Are ICD recipients able to foresee if they want to withdraw therapy or deactivation of their defibrillator shocks?∗☆

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A B S T R A C T

Background: Expert consensus statements on management of implantable cardioverter defibrillators (ICDs) emphasize the importance of having discussions about deactivation before and after implantation. These statements were developed with limited patient input. The purpose of this study was to identify the factors associated with patients’ experiences of end-of-life discussions, attitudes towards such discussions, and attitudes towards withdrawal of therapy (i.e., generator replacement and deactivation) at end-of-life, in a large national cohort of ICD-recipients.

Methods: We enrolled 3067 ICD-patients, administering the End-of-Life-ICD-Questionnaire.

Results: Most (86%) had not discussed ICD-deactivation with their physician. Most (69%) thought discussions were best at end-of-life, but 40% stated that they never wanted the physician to initiate a discussion. Those unwilling to discuss deactivation were younger, had experienced battery replacement, had a longer time since implantation, and had better quality-of-life. Those with psychological morbidity were more likely to desire a discussion about deactivation. Many patients (39%) were unable to foresee what to decide about deactivation in an anticipated terminal condition. Women, those without depression, and those with worse ICD-related experiences were more indecisive about withdrawal of therapy. Irrespective of shock experiences, those who could take a stand regarding deactivation chose to keep shock therapies active in many cases (30%).

Conclusions: Despite consensus statements recommending discussions about ICD-deactivation at the end-of-life, such discussion usually do not occur. There is substantial ambivalence and indecisiveness on the part of most ICD-patients in this nationwide survey about having these discussions and about expressing desires about deactivation in an anticipated end-of-life situation.

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1. Introduction

Recent expert consensus statements from the Heart Rhythm Society [1] and the European Heart Rhythm Association [2] have emphasized the importance of discussing the issue of deactivation toward the end-of-life with implantable cardioverter defibrillator (ICD) recipients, and initiating such discussions before ICD implantation. Communication about ICDs at the end-of-life presents many challenges, and it is unclear if clinicians and patients routinely discuss management of ICDs at the end-of-life and the alternative modes of dying [3,4]. In several small scale studies, investigators have examined patient preferences for discussions regarding death and attitudes about deactivation of ICDs at the end-of-life [5–14]. The majority of patients want to be involved in a deactivation discussion [6,11], yet some are reluctant [7,8,14] and also uncomfortable discussing advanced directives with their families [13]. Some investigators have found that ICD recipients want to have an end-of-life discussion sooner rather than later in the illness trajectory [12], preferably prior to implantation [11]. Others reported that patients prefer such discussion be held when it is suspected that their life expectancy is decreased [6,7]. Patients have reported mixed preferences about keeping their device activated at the end-of-life. Some investigators have provided patients with hypothetical scenarios and found that the majority of patients prefer to keep the ICD active if they had a serious illness and were unlikely to survive [5,7,10], even if it meant receiving multiple shocks at end-of-life [10]. Oth
attitudes towards ICD deactivation is needed [15]. Thus, consensus is lacking about when ambulatory patients prefer to receive information and engage in discussions about ICD deactivation at the end-of-life.

The purpose of this nationwide cross-sectional study was to identify the factors associated with patients’ experiences of end-of-life discussions, attitudes towards such end-of-life discussions, and attitudes towards withdrawal of therapy (i.e., generator replacement and deactivation) at end-of-life in a large national cohort of ICD recipients independently of psychological distress and quality-of-life. Specific aims were to 1) describe ICD patients’ experiences of end-of-life discussions – and attitudes towards – such end-of-life discussions and ICD therapy at end-of-life; 2) determine the association of sociodemographic and clinical variables (i.e., gender, age, education, ICD indication, time since implantation, type of ICD, shock experience, and prior ICD battery replacement) controlling for anxiety symptoms, depressive symptoms and quality-of-life (QOL), with patient’s experiences of end-of-life discussions; and 3) determine the association of these same variables with patient’s attitudes towards end-of-life discussions and withdrawal of therapy at end-of-life.

