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Title: Patient and professional factors that impact the perceived likelihood and confidence of healthcare professionals to discuss Implantable Cardioverter Defibrillator (ICD) deactivation in advanced heart failure: results from an international factorial survey

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Abstract

Background: Rate of ICD implantations is increasing in patients with advanced heart failure. Despite clear guideline recommendation, discussions addressing deactivation occur infrequently.

Aim: To explore patient and professional factors that impact perceived likelihood and confidence of healthcare professionals to discuss ICD deactivation.

Methods and Results: Between 2015 and 2016, an international sample of 262 healthcare professionals (65% nursing; 24% medical) completed an online factorial survey, encompassing demographic questionnaire and clinical vignettes. Each vignette had nine randomly manipulated and embedded patient-related factors, considered as independent variables, providing 1,572 unique vignettes for analysis. These factors were determined through synthesis of a systematic literature review, retrospective case note review and qualitative exploratory study. Results showed most healthcare professionals agreed deactivation discussions should be initiated by a cardiologist (95%, n=255) or specialist nurse (81%, n=215). In terms of experience, 84% (n=53) of cardiologists but only 30% (n=50) of nurses had previously been involved in a deactivation decision. Healthcare professionals valued patient involvement in deactivation decisions, however only 50% (n=130) actively involved family members. Five out of nine clinical factors were associated with an increased likelihood to discuss deactivation including advanced age, severe heart failure, presence of malignancy, receipt of multiple ICD shocks and more than three hospital admissions during the previous year. Furthermore, nationality and discipline significantly influenced likelihood and confidence in decision-making.

Conclusions: Guidelines recommend healthcare professionals discuss ICD deactivation, however practise is sub-optimal with multifactorial factors impacting on decision-making. The role and responsibility of nurses in discussing deactivation requires clarity and improvement.

Keywords: Defibrillators, implantable; Heart Failure; Decision-making; Survey; Terminal care

Introduction

There is a gap between guideline recommendations and everyday clinical practice concerning Implantable Cardioverter Defibrillator (ICD) deactivation[1]. Increasing rates of ICD implantation and an improved life expectancy with many elderly living with co-morbidities, intensifies the need for clarity on the role of the ICD in the advanced stages of any illness. A recent study found that one in four patients received futile and painful shocks from the device shortly before death[2]. Many factors are implicated including patients' lack of knowledge on the device and deactivation, their life-saving perception of the ICD[3] and the dialogue about deactivation characterised as "too little, too late"[1].

International and interdisciplinary discrepancies exist on who should discuss deactivation and when such discussions should occur[4,5]. In a survey of 384 Heart Rhythm Society members[6] deactivation was considered by most professionals questioned to be permissible if aligned with the patient's (78%, n=296) and/or carer's (72%, n-278) wishes. Studies have found nurses reluctant to engage in discussions, assigning sole responsibility for discussing and ultimately decision-making regarding deactivation with medical professionals[1,4]. In a recent position statement from the Council on Cardiovascular Nursing and Allied Professionals (CCNAP), the varied role of healthcare professionals across Europe was highlighted[7], reinforcing the need to improve international research and collaboration, as well as improve knowledge on country specific data to facilitate the development of strategies to improve the practice of ICD deactivation across healthcare systems. As the number of patients with an ICD increases, there is an urgent need to address this clinical concern to ensure quality of life during the palliative stage of illness.

Aim

To explore patient and professional factors that impact perceived likelihood and confidence of healthcare professionals to discuss ICD deactivation.

Methodology

Design
This cross-sectional factorial design study conformed to the Declaration of Helsinki[8] and was approved by the local research ethics committee. Originally developed by Rossi and Nock (1982)[9], the factorial survey combines the strengths of random manipulation of variables with the generalizability of a survey. The design has been successfully used in studies, for example, nurses' use of physical restraints[10], indicators of acute deterioration[11] and nurses' judgement of self-neglect[12]. Though a systematic and iterative process[13], twenty-one factors associated with ICD deactivation were generated from a systematic literature review[14], a retrospective case note review[1] and qualitative exploration (**Refer Appendix 1**). These factors were repeatedly reviewed and refined by four methodological and three clinical experts for content validity, until there were nine orthogonal and clinically relevant patient-related factors or variables[15-17] for inclusion within the survey.

Study instrument
The survey was distributed electronically using a secure IT platform to ensure complete anonymity. Participants received a short demographic questionnaire, a standard vignette, followed by six unique clinical vignettes (**Refer Appendix 2**).

Questionnaire

Demographic and experiential data were collected. Healthcare professionals were presented with short statements and asked to record on a zero to ten Likert scale the probability of referral for ICD deactivation. A score of zero indicated the patient would not be referred, while a score of ten indicated the healthcare professional would refer for deactivation.

Factorial survey
The nine patient-related factors or Independent Variables were: Age, Gender, Previous Discussion, Heart Failure Severity, Comorbidities, Number of Admissions, Number of Shocks, Treatment Intent and Social Support. Each factor had between three to five levels. Participants responded to a standard vignette that allowed the researcher to assess their engagement and comprehension of the instrument's scoring system. This was followed by six unique vignettes, in which the nine evidence-based factors had been randomly allocated. Participants' responses to vignettes were captured by two dependent variables. (**Refer Table 1**). A total of 200 vignettes were checked by the researcher (LH) prior to a pre-test with ten healthcare professionals with clinical experience of patients with an ICD. This determined time-to-complete the survey and content validity.

Table 1: Example of a clinical vignette (clinical factors or independent variables in italics) & two dependent variables

You review a *59-year-old man* with *moderate heart failure (NYHA III)* and *bowel cancer*. He has had *one admission* over the past year and has *experienced more than one shock*. Medical records show *no previous discussion about deactivation* with documented management plan to be *referral for cardiac transplant*. The patient *lives with family who share healthcare decisions.*
   Dependent variables:
   1. What is the likelihood that you would discuss ICD deactivation with this patient?
   2. How confident are you in the decision you have just made?

