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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

Loreena Hill, PhD; Sonja McIlfattrick, PhD; Brian J. Taylor, PhD; Tiny Jaarsma, PhD; Debra Moser, PhD; Paul Slater, PhD; Toni McAloon, PhD; Lana Dixon, MD; Patrick Donnelly, MD; Anna Stromberg, PhD; Donna Fitzsimons, PhD

Background: Rate of implantable cardioverter defibrillator (ICD) implantations is increasing in patients with advanced heart failure. Despite clear guideline recommendations, discussions addressing deactivation occur infrequently. Aim: The aim of this article is 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 a demographic questionnaire and clinical vignettes. Each vignette had 9 randomly manipulated and embedded patient-related factors, considered as independent variables, providing 1572 unique vignettes for analysis. These factors were determined through synthesis of a systematic literature review, a retrospective case note review, and a qualitative exploratory study. Results showed that most healthcare professionals agreed that deactivation discussions should be initiated by a cardiologist (95%, n = 255) or a specialist nurse (81%, n = 215). In terms of experience, 84% of cardiologists (n = 53) but only 30% of nurses (n = 50) 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 of 9 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 3 hospital admissions during the previous year. Furthermore, nationality and discipline significantly influenced likelihood and confidence in decision making. Conclusions: Guidelines recommend that healthcare professionals discuss ICD deactivation; however, practice is suboptimal with multifactorial factors impacting on decision making. The role and responsibility of nurses in discussing deactivation require clarity and improvement.

KEY WORDS: decision making, defibrillators, heart failure, implantable, survey, terminal care

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There is a gap between guideline recommendations and everyday clinical practice concerning implantable cardioverter defibrillator (ICD) deactivation. Increasing rates of ICD implantation and an improved life expectancy, with many older adults living with comorbidities, intensify the need for clarity on the role of the ICD in the advanced stages of any illness. A recent study found that 1 in 4 patients received futile and painful shocks from the device shortly before death. Many factors are implicated including patients’ lack of knowledge on the device and deactivation, their life-saving perception of the ICD, and the dialogue about deactivation characterized as “too little, too late.”

International and interdisciplinary discrepancies exist on who should discuss deactivation and when such discussions should occur. In a survey of 384 Heart Rhythm Society members, deactivation was considered by most professionals questioned to be permissible if aligned with the patient (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. In a recent position statement from the Council on Cardiovascular Nursing and Allied Professionals, the varied role of healthcare professionals across Europe was highlighted, 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**

The aim of this study is to explore patient and professional factors that impact perceived likelihood and confidence of healthcare professionals to discuss ICD deactivation.

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**Methodology**

**Design**

This cross-sectional, factorial-design study conformed to the Declaration of Helsinki and was approved by the local research ethics committee. Originally developed by Rossi and Nock (1982), 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, indicators of acute deterioration, and nurses’ judgment of self-neglect. Through a systematic and iterative process, 21 factors associated with ICD deactivation were generated from a systematic literature review, a retrospective case note review, and qualitative exploration (Supplemental Digital Content 1, http://links.lww.com/JCN/A57). These factors were repeatedly reviewed and refined by 4 methodological and 3 clinical experts for content validity, until there were 9 orthogonal and clinically relevant patient-related factors or variables 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 and a standard vignette, followed by 6 unique clinical vignettes (Supplemental Digital Content 2, http://links.lww.com/JCN/A58).

**Questionnaire**

Demographic and experiential data were collected. Healthcare professionals were presented with short statements and asked to record on a 0-to-10 Likert scale the probability of referral for ICD deactivation. A score of 0 indicated that the patient would not be referred, whereas a score of 10 indicated that the healthcare professional would refer for deactivation.

**Factorial Survey**

The 9 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 3 and 5 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 6 unique vignettes, in which the 9 evidence-based factors had been randomly allocated. Participants’ responses to vignettes were captured by 2 dependent variables (refer to Table 1). A total of 200 vignettes were checked by the researcher (L.H.) before a pretest with 10 healthcare professionals.
with clinical experience of patients with an ICD. This determined time to complete the survey and content validity.

Sample

Access to a convenience sample of healthcare professionals involved in the daily management of patients with an ICD was facilitated through professional organizations, for example, Irish Cardiac Society (n = 350), British Society of Heart Failure (n = 921), and Council on Cardiovascular Nursing and Allied Professionals (n = 2900). The survey was promoted on websites and 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 et al\(^1\) informed the analysis, which was conducted at 2 levels, “patient factors or independent variables” (within vignettes) followed by “professional factors” (questionnaire), with significance at \(P \leq .05\). The recommended analysis for factorial surveys\(^2\) is multivariate regression and analysis of variance (ANOVA), which examines the relationship between each independent variable and each 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\(^3\) was conducted, and \(P\) values were recalibrated accordingly.

Results

A total of 457 international professionals accessed the web link; 262 completed the survey (57% completion rate), which included a questionnaire, a standard vignette, and 6 unique vignettes (1834 total vignettes, 1572 unique vignettes).

