

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

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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

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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

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 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.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 characterized 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 (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, 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

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.

Methodology

Design

This cross-sectional, factorial-design study conformed to the Declaration of Helsinki⁸ and was approved by the local research ethics committee. Originally devel-

oped by Rossi and Nock⁹ (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,¹⁰ indicators of acute deterioration,¹¹ and nurses' judgment of self-neglect.¹² Through a systematic and iterative process,¹³ 21 factors associated with ICD deactivation were generated from a systematic literature review,¹⁴ a retrospective case note review,¹ 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 variables¹⁵⁻¹⁷ 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 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).

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.

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 al¹⁸ 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 surveys¹⁷ 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” analysis¹⁹ 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 2 Demographic and Professional Characteristics of Participants (N = 262)

Characteristics	n (%)
Gender	
Female	193 (74)
Age, mean (SD), y	45.8 (8.9); range, 26–65
Discipline	
Nursing	170 (65)
Medical	63 (24)
Cardiac physiologist (technician)	29 (11)
Current role	
Specialist nurse	150 (57)
Cardiologist	46 (18)
Cardiac physiologist	29 (11)
Other (ie, general nurse/physician, physiotherapist)	24 (9)
Electrophysiologist	13 (5)
Time in current role, y	
<1	11 (4)
1–5	68 (26)
6–10	59 (23)
>10	123 (47)

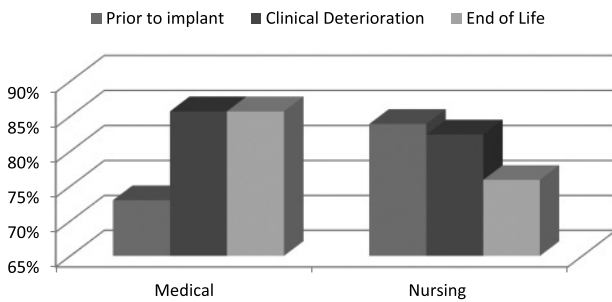


FIGURE 1. Percentage of healthcare professionals recommending discussion at 3 time points (N = 262).

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 $R^2 = 0.10$) 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 ($P = .01$), 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 $R^2 = 0.013$). 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 ($P = .04$), 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 3% of the 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 ($P < .01$); 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 characteristics are graphically displayed in Figure 2.

TABLE 3 Healthcare Professionals' Likelihood to Refer for Deactivation on a Likert Scale of 0–10 (N = 262)

Likert Scale	DNR Actioned	Comfort Care	Palliative Care Referral	Requests Deactivation	Less Than 12 mo to Live	Multiple Shocks
Mean (SD) score	9.89 (1.86)	9.70 (2.03)	8.75 (2.39)	8.23 (2.80)	7.56 (2.88)	6.31 (3.52)

Abbreviation: DNR, do not resuscitate.

TABLE 4 Independent Variables and Professional Characteristics With Dependent Variables (N = 262)

Independent and Professional Variables	Levels	Likelihood to Discuss Deactivation, Mean (SD)	Confidence in the Decision Made, Mean (SD)	
Patient age, y	39	5.99 (3.29)	Not significant	
	59	6.37 (3.13)		
	75	6.96 (3.05)		
	86	7.36 (2.96) ($P = .01$) ^a		
Comorbidities	Bowel cancer	7.38 (2.8) ($P < .01$) ^a	Not significant	
	Renal failure	6.78 (3.04)		
	Dementia	5.96 (3.38)		
No. admissions	None	Not significant	Not significant	
	1			
	>3			
No. shocks experienced	None	6.11 (3.18)	No significant	
	>1	6.60 (3.10)		
	Multiple shocks	6.95 (3.20) ($P < .01$) ^a		
Heart failure severity	NYHA II	5.69 (3.21)	8.17 (2.35)	
	NYHA III	6.44 (3.12)	8.28 (2.34)	
	NYHA IV	7.48 (2.95) ($P < .01$) ^a	8.54 (2.28) ($P = .02$) ^a	
	Previous discussion	Not significant	8.26 (2.41)	
Social support	No previous discussion	Not significant	8.17 (2.30)	
	Brief previous discussion		8.57 (2.24) ($P = .04$) ^a	
	Previous in-depth discussion		8.15 (2.39)	
	Lives alone		8.36 (2.27)	
Country of origin	Lives alone with support	Not significant	8.50 (2.31) ($P = .03$) ^a	
	Lives with family who share decisions		8.39 (2.19)	
	Ireland and Europe		6.33 (3.150)	8.07 (2.35)
	United Kingdom		6.41 (3.07)	9.19 (2.26) ($P < .01$) ^a
Discipline	United States	7.32 (3.50) ($P < .01$) ^a	8.98 (1.96) ($P = .02$) ^a	
	Medical	6.88 (3.35) ($P = .04$) ^a	8.14 (2.45)	
	Nursing	6.63 (3.08)	8.17 (2.06)	
	Healthcare science	5.46 (3.20)	8.36 (2.21)	
Times initiated discussion	1–10	6.47 (3.02)	8.69 (2.08)	
	10–25	6.88 (3.25)	9.90 (1.39) ($P < .01$) ^a	
	Multiple	7.93 (3.31) ($P < .01$) ^a	7.84 (2.33)	
Time in the current role, y	<1	Not significant	8.08 (2.25)	
	1–5	Not significant	8.43 (2.35) ^a	
	6–10		8.47 (2.36) ($P = .03$) ^a	
	>10		8.84 (1.98) ($P < .01$) ^a	
Male	8.15 (2.43)			
Gender	Female	Not significant	7.85 (2.64)	
	Yes	Not significant	8.41 (2.28) ($P = .01$) ^a	
Ethical or legal concerns	No	Not significant		