Sample
Access to a convenience sample of healthcare professionals involved in the daily management of patients with an ICD was facilitated through professional organisations, for example Irish Cardiac Society (n=350), British Society of Heart Failure (n=921) and CCNAP (n=2900). The survey was promoted on websites, news bulletins and at conference presentations. Emails inviting participation were sent by the international research team.

Statistical Analysis
Data were analysed using SPSS (version 22) with descriptive and inferential statistics. The framework developed by Miller[18] informed the analysis, which was conducted at two levels, 'patient factors or independent variables' (within vignettes) followed by 'professional factors' (questionnaire), with significance $p=<0.05$. The recommended analysis for factorial surveys[17] is Multivariate Regression and ANOVA, which examines the relationship between each independent variable and dependent variable. Multivariate Regression, ANOVA and Independent T-tests examined each professional factor against each dependent variable. Given the high level of statistical tests conducted, multiplicity was an issue. Therefore a 'false discovery rate' analysis[19] was conducted and p-values recalibrated accordingly.

Results

A total of 457 international professionals accessed the web-link; 262 completed the survey (57% completion rate) which included a questionnaire, standard vignette and six unique vignettes (1,834 total vignettes; 1,572 unique vignettes).

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Demographic Questionnaire

The sample consisted of predominately British residents (60%, n=161), followed by representation from Europe (21%, n=56) and America (17%, n=45). Participants were predominately female, specialist nurses and those with at least six years (70%, n=182) experience. Demographic details presented in Table 2.

Table 2: Demographic and professional characteristics of participants (n=262)

Characteristics	N (%) or Mean ± SD
Gender Female	193 (74%)
Age (years)	45.8 ±8.9 Range 26-65 years
Discipline Nursing Medical Cardiac Physiologist (Technician)	170 (65%) 63 (24%) 29 (11%)
Current Role Specialist Nurse Cardiologist Cardiac Physiologist Other (i.e .general nurse/physician, physiotherapist) Electro-Physiologist	150 (57%) 46 (18%) 29 (11%) 24 (9%) 13 (5%)
Time in Current Role Less than 1 year 1-5 years 6-10 years More than 10 years	11 (4%) 68 (26%) 59 (23%) 123 (47%)

Attitude towards the deactivation discussion

Most healthcare professionals stated that cardiologists (97%, n=255) or specialist nurses (82%, n=215) should initiate discussions concerning ICD deactivation, with some also placing responsibility on primary care physicians (63%, n=166). All physicians supported this view, as did the majority of nurses (96%, n=163). Four British nurses, two American and one nurse from Europe believed the discussion could be initiated by a specialist nurse. Healthcare professionals agreed that deactivation should be discussed - prior to device implantation (81%, n=213), when the patient's condition deteriorates (83%, n=218) and at the palliative stage (78%, n=205). Figure 1 demonstrates that nurses (84%, n= 167) were more in favour of discussing ICD deactivation prior to implantation, compared to physicians (73%, n=46). In contrast, a higher percentage of physicians stated ICD deactivation should be discussed when patient's care becomes palliative (86%, n=54) compared to nurses (76%, n=151). The presence of a deactivation policy was not associated with the likelihood of discussing deactivation (*p*=0.8), however healthcare professionals were more confident making this decision when a deactivation policy was present (*p*=0.03).

Figure 1: Percentage of healthcare professionals recommending discussion at three time-points (n=262)
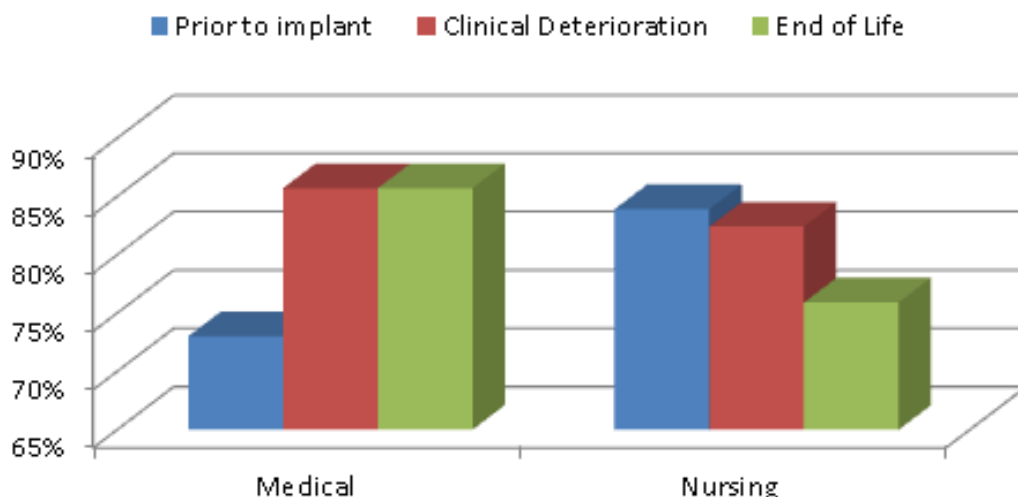
The majority of professionals (87%, n=232) expressed that they did not have ethical or legal concerns concerning ICD deactivation. Independent T-test found no significant difference in attitude between European professionals, compared to American colleagues (p=0.36).

Experience of involvement in the deactivation decision
Nearly all healthcare professionals (97%, n=255) stated the patient should be included in the decision to deactivate their device, but only 50% (n=130) actively involved family members. There was diversity of experience between disciplines with 84% (n=53) of physicians previously involved in an ICD deactivation decision, compared to approximately one third (30%, n=50) of nurses and 14% (n=4) of cardiac physiologists.

Healthcare professionals ranked their likelihood to refer patients for deactivation, based on six clinical statements. Mean values for each statement are documented in Table 3. Results indicate healthcare professionals are more likely to consider deactivation when a Do Not Resuscitate (DNR) order is placed, or when the patient requests comfort care.