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 6 years (70%, n = 182) of experience. Demographic details are presented in Table 2.

Attitude Toward 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 most nurses (96%, n = 163). Four British nurses, 2 American nurses, and 1 nurse from Europe believed that the discussion could be initiated by a specialist nurse. Healthcare professionals agreed that deactivation should be discussed—before 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 favor of discussing ICD deactivation before implantation, compared with physicians (73%, n = 46). In contrast, a higher percentage of physicians stated that ICD deactivation should be discussed when patient's care becomes palliative (86%, n = 54), compared with nurses (76%, n = 151). The presence of a deactivation policy was not associated with the likelihood of discussing deactivation \((P = .8)\); however, healthcare professionals were more confident in making this decision when a deactivation policy was present \((P = .03)\).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>193 (74)</td>
</tr>
<tr>
<td>Medical</td>
<td>63 (24)</td>
</tr>
<tr>
<td>Disciplines</td>
<td></td>
</tr>
<tr>
<td>Nursing</td>
<td>170 (65)</td>
</tr>
<tr>
<td>Medical</td>
<td>63 (24)</td>
</tr>
<tr>
<td>Cardiac physiologist (technician)</td>
<td>29 (11)</td>
</tr>
<tr>
<td>Current role</td>
<td></td>
</tr>
<tr>
<td>Specialist nurse</td>
<td>150 (57)</td>
</tr>
<tr>
<td>Cardiologist</td>
<td>46 (18)</td>
</tr>
<tr>
<td>Cardiologist</td>
<td>29 (11)</td>
</tr>
<tr>
<td>Other (ie, general nurse/physician, physiotherapist)</td>
<td>24 (9)</td>
</tr>
<tr>
<td>Electrophysiologist</td>
<td>13 (5)</td>
</tr>
<tr>
<td>Time in current role, y</td>
<td></td>
</tr>
<tr>
<td>&lt;1</td>
<td>11 (4)</td>
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<tr>
<td>1–5</td>
<td>68 (26)</td>
</tr>
<tr>
<td>6–10</td>
<td>59 (23)</td>
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<tr>
<td>&gt;10</td>
<td>123 (47)</td>
</tr>
</tbody>
</table>

### Table 1: Example of a Clinical Vignette and 2 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?

Clinical factors or independent variables are in italics.
Most 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 with American colleagues (P = .36).

Experience of Involvement in the Deactivation Decision

Nearly all healthcare professionals (97%, n = 255) stated that 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% of physicians (n = 53) previously involved in an ICD deactivation decision, compared with approximately one-third of nurses (30%, n = 50) and 14% of cardiac physiologists (n = 4).

Healthcare professionals ranked their likelihood to refer patients for deactivation based on 6 clinical statements. Mean values for each statement are documented in Table 3. Results indicate that healthcare professionals are more likely to consider deactivation when a “do not resuscitate” order is placed or when the patient requests comfort care.

Factorial Survey

A total of 262 participants reported on 1 standard and 6 randomly generated vignettes, generating 1834 vignettes for analysis. Responses to the standard vignette were consistent for both outcome variables—“likelihood of discussing deactivation” (mean [SD], 2.60 [2.11]) and “confidence in the decision made” (mean [SD], 7.96 [2.8]). The standard vignette was not included in further analysis, rendering 1572 unique vignettes for multiple regression and ANOVA. False discovery rate analysis found that 1 variable—“number of admission” (P = .04) —which when the P value was adjusted, was no longer significant (P = .07) (refer to Table 4).

Patient Factors That Impact Perceived Likelihood and Confidence to Discuss Implantable Cardioverter Defibrillator Deactivation

The 9 independent variables explained 10% of the variance (adjusted R² = 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 = .01), had a history of bowel cancer (P < .01), had more than 3 hospital admissions over the preceding 12 months (P < .01), had receipt of multiple shocks (P < .01), and experienced severe (New York Heart Association class IV) heart failure symptoms (P < .01).

The relationship between the 9 independent variables and professional confidence was found to be significant (P < .01); however, it could only explain 1% of the variance (adjusted R² = 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 = .04), experienced severe heart failure (P = .02), or lived with and was supported by family in healthcare decisions (P = .03). Table 4 outlines the relationship between independent variables and dependent variables.

Professional Factors That Impact Perceived Likelihood and Confidence to Discuss Implantable Cardioverter Defibrillator Deactivation

Six healthcare professional characteristics, namely, country of origin, gender, discipline, time in current role, times initiated a deactivation discussion, and ethical and legal concerns, explained 5% of the variance (adjusted R² = 0.026) in likelihood of discussing deactivation. Variables of country of origin, discipline, and times initiated deactivation discussion had a significant impact (P < .01); for example, healthcare professionals were more likely to discuss deactivation if they were American (P < .01) or physicians (P = .04) and had initiated a discussion concerning deactivation on multiple occasions (P < .01). Mean results of likelihood to discuss and professional confidence are graphically displayed in Figure 2.