2. Methods

2.1. Study Design, Sample and Data Collection

This was a cross-sectional, correlational study in which self-reported data was used. The study was performed in accordance with The Declaration of Helsinki and was approved by the Regional Ethics Committee for Human Research at the University of Linköping, Sweden. Patients were recruited from the Swedish ICD- and Pacemaker registry; a national quality database in which all recipients of cardiovascular implantable electronic devices in Sweden have been registered since the start in 1989. All adult patients eligible in the registry in 2011 (n = 5535) were sent an invitation to participate in the study during September to October 2012. After completing an informed consent explaining that the study was voluntary, 1502 did not respond, 700 patients declined to participate, 96 chose to withdraw from the study, and 170 did not return the questionnaire. One reminder was sent out 3–4 weeks following the first letter.

2.2. Measures and Instruments

2.2.1. Demographic and clinical variables

Socio-demographic variables collected included gender, age, marital status, and educational level. Information on clinical variables, including indication for ICD implantation, cardiac resynchronization therapy, battery replacement, and time since implantation were obtained from the Swedish ICD- and Pacemaker registry. Information on co-morbidities was self-reported. Satisfaction with the ICD, and experience of shocks was obtained through investigator-designed questions.

2.2.2. End-of-life concerns

Data on end-of-life perceptions and attitudes was collected using the “Experiences, Attitudes and Knowledge of End-of-Life Issues in Implantable Cardioverter Defibrillator Patients (EOL-ICD) Questionnaire”. The instrument is a self-rated questionnaire containing three domains that measure experiences [10 items], attitudes [18 items] and knowledge (11 items) of end-of-life in ICD patients. The EOL-ICD Questionnaire was originally developed and tested for content and construct validity and for homogeneity and reliability in a Swedish setting. The validity, as well as the reliability, properties were considered sufficient [16].

Respondents list their answer as “yes/no” or “no opinion,” “agree/don’t agree,” “true/false,” or “don’t know.” The experiences domain includes items about patients’ actual discussion experiences. Example items in the experiences domain are “I have discussed what a battery replacement involves with my ICD doctor or nurse,” and “I have told my next of kin (either in writing or orally) my wishes regarding the defibrillator shocks in my ICD, if I become seriously ill with some fatal disease.” The attitudes domain includes items about patients’ attitudes towards potential future discussions and future events. Examples of items on the attitudes domain are “I do not wish to have a conversation about turning off defibrillating shocks with my doctor,” “I want to have the battery in my ICD replaced even if I am seriously ill suffering from another disease,” and “I want to have the defibrillating shocks in my ICD even if dying of cancer or another serious disease.” The knowledge domain involves questions such as “Turning off the defibrillating shocks in an ICD is the same as active euthanasia,” and “An ICD always gives defibrillating shocks in connection with end-of-life.” In this paper we are reporting results from the experiences and attitudes domains only.

2.2.3. Psychological measures and quality-of-life

Given the possibility that psychological distress might influence patients’ experiences and attitudes toward end-of-life concerns, questionnaires assessing QOL, anxiety symptoms, and depressive symptoms were also included in the survey. Quality-of-life was measured using the EuroQol-5D [17], an instrument with well-established reliability and validity. Anxiety and depression symptoms were assessed using the 8-item Hospital Anxiety and Depression Scale (HADS) [18], which has been used extensively in the evaluation of anxiety and depression symptoms in both hospitalized and non-hospitalized patients.

2.3. Statistical analysis

Data were analyzed with SPSS software, version 21.0 (SPSS, Chicago, Illinois). Probability values of < .05 were considered significant. Comparisons between study participants and non-participants on background characteristics were performed using the Chi-square test for nominal variables (e.g., gender, ICD indication) and two-tailed Student’s t-test for independent samples for continuous variables (e.g., age, time since implantation). Simple frequencies and proportions were used to describe the patient sample, frequency and timing of occurrence of discussions about ICD deactivation, and attitudes about battery replacement and deactivation.