Table 3: Healthcare professionals' likelihood to refer for deactivation on Likert scale of 0-10 (n=262)

Likert Scale	DNR Actioned	Comfort care	Palliative care referral	Requests deactivation	Less than 12 months to live	Multiple shocks
Mean score Standard Deviation	9.89 ±1.86	9.70 ± 2.03	8.75 ± 2.39	8.23 ± 2.80	7.56 ±2.88	6.31 ± 3.52

Factorial Survey
A total of 262 participants reported on one standard and six randomly generated vignettes, generating 1,834 vignettes for analysis. Responses to the standard vignette were consistent for both outcome variables - 'Likelihood of discussing deactivation' (*M*=2.60, *SD* ±2.11) and 'Confidence in the decision made' (*M*=7.96, *SD*± 2.8). The standard vignette was not included in further analysis, rendering 1,572 unique vignettes for Multiple Regression and ANOVA. False discovery rate analysis found one variable- *number of admission* (p=0.04) which when the p-value was adjusted, was no longer significant (p=0.07) (see Table 4).

Patient factors that impact perceived likelihood and confidence to discuss ICD deactivation
The nine independent variables explained 10% of the variance (Adjusted R^2=0.10) in healthcare professionals' likelihood of discussing deactivation. Five independent variables were significantly related to their likelihood of discussing deactivation- *patient age, comorbidities, number of admissions, number of shocks experienced* and *heart failure severity*. Healthcare professionals were more likely to discuss deactivation when the patient was of an advanced age (p=0.01), had a history

of bowel cancer ($p<0.01$), more than three hospital admissions over the preceding twelve months ($p<0.01$), receipt of multiple shocks ($p<0.01$), and experienced severe (NYHA IV) heart failure symptoms ($p<0.01$).

The relationship between the nine independent variables and professional confidence was found to be significant ($p<0.01$), however it could only explain 1% of the variance (Adjusted R^2 =0.013). Three factors had a significant impact, with healthcare professionals more confident in decision-making when the patient had a *previous in-depth discussion* on deactivation ($p=0.04$), experienced *severe heart failure* ($p=0.02$) or *he/she lived with and was supported by family in healthcare decisions* ($p=0.03$). Table 4 outlines the relationship between independent variables and dependent variables.

Table 4: Independent Variables & Professional Characteristics with Dependent Variables (n=262)

Independent & Professional variables	Levels	Likelihood to discuss deactivation M±SD	Confidence in the decision made M±SD
Patient age	39 yrs 59 yrs 75 yrs 86 yrs	5.99 ± 3.29 6.37± 3.13 6.96± 3.05 7.36 ± 2.96 (p=0.01)	Not significant
Comorbidities	Bowel cancer Renal failure Dementia	7.38± 2.8 (p<0.01) 6.78 ± 3.04 5.96 ± 3.38	Not significant
Number of Admissions	No admissions 1 admission >3 admissions	Not significant	Not significant
Number of shocks experienced	No experience of shock Experienced >1 shock Experienced multiple shocks	6.11 ± 3.18 6.60 ± 3.10 6.95 ± 3.20 (p<0.01)	No significant
Heart Failure severity	NYHA II NYHA III NYHA IV	5.69 ± 3.21 6.44 ± 3.12 7.48 ± 2.95 (p<0.01)	8.17 ± 2.35 8.28 ± 2.34 8.54 ± 2.28 (p=0.02)
Previous Discussion	No previous discussion Brief previous discussion Previous in-depth discussion	Not significant	8.26 ± 2.41 8.17 ± 2.30 8.57 ± 2.24 (p=0.04)
Social support	Lives alone Lives alone with support Lives with family who share decisions	Not significant	8.15 ± 2.39 8.36 ± 2.27 8.50 ± 2.31 (p=0.03)
Country of Origin	Ireland & Europe UK US	6.33 ± 3.150 6.41 ± 3.07 7.32 ± 3.50 (p<0.01)	8.39 ± 2.19 8.07 ± 2.35 9.19 ± 2.26 (p<0.01)
Discipline	Medical Nursing Healthcare Science	6.88 ± 3.35 (p=0.04) 6.63 ± 3.08 5.46 ± 3.20	8.98 ± 1.96 (p=0.02) 8.14 ± 2.45 8.17 ± 2.06
Times initiated discussion	1-10 times 10-25 times Multiple	6.47 ± 3.02 6.88 ± 3.25 7.93 ± 3.31 (p<0.01)	8.36 ± 2.21 8.69 ± 2.08 9.90 ± 1.39 (p<0.01)
Time in Current role	<1 year 1-5 years 6-10 years	Not significant	7.84 ± 2.33 8.08 ± 2.25 8.43 ± 2.35

	>10 years		8.47 ± 2.36 (*p*=0.03)
Gender	Male	Not significant	8.84 ± 1.98 (*p*<0.01)
	Female		8.15 ± 2.43
Ethical or legal concerns	Yes	Not significant	7.85 ± 2.64
	No		8.41 ± 2.28 (*p*=0.01)

[ANOVA posthoc with adjusted p values]

Professional factors that impact perceived likelihood and confidence to discuss ICD deactivation
Six healthcare professional characteristics, namely country of origin, gender, discipline, time in current role, times initiated a deactivation discussion, ethical and legal concerns explained 3% of variance (Adjusted R^2 =0.026) in likelihood of discussing deactivation. Variables of *country of origin, discipline* and *times initiated deactivation discussion* had a significant impact (*p*<0.01), for example, healthcare professionals were more likely to discuss deactivation if American (*p*<0.01), being a physician (*p*=0.04) and had initiated a discussion concerning deactivation on multiple occasions (*p*<0.01). Mean results of likelihood to discuss and professional characteristics are graphically displayed in Figure 2.