![FIGURE 1. Percentage of healthcare professionals recommending discussion at 3 time points (N = 262).](image)
The 6 professional characteristics explained 6% (adjusted $R^2 = 0.055$) of the variance, with all 6 factors significantly impacting ($P < .01$) professionals’ confidence. For example, male healthcare professionals ($P < .01$), professionals who were American ($P < .01$), and those who were physicians ($P = .02$), with more than 6 years in the current post ($P = .03$), who initiated a deactivation discussion on multiple occasions ($P < .01$), and who have no ethical or legal concerns ($P = .01$) 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.

**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, despite international guideline recommendations. Five patient-related factors and 3 healthcare professional factors influenced the likelihood that ICD deactivation would be discussed. The percentage of variance predicted by our regression models was small; however, in comparison with similar published factorial studies, 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 that professional practice was influenced by several key clinical indicators, which support and extend published findings of a professional survey conducted by Marinskis et al²⁵ (2010). Their study examined professional attitudes from 47 centers of the European Heart Rhythm Association's research network and found that 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 Only less than half of Italian physicians (43%) would not inform competent patients of their prognosis, compared with most Swedish physicians (89%). In addition, physicians in Belgium (89%) were more likely (P < .01) to disclose information to next of kin, compared with Dutch physicians (48%). In contrast, a survey of Dutch and Swedish nurses (n = 275) found that Dutch nurses were more willing to discuss prognosis in comparison with Swedish nurses (P < .01).⁴ Finally, a British study found that 53% of dying patients with an ICD (n = 23) had a discussion about prognosis, with a third of these discussions (n = 17) broaching the subject of deactivation.¹

This study found that American physicians and nurses were more apt to discuss deactivation in comparison with European colleagues, a result that both supports²⁷ and conflicts²⁸ with previous evidence. An American study by Kelley et al²⁷ surveyed 558 physicians and found that, when presented with 5 clinical scenarios, more than half (56%–83%) would initiate a discussion concerning deactivation. In contrast, Dunlay et al²⁸ reported that most physicians (52%, n = 49) would hesitate to discuss palliative issues. Reasons included...
personal discomfort (11%), fear of destroying hope (9%), or lack of time (8%). In this study, most professionals had no ethical or legal concerns; however, the minority who had (13%) were less confident in decision making. There is increasing evidence that nurses and physicians 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 the 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 that specialist nurses had the necessary attributes to initiate a discussion about deactivation. The data, however, do expose a lack of nursing contribution to the final decision concerning deactivation, because only 30% of nurses (n = 50) within the sample reported previous involvement. This could be explained by the structure of the healthcare system 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 that the best time to discuss deactivation was before implant and not when the patient required palliative care—the reverse attitude compared with physicians. Specialist nurses through nurse-based clinics can, however, play a key role in the effective management of patients with a cardiac device.35

Generalized reluctance to discuss palliative issues, such as deactivation, is well recognized 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, because 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 before implant and periodically during the disease trajectory, as per clinical guidelines.24 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 (mean [SD], 9.70 [2.03]) and/or has the support of family (P = .014).

Many professionals value shared decision making within clinical practice, which required the relay of accurate and timely information to ensure that 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 Association38 provided a “road map” 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 practice. For example, a recent retrospective case note review found that only 32% of all palliative discussions had family involvement.1

Results of a survey carried out on Belgian and Scandinavian nurses (n = 425) may provide an explanation—although nurses recognized 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 patient40 and 20% agreed with the statement “I do not have time to take care of families.” Interestingly, the more experienced nurses 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-centered information and discussion.

Limitations of the study include the diverse representation across countries and disciplines, as well as the data collection instrument. A number of strategies were used to promote recruitment, with the most effective being a personalized email sent by members of the research team. The innovative survey instrument engaged participants as there was a complete data set from all professionals who commenced the survey. Despite scrupulous preparation and refinement, the 9
What’s New and Important?

- Five patient factors—advanced age, presence of malignancy, more than 3 hospital admissions over the previous year, receipt of multiple shocks, and severe heart failure symptoms (New York Heart Association class IV)—increased professionals’ likelihood to discuss ICD deactivation.
- The practice of discussing ICD deactivation varies across countries, with American, medical, and nursing professionals more likely to discuss ICD deactivation, in comparison with their European colleagues.
- Nurses are reluctant and lacked confidence in discussing ICD deactivation compared with physicians.

Implications for Practice

- A multidisciplinary approach is necessary to improve the clinical management of the discussion and decision concerning ICD deactivation.
- Innovative educational strategies should be developed to improve patients and family members’ understanding of the functionality of the ICD.
- Additional training and support are required for nurses to improve involvement in palliative discussions that include ICD deactivation.

Conclusion

Decision making regarding ICD deactivation is complex, multifactorial with lack of a coherent multidisciplinary approach to practice internationally. The cross-country variation in attitudes and decision making sparks concern and confirms that further investigation is warranted on the sociocultural issues and interesting interprofessional differences, which may have a bearing on the overall European reluctance to initiate a discussion leading to ICD deactivation compared with 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 medicolegal 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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