A series of logistic regression models was used to determine the association of sociodemographic and clinical variables (i.e., gender, age, education, ICD indication, and two-tailed Student’s t-test for independent samples for continuous variables (e.g., age, time since implantation, type of ICD (CRT-D versus ICD), shock experience, and prior ICD battery replacement) controlling for anxiety symptoms, depressive symptoms and QOL, with patient’s experiences of end-of-life discussions and attitudes towards end-of-life discussions and withdrawal of therapy at end-of-life. In these models we determined predictors of a “yes” or “no” answer to each question about experiences of end-of-life discussions, and attitudes towards end-of-life discussions and withdrawal of therapy at the end-of-life. Each of the predictor variables were forced into the model in order to provide simultaneous control for all variables.

Chi-square tests were used to determine bivariate association of socio-demographic, clinical, and psychological measures with (1) attitudes on elective generator replacement at end-of-service indicator; (2) attitudes on deactivation at end-of-life, and (3) attitudes about maintaining ICD therapy in the context of terminal illness. For the Chi-square tests, post-hoc examination of the standardized residuals that exceeded the critical value of the distribution was used to determine which cell or cells contributed to the significant difference.

Multinomial logistic regression was used to determine predictors of the response to the item asking for patients’ attitudes regarding the item, “I want to have the defibrillating shocks in my ICD even if dying of cancer or other serious disease”. Because this item has three potential responses (i.e., yes, no, or can’t take a stand), multinomial versus logistic regression was used.

Finally, given the finding that a large percentage of respondents were indecisive with regard to ability to make a decision about withdrawal of therapy and deactivation under specific circumstances, we conducted an additional analysis using linear regression to determine predictors of indecisiveness. The dependent variable was created by averaging items from the attitude domain. These items focused on ability to come to a decision about battery replacement under the circumstances of having not received shocks, being seriously ill and having reached an advanced age, plus two questions about choosing to keep the ICD active even if dying from cancer or other serious illness, or if receiving shocks daily. Predictors included in the regression analysis involved background characteristics, clinical characteristics, and psychological measures. Predictors were forced into the model to provide simultaneous control of all variables.

3. Results

Of the 5535 patients approached, 1502 did not respond, 700 patients declined to participate, 96 chose to withdraw from the study, and 170 did not return the questionnaire despite one reminder. A total of 3067 patients completed the survey (55% response rate). No statistically significant differences were found in background characteristics in terms of age, gender, time since implantation, or ICD indication between participants and non-participants.

3.1. Background Characteristics

Sample characteristics are presented in Table 1. The mean age of the sample was 66 years with a range of ages enrolled from 19 to 94 years, and 80% were male. Time since implantation ranged from one to 23 years with a mean of 4.7 years, 23% had a CRT-D implanted and 25% had previously undergone an elective battery replacement. The majority (64%) had received their ICD as a secondary prevention treatment, while the remainder had received their ICD for primary prevention, usually in the context of heart failure.

The vast majority (96%) of patients rated their general experience as an ICD recipient as “very,” or “rather good” compared to only 4% who rated it “rather” or “very bad”. Sixteen percent of patients stated that they had religious faith or a religious outlook on life that helped them manage life as an ICD recipient. A total of 35% of patients had experienced one or more defibrillating shocks. In connection with the latest
shock, the pain as well as the anxiety experience was considered mild (4.6 and 4.5, respectively), when rated on a visual analog scale (where 0 means no pain/anxiety and 10 the worst possible pain/anxiety imaginable). Of the sample, only 4% had, at some point, considered deactivation of their ICD.

