar DO, Boncinelli L, *et al*. EHRA Expert Consensus Statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy. *Europace*. 2010;12(10):1480-9.
5. Marinskis G, van Erven L. Deactivation of implanted cardioverter-defibrillators at the end of life: results of the EHRA survey. *Europace*. 2010;12(8):1176-7.
6. Stoevelaar R, Brinkman-Stoppelenburg A, van Driel AG, *et al*. Implantable cardioverter defibrillator deactivation and advance care planning: a focus group study.*Heart* 2020;106:190-195.
7. MacIver J, Tibbles A, Billia F, *et al*. Patient perceptions of implantable cardioverter-defibrillator deactivation discussions: A qualitative study. *SAGE* Open Med. 2016;4:2050312116642693.

8. Gardiner C, Ingleton C, Gott M, *et al*. Exploring the transition from curative care to palliative care: a systematic review of the literature. *BMJ supportive & palliative care*. 2011;1(1):56-63.
9. Fluur C, Bolse K, Strömberg 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(3):202-7.
10. Fluur C, Bolse K, Strömberg A, *et al*. Spouses' reflections on implantable cardioverter defibrillator treatment with focus on the future and the end-of-life: a qualitative content analysis. *J Adv Nurs*. 2014;70(8):1758-69.
11. Hill LM, McIlfatrick S, Taylor B, *et al*. Implantable cardioverter defibrillator (ICD) functionality: patient and family information for advanced decision-making. *BMJ Support Palliat Care*. 2019 Nov 26:bmjspcare-2019-001835. doi: 10.1136/bmjspcare-2019-001835.
12. Kramer DB, Ottenberg AL, Gerhardson S, *et al*. "Just Because We Can Doesn't Mean We Should": views of nurses on deactivation of pacemakers and implantable cardioverter-defibrillators. *J Interv Card Electrophysiol.* 2011;32(3):243-52.
13. Kutcher GR, Soroka JT. Deactivating a Pacemaker in Home Care Hospice: Experiences of the Family Caregivers of a Terminally Ill Patient. *Am J Hosp Palliat Care*. 2020;37(1):52-7.
14. Lee MC, Sulmasy DP, Gallo J, *et al.* Decision-Making of Patients With Implantable Cardioverter-Defibrillators at End of Life: Family Members' Experiences. *Am J Hosp Palliat Care*. 2017;34(6):518-23.
15. Mueller PS, Ottenberg AL, Hayes DL, *et al*. "I felt like the angel of death": role conflicts and moral distress among allied professionals employed by the US cardiovascular implantable electronic device industry. *J Interv Card Electrophysiol*. 2011;32(3):253-61.
16. 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(12):1628-33.
17. Stoevelaar R, Brinkman-Stoppelenburg A, van Driel AG, *et al*. Implantable cardioverter defibrillator deactivation and advance care planning: a focus group study. *Heart*. 2020;106(3):190-5.
18. Ali-Ahmed F, Matlock D, Zeitler EP, *et al*. Physicians' perceptions of shared decision-making for implantable cardioverter-defibrillators: Results of a physician survey. *Journal of Cardiovascular Electrophysiology*. 2019;30(11):2420-6.
19. Conelius J. The development, refinement, and psychometric testing of the attitude toward advanced directive survey in implantable cardioverter defibrillator patients. *J Cardiovasc Nurs.* 2013;28(3):238-44.
20. Hill L, McIlfatrick S, Taylor BJ, *et al*. Patient and Professional Factors That Impact the Perceived Likelihood and Confidence of Healthcare Professionals to Discuss Implantable Cardioverter Defibrillator Deactivation in Advanced Heart Failure: Results From an International Factorial Survey. *J Cardiovasc Nurs*. 2018;33(6):527-35.
21. Hjelmfors L, Strömberg A, Friedrichsen M, *et al*. Communicating prognosis and end-of-life care to heart failure patients: a survey of heart failure nurses' perspectives. *Eur J Cardiovasc Nurs*. 2014;13(2):152-61.
22. Miller JL, Chung ML, Etaee F, *et al.* Missed opportunities! End of life decision making and discussions in implantable cardioverter defibrillator recipients. *Heart Lung.* 2019;48(4):313-9.
23. Thompson JH, Thylén I, Moser DK. Shared Decision-Making About End-of-Life Care Scenarios Compared Among Implantable Cardioverter Defibrillator Patients: A National Cohort Study. *Circ Heart Fail.* 2019;12(10):e005619.
24. Thylén I, Wenemark M, Fluur C, Stromberg A, *et al*. Development and evaluation of the EOL-ICDQ as a measure of experiences, attitudes and knowledge in end-of-life in patients living with an implantable cardioverter defibrillator. *Eur J Cardiovasc Nurs*. 2014;13(2):142-51.
25. Mooney M, McKee G, McDermott E, *et al.* Patients' knowledge and opinions of ICDs during life, illness and at the time of death. *Br J Nurs*. 2019 Apr 11;28(7):446-451. doi: 10.12968/bjon.2019.28.7.446. PMID: 30969861.

26. Buchhalter LC, Ottenberg AL, Webster TL, *et al*. Features and outcomes of patients who underwent cardiac device deactivation. *JAMA Intern Med*. 2014;174(1):80-5.

27. Pasalic D, Gazelka HM, Topazian RJ, *et al*. Palliative Care Consultation and Associated End-of-Life Care After Pacemaker or Implantable Cardioverter-Defibrillator Deactivation. *Am J Hosp Palliat Care*. 2016;33(10):966-71.
28. Trussler A, Alexander B, Campbell D, *et al*. Deactivation of Implantable Cardioverter Defibrillator in Patients With Terminal Diagnoses. *Am J Cardiol*. 2019;124(7):1064-8.
29. Goldstein NE, Mather H, McKendrick K, *et al*. Improving Communication in Heart Failure Patient Care*. J Am Coll Cardiol*. 2019;74(13):1682-92.
30. Shah P, Thornton I, Turrin D, *et al*. Informed Consent. StatPearls. Treasure Island (FL): StatPearls Publishing

31. Hayhoe B, Howe A. Advance care planning under the Mental Capacity Act 2005 in primary care. *Br J Gen Pract*. 2011;61(589):e537-41.
32. General Medical Council. Treatment and care towards the end of life: good practice in decision making, 2010. Avaliable at: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life [Accessed 13 December 2020]
33. Macmillan Cancer Support. Palliative Care And End Of Life Framework: Macmillan Cancer Support; 2012. Avalaible at: Palliative Care And End Of Life Framework: Macmillan Cancer Support; 2012. [Accessed 13 December 2020]
34. World Health Organisation. Palliative Care, 2020. Avaliable at: https://www.who.int/news-room/fact-sheets/detail/palliative-care [Accessed 13 December 2020]
35. Kim J, Park HW, An M, *et al*. Exploring Advance Directive Perspectives and Associations with Preferences for End-of-Life Life-Sustaining Treatments among Patients with Implantable Cardioverter-Defibrillators. *Int J Environ Res Public Health*. 2020;17(12).
36. 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(7):1008-26.
37. Korfage IG, Carreras G, Arnfeldt Christensen CM, et al. Advance care planning in with advanced cancer: A 6-country, cluster-randomised clinical trial. PLoS Medicine 2020;17(11): e1003422
38. 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(5):296-9.
39. Javid M, Squirrell S, Farooqi F.Please don’t shock me: a qi project on implantable cardioverter defibrillators (icds) at the end of life care & dnar. *Heart*. (103Suppl 5).2017; A1-A162.