Figure 2: Professional Characteristics and likelihood to discuss deactivation (n=262)
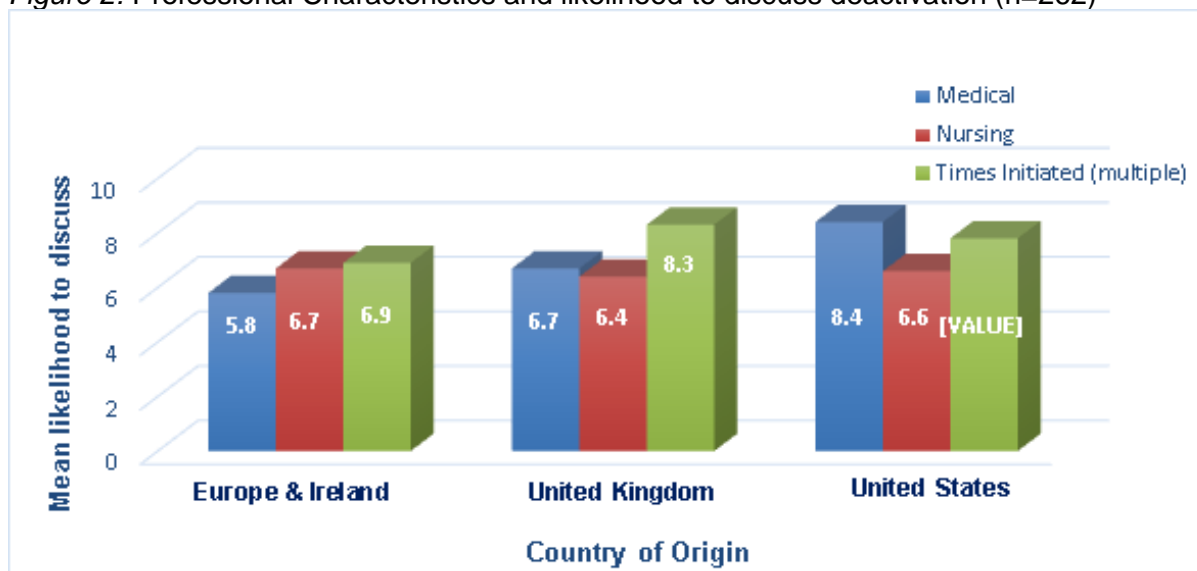
The six professional characteristics explained 6% (Adjusted R^2=0.055) of the variance, with all six factors significantly impacting (*p*<0.01) professionals' confidence. For example, male healthcare professionals (*p*<0.01), professionals who were American (*p*<0.01), being a physician (*p*=0.02), more than six years in current post (*p*=0.03), initiated a deactivation discussion on multiple occasions (p<0.01), and have no ethical or legal concerns (*p*=0.01) were more confident in their decision making (Refer to Table 4). Mean results of confidence in decision made and professional characteristics are graphically presented in Figure 3.

Figure 3: Professional Characteristics and confidence in decision (n=262)
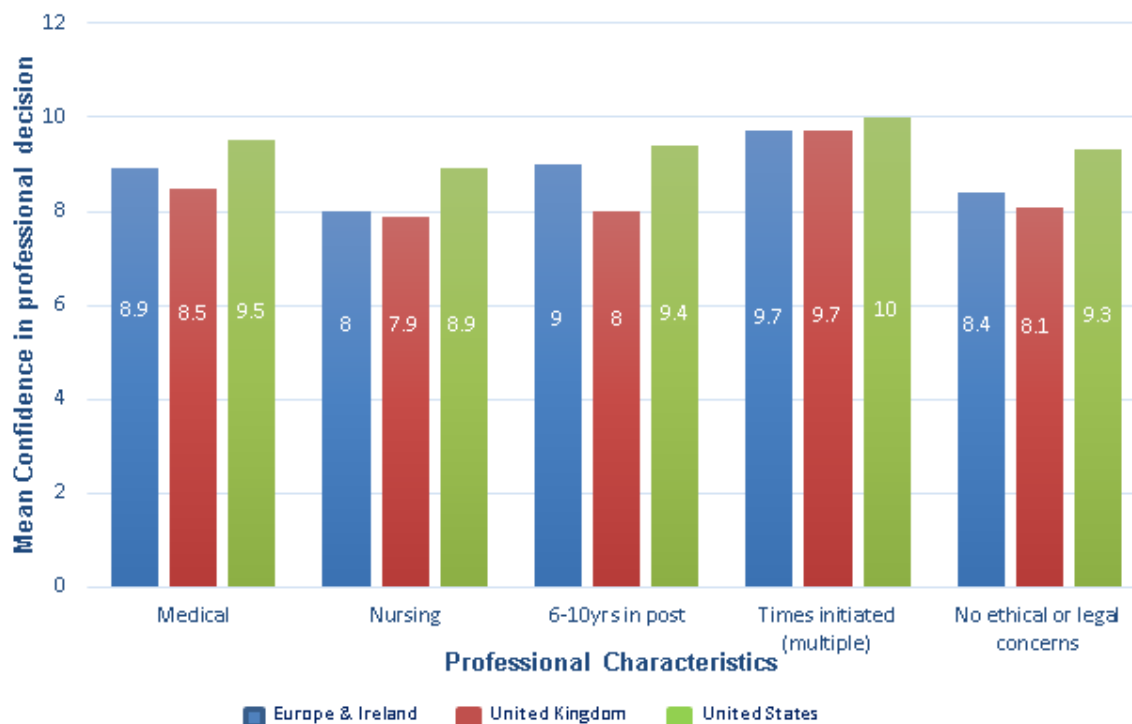
Discussion

This study's unique methodology, through the random manipulation of patient-related factors aimed to confidently extrapolate their influence on clinical decision-making. Results illustrate a number of disparities in clinical practice[2], despite international guideline recommendations[20,21,22]. Five patient-related factors and three healthcare professional factors influenced the likelihood that ICD deactivation would be discussed. The percent of variance predicted by our regression models was small, however on comparison to similar published factorial studies[23,24] confidence can be placed on our findings. Physicians and more specifically cardiologists, accepted the responsibility to discuss and decide whether to deactivate an ICD, more than nurses. Finally, there was a consensus of agreement among healthcare professionals on the need to more actively include patients and family members in discussions and decisions that affect care.