3.2. Experiences and Attitudes toward Withdrawal-of-Therapy-Discussions

Only 43% of patients had at some time discussed what a forthcoming battery replacement would involve with their physician, and 32% had discussed the topic with a family member. Among the predictors entered into the model, QoL, age, time since implantation, and prior battery replacement independently predicted whether patients had had such a discussion (Table 2). Patients with better QoL, those younger than 65, those who had the ICD implanted for a longer period of time, and those who had a prior battery replacement were more likely to have discussed battery replacement with their clinician. With regard to predictors of having such a discussion with their family members, again, patients with better QoL, those younger than 65, those with the ICD for a longer period of time, and those who had a prior battery replacement were more likely to have discussed battery replacement with their next-of-kin (Table 2).

The vast majority (86%) had not had a discussion with their clinician about what ICD deactivation and turning off defibrillating shocks would involve. Logistic regression demonstrated that anxious patients, younger patients, and those who had received ICD shocks and prior battery replacement were more likely to have had such a discussion (Table 2). Just one-tenth of patients had discussed the implications of ICD deactivation with their family members. Independent predictors of this discussion with family members were presence of anxiety symptoms, having received prior defibrillating shocks or prior battery replacement (Table 2). Only 7% had told their family members of their wishes for ICD deactivation if they become seriously ill with a fatal disease. Only female patients with better QoL, those younger than 65, those with the ICD implanted for a longer period of time, and those who had received prior battery replacement independently predicted whether patients had had such a discussion with their family members (Table 2).

Table 1
Demographic and clinical characteristics, N = 3067.

| Characteristic                          | Value a |
|----------------------------------------|---------|
| Demographics                           |         |
| Age (years)                            | 65.9    |
| Gender (male)                          | 2438    |
| Education (lower) b                    | 1009    |
| Clinical factors                       |         |
| Time since implantation (years)        | 4.7     |
| ICD-indication (primary prevention)     | 1109    |
| Resynchronization therapy (CRT-D yes)  | 717     |
| Shock experience (yes)                 | 1056    |
| Generator replacement (yes)            | 774     |
| Co-morbidity c                         |         |
| Myocardial infarction                  | 1037    |
| Atrial fibrillation                    | 1280    |
| Heart failure                          | 1606    |
| Chronic obstructive pulmonary disease  | 448     |
| Diabetes mellitus                      | 612     |
| Stroke                                 | 272     |
| Cancer                                 | 202     |
| Psychological measures d               |         |
| Quality-of-life index, mean            | .818    |
| Quality-of-life, visual analog scale   | .728    |
| Anxiety                                | 485     |
| Depression                             | 263     |

a Data are presented as mean ± SD or n (%).
b Compulsory secondary school, with a total education time < 9 years.
c Self-reported by subjects.
d Psychological measures: QoL was assessed with EQ-5D (mean index score and visual analog score–VAS; a higher score indicated a better QoL), anxiety and depression with HADS (categorical with a cut-offs ≥8 indicating anxiety/depression).

3.3. Timing of Discussions about ICD Deactivation

With regard to attitudes about discussion surrounding ICD deactivation in an anticipated end-of-life situation, 40% of patients stated that they never wanted the physician to initiate a discussion, while 84% stated they wanted to broach the question about deactivation when they felt it was needed. Most patients (69%) stated that they preferred discussing what is involved with ICD deactivation during the last days in life, yet 50% also said they would like the discussion to be held in connection with the ICD implantation. Overall, most people would prefer these discussions be held when their health deteriorates, rather than routinely (Table 3).

We determined predictors of the attitude of never wanting the physician to discuss ICD deactivation. Based on logistic regression, the patients who did not want to discuss ICD deactivation were more likely to be younger and without symptoms of anxiety. In addition, these patients were more likely to have received prior ICD shocks (Table 4).