Abbreviation: NYHA, New York Heart Association.

^aAnalysis of variance post hoc with adjusted P values.

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,² despite international guideline recommendations.^{20–22} 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,^{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.

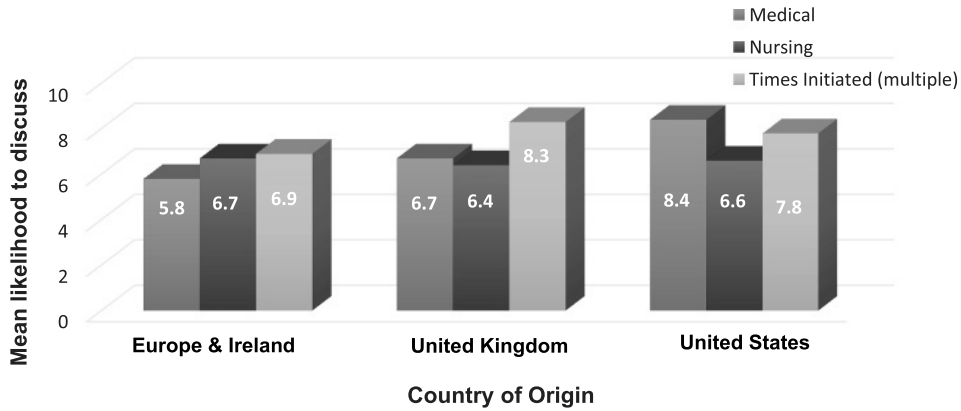


FIGURE 2. Professional characteristics and likelihood to discuss deactivation (N = 262).

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 informa-

tion 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

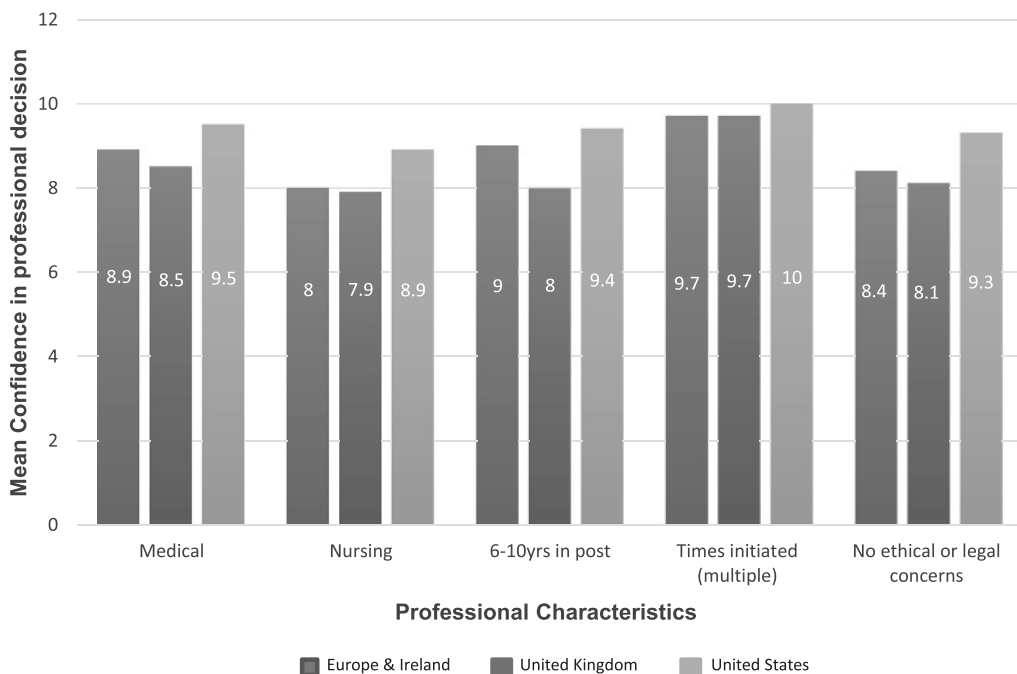


FIGURE 3. Professional characteristics and confidence in decision (N = 262).