Cross country variation
The study confirmed professional practice was influenced by several key clinical indicators, which support and extend published findings of a professional survey conducted by Marinskis and van Erven (2010)[25]. Their study examined professional attitudes from 47 centres of the European Heart Rhythm Association's (EHRA) research network and found 83% would consider deactivation if the patient was experiencing multiple shocks, however only 4% of professionals routinely discussed deactivation. The reluctance to discuss palliative issues varies internationally, as illustrated in the study by Voohees et al.[26]. Just under half of Italian physicians (43%) would not inform competent patients of their prognosis, compared to most Swedish physicians (89%). In addition, physicians in Belgium (89%) were more likely ($p<0.01$) to disclose information to next of kin, compared to Dutch physicians (48%). In contrast, a survey of Dutch and Swedish nurses (n=275) found Dutch nurses more willing to discuss prognosis in comparison to Swedish nurses ($p<0.01$)[4]. Finally a British study found 53% (n=23) of dying patients with an ICD had a discussion about prognosis, with a third (n=17) of these discussions broaching the subject of deactivation[1].

This study found American physicians and nurses were more apt to discuss deactivation in comparison to European colleagues, a result that both supports[27] and conflicts[28] with previous

evidence. An American study by Kelley et al.[27] surveyed 558 physicians and found when presented with five clinical scenarios, more than half (56% - 83%) would initiate a discussion concerning deactivation. In contrast, Dunlay et al.[28] reported a majority (52%; n=49) of physicians would hesitate to discuss palliative issues. Reasons included personal discomfort (11%), fear of destroying hope (9%), or lack of time (8%). In this study the majority of professionals had no ethical or legal concerns[29], however the minority who had (13%) were less confident in decision-making. There is increasing evidence that nurses[30] and physicians[31] can experience moral distress, with a detrimental impact on clinical care. Moral distress is the result of perceived aggressive or "futile" care, therefore highlighting the need for additional support for professionals when managing dying patients with an ICD.

In summary, there was cross country variation in healthcare professionals' decision to discuss ICD deactivation, as evident in this study and the published literature[26,27].

Medical dominance of the final decision
The discipline with highest representation within the sample was nursing (65%, n=168), indicating their predominance in clinical settings, high level of involvement with patients with an ICD and increased willingness to participate in the survey[32,33]. Specialist nurses were patients' main professional support, possessing evidence-based knowledge and skills to address palliative concerns[4]. This is reflected in our results whereby most professionals (81%, n=215) felt specialist nurses had the necessary attributes to initiate a discussion about deactivation. The data however does expose a lack of nursing contribution to the final decision concerning deactivation, as only 30% (n=50) of nurses within the sample reported previous involvement. This could be explained by the structure of the healthcare system[34] and the traditional role of physicians to diagnose and make treatment decisions. In addition, it may also be explained by the findings illustrated in **Figure 1,** whereby nurses perceived the best time to discuss deactivation was prior to implant and not when the patient required palliative care, the reverse attitude compared to physicians. Specialist nurses through nurse-based clinics can however play a key role in the effective management of patients with a cardiac device[35].

Generalised reluctance to discuss palliative issues, such as deactivation is well recognised across all clinical settings and professions. Potential solutions have been suggested including additional training[4,26], with improved knowledge and skills acquisition[27]. An alternative strategy is clarification of roles and sharing of the responsibility concerning deactivation, facilitated by a multidisciplinary team approach. This approach has been successfully implemented within the oncology setting, as patients receiving care from a multidisciplinary team showed an improved survival [36], better patient experience and quality of life[37].

In summary, our study indicates that the current practice of discussing and deactivating an ICD is predominantly a task performed by physicians with minor input from specialist nurses. A paradigm shift toward a team-based approach, as routinely used in oncology and palliative medicine, is advocated.

Improved inclusion of patients and carers
The healthcare professionals in this study agreed that patients should be informed about deactivation prior to implant and periodically during the disease trajectory, as per clinical guidelines[21]. Furthermore, the decision to deactivate an ICD was deemed to require agreement between the cardiologist, patient and his/her family. Healthcare professionals were more confident being involved in such decisions when the patient initiates the conversation ($M = 9.70 \pm 2.03$) and/or has the support of family ($p=0.014$). Many professionals value shared decision-making within clinical practice, which required the relay of accurate and timely information to ensure individual patient's preferences inform treatment choices. Indeed, studies have shown that patients with an ICD have diverse preferences to discuss ICD deactivation[14]. The scientific statement published by the American Heart Association[36] provided a "roadmap" to guide discussions and enable shared decision-making, proven to restore hope and control over illness experience as perceived by patients and families[39]. Despite studies advising involvement of the family to provide patients' psychological support and in some cases to act as surrogate decision-makers, there is limited evidence of its application in practise. For example, a

recent retrospective case note review found only 32% of all palliative discussions had family involvement[1].

Results of a survey carried out on Belgium and Scandinavian nurses (n=425) may provide an explanation – while nurses recognised the patient's family as important to their care, they were reluctant to actively invite family members to be involved in the care of the patient[40] and 20% agreed with the statement "I do not have time to take care of families". Interestingly the more experienced nurse and those nurses from Scandinavian countries possessed a more positive attitude. In summary, improved patient and family involvement in patients' management plan is warranted to facilitate shared clinical decision-making through the delivery of patient-centred information and discussion.

Limitations of the study include the diverse representation across countries and disciplines, as well as the data collection tool. A number of strategies were used to promote recruitment, the most effective being a personalised email sent by members of the research team. The innovative survey instrument engaged participants as there was a complete dataset from all professionals who commenced the survey. Despite scrupulous preparation and refinement, the nine independent variables only explained 10% of the variance for likelihood to discuss deactivation and 3% of variance concerning professionals' confidence. Similar effect sizes have been reported in previous professional factorial surveys[23,24]. It is be acknowledged that the nine variables selected may not truly reflect those, perhaps more implicit factors professionals' base their decision whether to discuss deactivation on. Nevertheless results strengthen our opinion that healthcare professionals make clinical decisions based on a multitude of factors and which could be deemed idiosyncratic.