3.4. Attitudes toward Withdrawal of Therapy at the Battery-End-of-Service

The majority of patients stated that even if no shock therapy had been delivered (79%) they would like to replace the ICD battery when it has reached the end-of-service indicator, while 16% could not take a stand on this item, and 5% would not want to replace the ICD battery in this circumstance. The prevalence of these attitudes by various socio-demographic, implantation, psychological and end-of-life discussion experiences are indicated in Table 5. From bivariate analyses, there were no differences in the prevalence of these attitudes based on gender, whether the ICD was inserted for primary or secondary prevention, type of ICD (i.e., CRT-D or ICD), receipt of prior shocks, symptoms of anxiety, or prior discussions with the ICD team about deactivation. There were significant differences based on age, education, time since ICD implantation, prior battery replacement, having had discussions with the ICD team about battery replacement and about illness trajectory. Specifically, patients who were younger, those with lower levels of education, and those with depressive symptoms were more likely to state that they did not want the battery replaced even if no shocks had been delivered. Significantly more patients who had their ICD for 5 or fewer years were unable to take a stand than those who had their ICD for longer than 5 years. Patients who had a prior battery replacement were less likely to state they could not take a stand regarding battery replacement if no shocks had been delivered. Patients who had any prior discussion with the ICD team about battery replacement were less likely to be unable to take a stand as were those who had a prior discussion about illness trajectory.

The majority of patients also reported wanting to replace the battery even when they reached a very advanced age (63%), while 27% could not take a stand, and 10% did not want the battery replaced in this circumstance. The prevalence of these attitudes by various socio-demographic, implantation, psychological and end-of-life discussion experiences are indicated in Table 6. Younger patients more commonly said they did not want the battery replaced even at an advanced age, and men more commonly said they did want it replaced than did women, although women more commonly than men were unable to take a stand. Those who had no prior discussion about battery...
Table 2
Logistic regression results for experiences of, and attitudes towards, withdrawal-of-ICD-therapy-discussions, N = 3067.