personal discomfort (11%), fear of destroying hope (9%), or lack of time (8%). In this study, most professionals had no ethical or legal concerns²⁹; however, the minority who had (13%) were less confident in decision making. There is increasing evidence that nurses³⁰ and physicians³¹ 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 system³⁴ 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.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 (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 Association³⁶ 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.

independent variables only explained 10% of the variance for likelihood to discuss deactivation and 3% of the variance concerning professionals' confidence. Similar effect sizes have been reported in previous professional factorial surveys.^{23,24} It is to be acknowledged that the 9 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 that could be deemed idiosyncratic.

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.

REFERENCES

1. Hill L, McIlpatrick S, Taylor BJ, et al. Implantable cardioverter defibrillator (ICD) deactivation discussions: reality versus recommendations. *Eur J Cardiovasc Nurs*. 2015; 15(1):20–29.
2. Kinch Westerdahl A, Sjöblom J, Mattiasson AC, Rosenqvist M, Frykman V. Implantable cardioverter-defibrillator therapy before death: high risk for painful shocks at end of life. *Circulation*. 2014;129(4):422–429.
3. Strömberg A, Fluor C, Miller J, Chung ML, Moser DK, Thylén I. ICD recipients' understanding of ethical issues, ICD function, and practical consequences of withdrawing the ICD in the end-of-life. *Pacing Clin Electrophysiol*. 2014; 37(7):834–842.
4. Van der Wal MHL, Hjelmfors L, Mårtensson J, Friedrichsen M, Strömberg A, Jaarsma T. Variables related to communication about prognosis between nurses and patients at heart failure clinics in Sweden and the Netherlands. *J Cardiovasc Nurs*. 2018;33(2):E1–E6. doi:10.1097/JCN.0000000000000416.
5. Tagney J. Can nurses in cardiology areas prepare patients for implantable cardioverter defibrillator implant and life at home? *Nurs Crit Care*. 2004;9(3):104–114.
6. Daeschler M, Verdino RJ, Caplan AL, Kirkpatrick JN. Defibrillator deactivation against a patient's wishes: perspectives of electrophysiology practitioners. *Pacing Clin Electrophysiol*. 2015;38(8):917–924.
7. Jaarsma T, Deaton C, Fitzsimmons D, et al. Research in cardiovascular care: a position statement of the Council on Cardiovascular Nursing and Allied Professionals of the European Society of Cardiology. *Eur J Cardiovasc Nurs*. 2014;13(1):9–17.
8. World Medical Association Human Experimentation. Code of Ethics of the World Medical Association. *Br Med J*. 1964;2(5402):177. <https://doi.org/10.1136/bmj.2.5402.177>.
9. Rossi PH, Nock SL, eds. *Measuring Social Judgements: The Factorial Survey Approach*. Beverly Hills, CA: Sage Publications; 1982.
10. Ludwick R. Clinical decision making: recognition of confusion and application of restraints. *Orthop Nurs*. 1999;18(1): 65–72.
11. Rattray JE, Lauder W, Ludwick R, et al. Indicators of acute deterioration in adult patients nursed in acute wards: a factorial survey. *J Clin Nurs*. 2011;20:723–732.
12. Lauder W, Scott PA, Whyte A. Nurses' judgements of self-neglect. A factorial survey. *Int J Nurs Stud*. 2001;38(5): 601–608.
13. Taylor BJ. Factorial surveys: using vignettes to study professional judgement. *Br J Soc Work*. 2006;36(7): 1187–1207.
14. Hill L, McIlpatrick S, Taylor B, Dixon L, Harbinson M, Fitzsimons D. Patients' perception of implantable cardioverter defibrillator deactivation at the end of life. *Palliat Med*. 2015;29(4):310–323. <http://pmj.sagepub.com/content/early/2014/09/17/0269216314550374>.
15. Auspurg K, Hinz T, eds. *Factorial Survey Experiments. Series Quantitative Applications in the Social Sciences*. Newbury Park, CA: Sage; 2015.