Conclusion

Decision-making regarding ICD deactivation is complex, multifactorial with lack of a coherent multidisciplinary approach to practise internationally. The cross-country variation in attitudes and decision-making sparks concern, and confirms that further investigation is warranted on the socio-cultural issues and interesting interprofessional differences, which may have a bearing on the overall European reluctance to initiate a discussion leading to ICD deactivation compared to American counterparts. Furthermore, ICD deactivation is an important clinical issue for patients and carers, with our findings supporting the value of additional research and development on the regulatory and medico-legal considerations of this clinical decision. Nurses play an important role in the care of patients with advanced heart disease and their families. Our findings indicate that the nurses' role in supporting effective decision making requires improvement. Advanced communication training and clinical mentorship would aid knowledge and skills to ultimately improve the care and reduce suffering of palliative patients with an ICD.

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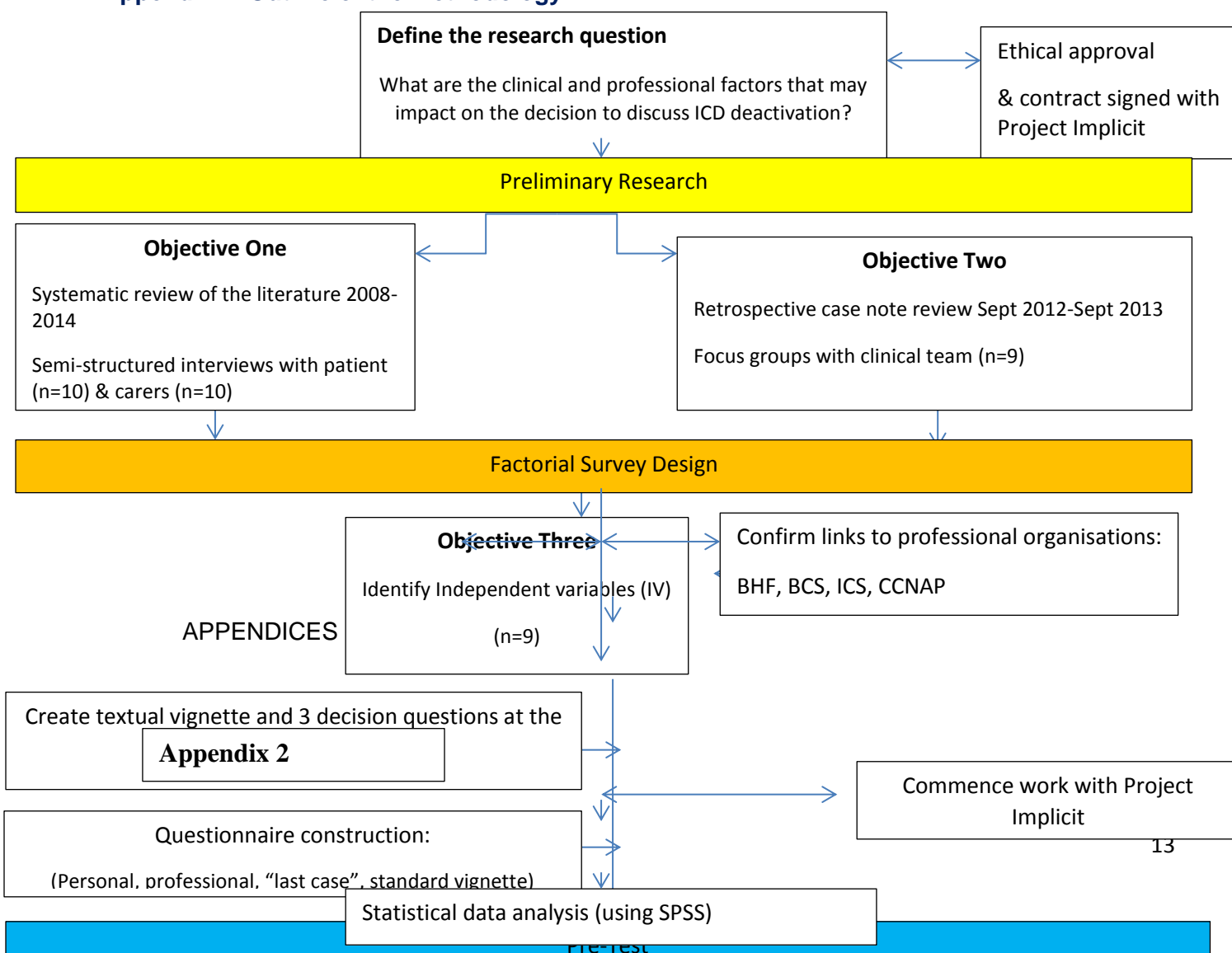
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Hill L, McIlfatrick S, Taylor BJ, Jaarsma T, Moser D, Slater P, McAloon T, Dixon L, Donnelly P, Stromberg A & Fitzsimons D (2018) Patient and professional factors that impact the perceived likelihood and confidence of healthcare professionals to discuss Implantable Cardioverter Defibrillator deactivation in advanced heart failure: results form an international factorial survey. *Journal of Cardiovascular Nursing*, *33*(6), 527-535.

Table 5: What's new and implications for practice

What's new?	Implications for Practice
1: Five patient factors- 'Advanced age, presence of malignancy, more than 3 hospital admissions over previous year, receipt of multiple shocks, severe heart failure symptoms (NYHA IV)' increased professional's likelihood to discuss ICD deactivation.	1: A multidisciplinary approach is necessary to improve the clinical management of the discussion and decision concerning ICD deactivation.
2: The practise of discussing ICD deactivation varies across countries with American, medical and nursing professionals were more likely to discuss ICD deactivation, in comparison to their European colleagues	2: Innovative educational strategies should be developed to improve patients' and family members' understanding of the functionality of the ICD
3: Nurses are reluctant and lacked confidence in discussing ICD deactivation compared to physicians.	3: Additional training and support required for nurses to improve involvement in palliative discussions that include ICD deactivation

Appendix 1: Outline of the methodology

Define the research question

What are the clinical and professional factors that may impact on the decision to discuss ICD deactivation?