| B                | P value | Odds ratio | 95% CI   |
|------------------|---------|------------|----------|
| B                |         |            |          |
| Discuss what battery replacement involves with ICD physician or nurse, Omnibus p value < .001 |
| Symptoms of depression | −0.311 | .086       | .733     | 0.513–1.046 |
| Symptoms of anxiety      | .086   | .534       | 1.089    | .832–1.427  |
| Quality-of-life score    | .480   | .045       | 1.615    | 1.010–2.584 |
| Male                    | .071   | .511       | 1.074    | .869–1.327  |
| Age < 65 years (vs. ≥65 years) | .299 | < .001     | 1.349    | 1.123–1.620 |
| ≤9 years of education (vs. ≥9 years) | −0.086 | .361       | 0.918    | 0.764–1.103 |
| Time since implantation of ICD, years | .122 | < .001     | 1.130    | 1.090–1.173 |
| CRT-D (vs. ICD only)    | .065   | .547       | 1.067    | .864–1.317  |
| Secondary prevention (vs. primary) | .129 | .187       | 1.137    | .939–1.377  |
| Received ICD shocks     | .055   | .567       | 1.057    | .874–1.278  |
| Had prior generator replacement | 1.558 | < .001     | 4.739    | 3.565–6.298 |
| Discuss what battery replacement involves with family, Omnibus p value < .001 |
| Symptoms of depression | −0.248 | .183       | .781     | 0.543–1.213 |
| Symptoms of anxiety      | .125   | .375       | 1.133    | .860–1.249  |
| Quality-of-life score    | .511   | .039       | 1.667    | 1.027–2.707 |
| Male                    | .179   | .098       | 1.196    | .968–1.477  |
| Age < 65 years (vs. ≥65 years) | .325 | .001       | 1.384    | 1.149–1.667 |
| ≤9 years of education (vs. ≥9 years) | .026  | .787       | 1.026    | .850–1.239 |
| Time since implantation of ICD, years | .110 | < .001     | 1.117    | 1.080–1.155 |
| CRT-D (vs. ICD only)    | .151   | .172       | 1.163    | .936–1.445  |
| Secondary prevention (vs. primary) | .152 | .140       | 1.165    | .951–1.426  |
| Received ICD shocks     | −0.060 | .545       | .942     | .776–1.143  |
| Had prior generator replacement | 1.169 | < .001     | 3.219    | 2.479–4.180 |
| Discuss with ICD physician or nurse what turning off defibrillating shocks involves, Omnibus p value < .001 |
| Symptoms of depression | −0.079 | .708       | .924     | 0.613–1.393 |
| Symptoms of anxiety      | .494   | .002       | 1.638    | 1.198–2.239 |
| Quality-of-life score    | −0.186 | .518       | .830     | .472–1.460  |
| Male                    | −0.034 | .804       | .967     | .741–1.262  |
| Age < 65 years (vs. ≥65 years) | .311 | .008       | 1.364    | 1.084–1.717 |
| ≤9 years of education (vs. ≥9 years) | .123  | .306       | 1.131    | .894–1.430  |
| Time since implantation of ICD, years | .014 | .476       | 1.014    | .976–1.052 |
| CRT-D (vs. ICD only)    | .014   | .922       | 1.014    | .770–1.335  |
| Secondary prevention (vs. primary) | −.042 | .752       | .959     | .739–1.244  |
| Received ICD shocks     | .585   | < .001     | 1.795    | 1.422–2.265 |
| Had prior generator replacement | .735 | < .000     | 2.086    | 1.504–2.893 |
| Discuss with family what turning off defibrillating shocks involves, Omnibus p value < .001 |
| Symptoms of depression | .013   | .955       | 1.013    | .654–1.569  |
| Symptoms of anxiety      | .582   | .001       | 1.789    | 1.179–2.503 |
| Quality-of-life score    | −.294  | .342       | .746     | .407–1.366  |
| Male                    | .201   | .167       | 1.223    | .920–1.626  |
| Age < 65 years (vs. ≥65 years) | .142 | .281       | 1.152    | .890–1.491  |
| ≤9 years of education (vs. ≥9 years) | .152  | .250       | 1.165    | .899–1.509  |
| Time since implantation of ICD, years | .017 | .417       | 1.017    | .976–1.051 |
| CRT-D (vs. ICD only)    | −.105  | .508       | .900     | .660–1.229  |
| Secondary prevention (vs. primary) | −.059 | .689       | .943     | .706–1.258  |
| Received ICD shocks     | .511   | < .001     | 1.667    | 1.285–2.163 |
| Had prior generator replacement | .505  | .007       | 1.658    | 1.147–2.396 |
| Discuss with family wishes if seriously ill with fatal disease, Omnibus p value < .001 |
| Symptoms of depression | .068   | .808       | 1.070    | .621–1.842  |
| Symptoms of anxiety      | .139   | .531       | 1.149    | .744–1.773  |
| Quality-of-life score    | −.683  | .058       | 1.055    | .249–1.024  |
| Male                    | .359   | .036       | 1.432    | .102–2.003  |
| Age < 65 years (vs. ≥65 years) | .114 | .479       | 1.121    | .818–1.536  |
| ≤9 years of education (vs. ≥9 years) | .069  | .672       | 1.071    | .779–1.475  |
| Time since implantation of ICD, years | −.009 | .750       | .991     | .941–1.045  |
| CRT-D (vs. ICD only)    | .106   | .564       | 1.112    | .776–1.452  |
| Secondary prevention (vs. primary) | −.142 | .422       | .867     | .613–1.237  |
| Received ICD shocks     | .158   | .341       | 1.171    | .846–1.622  |
| Had prior generator replacement | .705  | .002       | 2.023    | 1.288–3.179 |
| Discuss illness trajectory with ICD physician or nurse, Omnibus p value < .001 |
| Symptoms of depression | −.221  | .183       | .802     | .579–1.110  |
| Symptoms of anxiety      | .055   | .686       | 1.057    | .823–1.357  |
| Quality-of-life score    | −.272  | .209       | 1.762    | .499–1.165  |
| Male                    | −.377  | < .001     | .686     | .561–1.838  |
| Age < 65 years (vs. ≥65 years) | .461 | < .001     | 1.585    | 1.340–1.876 |
| ≤9 years of education (vs. ≥9 years) | −.443 | < .001     | .642     | .539–.764  |
| Time since implantation of ICD, years | .011 | .458       | 1.012    | .598–1.043  |
| CRT-D (vs. ICD only)    | .387   | < .001     | 1.472    | 1.212–1.787 |
| Secondary prevention (vs. primary) | −.080 | .386       | .923     | .770–1.107  |
| Received ICD shocks     | .465   | < .001     | 1.592    | 1.337–1.896 |