16. Burns KE, Duffett M, Kho ME, et al. A Guide for the design and conduct of self-administered surveys of clinicians. *CMAJ*. 2008;179(3):245–252.
17. Wallander L. 25 years of factorial surveys in sociology: a review. *Soc Sci Res*. 2009;38:505–520.
18. Miller JL, Rossi PH, Simpson JE. Felony punishments: a factorial survey of perceived justice in criminal sentencing. *J Crim Law Criminol*. 1991;82(2):396–421.
19. Benjamini Y, Hochberg Y. Controlling the false discovery rate: a practical and powerful approach to multiple testing. *J R Statist Soc B*. 1995;57(1):289–300.
20. Jaarsma T, Beattie JM, Ryder M, et al. Advanced Heart Failure Study Group of the HFA of the ESC. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail*. 2009;11:433–443.
21. Padeletti L, Omar 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;12:1480–1489.
22. 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;7:1008–1026.
23. Killick C, Taylor BJ. Judgements of social care professionals on elder abuse referrals: a factorial survey. *Br J Soc Work*. 2012;42(5):814–832.
24. Baughman KR, Ludwick R, Merolla D, et al. Disentangling consumer and provider predictors of advance care planning. *Am J Hosp Palliat Care*. 2013;30(7):717–725.
25. Marinskis G, Van Erven L. EHRA Scientific Initiatives Committee. Deactivation of implanted cardioverter-defibrillators at the end of life: results of the EHRA survey. *Europace*. 2010;12(8):1176–1177.
26. Voohees J, Rietjens J, Onwuteaka-Philipsen B, et al. Discussing prognosis with terminally ill cancer patients and relatives: a survey of physicians' intentions in seven countries. *Patient Educ Couns*. 2009;77:430–436.
27. Kelley AS, Reid MC, Miller DH, Fins JJ, Lachs MS. Implantable cardioverter-defibrillator deactivation at the end of life: a physician survey. *Am Heart J*. 2009;157(4):702.e1–708.e1.
28. Dunlay SM, Foxen JL, Cole T, et al. A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. *Palliat Med*. 2015;29(3):260–267.
29. Kramer DB, Kesselheim AS, Brock DW, Maisel WH. Ethical and legal views of physicians regarding deactivation of cardiac implantable electrical devices: a quantitative assessment. *Heart Rhythm*. 2010;7(11):1537–1542.
30. Elpern EH, Covert B, Kleinpell R. Moral distress of staff nurses in a medical intensive care unit. *Am J Crit Care*. 2005;14(6):523–530.
31. Dzenge E, Colaizzi A, Roland M, et al. Moral distress amongst American physician trainees regarding futile treatments at the end of life: a qualitative study. *J Gen Intern Med*. 2016;31(1):93–99.
32. Cook JV, O'Dickinson H, Eccles M. Response rates in postal surveys of healthcare professionals between 1996 and 2005: an observational study. *BMC Health Serv Res*. 2009;9:160.
33. Lusk C, Delclos GL, Burau K, Drawhorn DD, Aday LA. Mail versus internet surveys: determinants of method of response preferences among health professionals. *Eval Health Prof*. 2007;30(2):186–210.
34. Seferovic PM, Stoerk S, Filippatos G, et al. Committee of National Heart Failure Societies or Working Groups of the Heart Failure Association of the European Society of Cardiology. Organization of heart failure management in European Society of Cardiology member countries: survey of the Heart Failure Association of the European Society of Cardiology in collaboration with the Heart Failure National Societies/Working Groups. *Eur J Heart Fail*. 2013;15(9):947–959.
35. Bøse K, Johansson I, Strömberg A. Organisation of care for Swedish patients with an implantable cardioverter defibrillator, a national survey. *J Clin Nurs*. 2011;20(17–18):2600–2608.
36. Kesson EM, Allardice GM, George WD, Burns HJ, Morrison DS. Effects of multidisciplinary team working on breast cancer survival: retrospective, comparative, interventional cohort study of 13 722 women. *BMJ*. 2012;344:e2718.
37. Taylor C, Shewbridge A, Harris J, Green JS. Benefits of multidisciplinary teamwork in the management of breast cancer. *Breast Cancer (Dove Med Press)*. 2013;5:79–85.
38. Allen LA, Stevenson LW, Grady KL, et al. Decision making in advanced heart failure. A scientific statement from the American Heart Association. *Circulation*. 2012;125:1928–1952.
39. Caldwell PH, Arthur HM, Demers C. Preferences of patients with heart failure for prognosis communication. *Can J Cardiol*. 2007;23(10):791–796.
40. Luttik MLA, Goossens E, Agren A, et al. Undertaking Nursing Interventions Throughout Europe (UNITE) research group. Attitudes of nurses towards family involvement in the care for patients with cardiovascular diseases. *Eur J Cardiovasc Nurs*. 2017;16(4):299–308.