Ethical approval
& contract signed with Project Implicit

Preliminary Research

Objective One

Systematic review of the literature 2008-2014

Semi-structured interviews with patient (n=10) & carers (n=10)

Objective Two

Retrospective case note review Sept 2012-Sept 2013

Focus groups with clinical team (n=9)

Factorial Survey Design

Objective Three

Identify Independent variables (IV)

(n=9)

Confirm links to professional organisations:

BHF, BCS, ICS, CCNAP

APPENDICES

Create textual vignette and 3 decision questions at the

Appendix 2

Commence work with Project Implicit

Questionnaire construction:

(Personal, professional, "last case", standard vignette)

Statistical data analysis (using SPSS)

Pre-Test

Hill L, McIlfatrick S, Taylor BJ, Jaarsma T, Moser D, Slater P, McAloon T, Dixon L, Donnelly P, Stromberg A & Fitzsimons D (2018) 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 form an international factorial survey. *Journal of Cardiovascular Nursing*, *33*(6), 527-535.

Survey: 1/23

Please answer some questions about your professional characteristics.

Next

Decline to answer

Survey: 2/23

Country of origin:

Select your answer by clicking on it once (it will turn yellow).
You can change your answer by selecting another option.
To confirm, click the selected (yellow) button a second time.

Ireland
United Kindom
Europe
USA

Decline to answer

Survey: 4/23

Gender:

Male
Female

Decline to answer

Survey: 5/23

Age:

[   ]

Next

Decline to answer

Survey: 6/23

Discipline:

Medical
Nursing
Healthcare Science (Cardiac Physiologist)

Decline to answer

Survey: 7/23

Current Role:

Cardiologist
Electro-physiologist
Specialist Heart Failure nurse
Cardiac Physiologist
Other

Decline to answer

Survey: 9/23

Time in current role:

| <1 year |
| 1-5 years |
| 6-10 years |
| >10 years |

Decline to answer

Survey: 10/23

Next, please answer some questions about your organisational characteristics.

Next

Decline to answer

Survey: 11/23

Has your organisation a ICD deactivation policy?

| Yes |
| No |
| Don't know |

Decline to answer

Survey: 12/23

What professional(s) should initiate a discussion concerning deactivation with the patient? (Tick all that apply)

| Cardiologist |
| General Practitioner |
| Primary disease consultant |
| Specialist Nurse |
| Cardiac Physiologist |
| Other |

Finished and continue

To select an option, click on a button, and it will turn BLUE.
To unselect, click it once more.
When you are done selecting all the applicable options, click on the "Finished and continue" button.
The Finished button will turn YELLOW and you can confirm by clicking it a second time.

Decline to answer

Survey: 13/23

If other, please specify.

Next

Decline to answer

Survey: 14/23

In your experience who should make the final decision regarding ICD deactivation?

| Lead professional |
| Patient |
| Lead professional with the patient |
| Family/partners |
| Lead professional with patient and family/partner |

Decline to answer

15

Survey: 15/23

Next, please answer some questions about experiential factors on ICD deactivation.

Next

Decline to answer

Survey: 16/23

During your professional career have you initiated a discussion with a patient or family member about ICD deactivation?

Yes
No

Decline to answer

Survey: 18/23

How often have you made the decision to deactivate a patients ICD?

Never
1-5 times
6-10 times
More than 10 times

Decline to answer

Survey: 19/23

Have you any ethical, legal or religious concerns about ICD deactivation?

Yes
No

Decline to answer

Survey: 21/23

How would you feel about initiating a conversation about ICD deactivation with a patient who is reluctant to discuss end of life issues?

Uncomfortable 0
1
2
3
4
5
6
7
8
9
Relaxed 10

Decline to answer

Hill L, McIlfatrick S, Taylor BJ, Jaarsma T, Moser D, Slater P, McAloon T, Dixon L, Donnelly P, Stromberg A & Fitzsimons D (2018) 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 form an international factorial survey. *Journal of Cardiovascular Nursing*, *33*(6), 527-535.

In which clinical settings should ICD deactivation be discussed with the patient? (Tick all that apply)

| Prior to device implantation |
| When there has been deterioration in the patients health |
| End of life |

| Finished and continue |

To select an option, click on a button, and it will turn BLUE.
To unselect, click it once more.
When you are done selecting all the applicable options, click on the "Finished and continue" button.
The Finished button will turn YELLOW and you can confirm by clicking it a second time.

| Decline to answer |

You are going to read about 7 patient profiles. Please answer two questions for each of them.

| Next |

| Decline to answer |

Profile 1:

You review a 39 year old man with mild heart failure (NYHA II). He has had no admissions over the past year and no experience of a shock. Medical records show no previous discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives with family who share healthcare decisions.

What is the likelihood that you would discuss ICD deactivation with this patient?

| Not at all likely 0 |
| 1 |
| 2 |
| 3 |
| 4 |
| 5 |
| 6 |
| 7 |
| 8 |
| 9 |
| Very likely 10 |

| Decline to answer |

Hill L, McIlfatrick S, Taylor BJ, Jaarsma T, Moser D, Slater P, McAloon T, Dixon L, Donnelly P, Stromberg A & Fitzsimons D (2018) 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 form an international factorial survey. *Journal of Cardiovascular Nursing*, *33*(6), 527-535.

Profile 1:

You review a 39 year old man with mild heart failure (NYHA II). He has had no admissions over the past year and no experience of a shock. Medical records show no previous discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives with family who share healthcare decisions.

How confident are you in the decision you have just made?

Not at all confident 0
1
2
3
4
5
6
7
8
9
Very confident 10

Decline to answer

Profile 2:

You review a 86 year old man with moderate heart failure (NYHA III) and advanced renal failure. The patient has had no admission over the past year and no experience of a shock. Medical records show a previous in-depth discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives with a family member who shares healthcare decisions.

What is the likelihood that you would discuss ICD deactivation with this patient?

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

Profile 2:

You review a 86 year old man with moderate heart failure (NYHA III) and advanced renal failure. The patient has had no admission over the past year and no experience of a shock. Medical records show a previous in-depth discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives with a family member who shares healthcare decisions.

How confident are you in the decision you have just made?

Not at all confident 0
1
2
3
4
5
6
7
8
9
Very confident 10

Decline to answer

18

Hill L, McIlfatrick S, Taylor BJ, Jaarsma T, Moser D, Slater P, McAloon T, Dixon L, Donnelly P, Stromberg A & Fitzsimons D (2018) 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 form an international factorial survey. *Journal of Cardiovascular Nursing, 33*(6), 527-535.

Profile 3:

You review a 39 year old patient with mild heart failure (NYHA II) and dementia. The patient has had 1 admission over the past year and has experienced multiple shocks. Medical records show a brief discussion in the past about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives alone and receives support from family and friends.

What is the likelihood that you would discuss ICD deactivation with this patient?

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

Profile 3:

You review a 39 year old patient with mild heart failure (NYHA II) and dementia. The patient has had 1 admission over the past year and has experienced multiple shocks. Medical records show a brief discussion in the past about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives alone and receives support from family and friends.

How confident are you in the decision you have just made?

Not at all confident 0
1
2
3
4
5
6
7
8
9
Very confident 10

Decline to answer

Profile 4:

You review a 75 year old man with severe heart failure (NYHA IV) and advanced renal failure. The patient has had no admission over the past year and has experienced more than 1 shock. Medical records show no previous discussion about deactivation with documented management plan to continue present treatment. The patient lives alone and receives support from family and friends.

What is the likelihood that you would discuss ICD deactivation with this patient?

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

8/22

Profile 4:

You review a 75 year old man with severe heart failure (NYHA IV) and advanced renal failure. The patient has had no admission over the past year and has experienced more than 1 shock. Medical records show no previous discussion about deactivation with documented management plan to continue present treatment. The patient lives alone and receives support from family and friends.

How confident are you in the decision you have just made?

Not at all confident 0
1
2
3
4
5
6
7
8
9
Very confident 10

Decline to answer

9/22

Profile 5:

You review a 59 year old patient with severe heart failure (NYHA IV) and advanced renal failure. The patient has had 1 admission over the past year and has experienced multiple shocks. Medical records show no previous discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives alone and receives support from family and friends.

What is the likelihood that you would discuss ICD deactivation with this patient?

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

20

Profile 5:

You review a 59 year old patient with severe heart failure (NYHA IV) and advanced renal failure. The patient has had 1 admission over the past year and has experienced multiple shocks. Medical records show no previous discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives alone and receives support from family and friends.

How confident are you in the decision you have just made?

Not at all confident 0
1
2
3
4
5
6
7
8
9
Very confident 10

Decline to answer

Profile 6:

You review a 59 year old woman with moderate heart failure (NYHA III) . The patient has had more than 3 admissions over the past year and no experience of a shock. Medical records show a previous in-depth discussion about deactivation with documented management plan to continue present treatment. The patient lives alone with no family or friends.

What is the likelihood that you would discuss ICD deactivation with this patient?

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

Profile 6:

You review a 59 year old woman with moderate heart failure (NYHA III) . The patient has had more than 3 admissions over the past year and no experience of a shock. Medical records show a previous in-depth discussion about deactivation with documented management plan to continue present treatment. The patient lives alone with no family or friends.

How confident are you in the decision you have just made?

Not at all confident 0
1
2
3
4
5
6
7
8
9
Very confident 10

Decline to answer

Profile 7:

You review a 86 year old woman with mild heart failure (NYHA II) and dementia. The patient has had no admission over the past year and has experienced multiple shocks. Medical records show no previous discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives alone and receives support from family and friends.

What is the likelihood that you would discuss ICD deactivation with this patient?

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

Profile 7:

You review a 86 year old woman with mild heart failure (NYHA II) and dementia. The patient has had no admission over the past year and has experienced multiple shocks. Medical records show no previous discussion about deactivation with documented management plan being to refer for further cardiac investigations. The patient lives alone and receives support from family and friends.

How confident are you in the decision you have just made?

Not at all confident 0
1
2
3
4
5
6
7
8
9
Very confident 10

Decline to answer

On a scale of 0-10, how likely would you be to refer the patient for deactivation of ICD in the following instances?
a. When the patient requests comfort care only

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

22

Hill L, McIlfatrick S, Taylor BJ, Jaarsma T, Moser D, Slater P, McAloon T, Dixon L, Donnelly P, Stromberg A & Fitzsimons D (2018) 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 form an international factorial survey. *Journal of Cardiovascular Nursing*, *33*(6), 527-535.

On a scale of 0-10, how likely would you be to refer the patient for deactivation of ICD in the following instances?

b: When you believe the patient has less than 12 months to live

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

On a scale of 0-10, how likely would you be to refer the patient for deactivation of ICD in the following instances?

c: When the patient has been seen by palliative care

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

On a scale of 0-10, how likely would you be to refer the patient for deactivation of ICD in the following instances?

d: When the patient has extreme anxiety about the ICD and requests deactivation

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

On a scale of 0-10, how likely would you be to refer the patient for deactivation of ICD in the following instances?

e: When a DNR is being actioned

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

On a scale of 0-10, how likely would you be to refer the patient for deactivation of ICD in the following instances?

f: When the patient has sustained >10 shocks in 24 hour period

Not at all likely 0
1
2
3
4
5
6
7
8
9
Very likely 10

Decline to answer

Can you give a brief example from a recent clinical case in which you considered ICD deactivation?

Patient characteristics: age, co-morbidities, DNA order
Context: where the discussion took place, patient wishes, family involvement
Decision made:deactivated or active
Rationale:

Next

Decline to answer

Are there any other factors, not included within the vignettes, that you feel are important in the deactivation decision? Please specify.

Next

Decline to answer