(continued on next page)
replacement more commonly were unable to take a stand on this issue, while those who had a prior discussion more commonly said they wanted battery replacement even at an advanced age. There were no differences in attitudes based on education level, ICD indication, ICD type, time since implantation, prior shock experience, prior generator replacement, presence of symptoms of anxiety or depression, or prior discussions about illness trajectory or ICD deactivation.

A majority of patients (55%) desired battery replacement even if seriously ill, while 34% were unable to take a stand on this issue, and 11% said no. The prevalence of these attitudes by various socio-demographic, implantation, psychological and end-of-life discussion experiences are indicated in Table 7. Women either more commonly said they could not take a stand or said no to this issue, those with a CRT-D less commonly said no, and those who had discussed deactivation with their ICD team more commonly said no. There were no differences in attitudes based on age, education level, ICD indication, time since implantation, prior shock experience, prior generator replacement, presence of symptoms of anxiety or depression, or prior discussions about illness trajectory or battery replacement.

3.5. Attitudes toward ICD Deactivation at End-of-Life

More patients “could not take a stand (39%) about whether they would like to have the ICD deactivated if a terminal illness developed” than said “yes (22%), they would like it deactivated” or “no (39%), they do not want it deactivated even if a terminal illness like cancer developed”. There were no differences in the prevalence of these attitudes based on age, education level, ICD indication, time since implantation, receipt of previous shocks, symptoms of anxiety, depressive symptoms, having had a prior discussion with the physician about battery replacement, or having had a prior discussion with the physician about illness trajectory (Table 8). There were differences based on gender, type of ICD, prior battery replacement, and prior discussions with the physician about deactivation. Specifically, women were less likely to say “yes, they would like to have the ICD deactivated if a terminal illness developed”, as were those with prior battery replacement. Those with a CRT-D were more likely to say “yes”, and those who had a prior discussion with their physician about deactivation were less likely to say they often “could not take a stand” (Table 8). Multinomial logistic regression revealed that only gender, having had a prior discussion about ICD deactivation with the physician, and CRT-D therapy predicted this attitude. Compared to patients who stated “no” to the item asking if they would like to have the ICD deactivated if a terminal illness developed, those who said “yes” were more likely to be men (Odds ratio 1.79, 95% confidence intervals (CI) 1.36–2.34, p < .001) and more likely to have a CRT-D versus ICD implanted (Odds ratio 1.35, 95% CI 1.06–1.73, p = .017). No other covariates entered into the model.

3.6. Predictors of indecisiveness

Given our unexpected findings of a large number of patients who were indecisive (i.e., unable to take a stand) about a number of end-of-life issues related to their ICD, we conducted a secondary analysis to further explore this phenomenon. We used linear regression in order to determine predictors of indecisiveness from the following variables: gender, age; education level; type of ICD; ICD indication; time since implantation; history of myocardial infarction, heart failure or cancer; quality-of-life score; depressive symptoms; anxiety symptoms; prior discussions with the ICD team about battery replacement and ICD deactivation; general experiences with the ICD; prior ICD shocks; anxiety related to ICD shocks; and pain related to ICD shocks.

Table 2 (continued)

| Had prior generator replacement | B         | P value | Odds ratio | 95% CI |
|--------------------------------|-----------|---------|------------|--------|
| Discussed heart disease development with family, Omnibus p value < .001 | .259      | .052    | 1.295      | .997–1.682 |
| Symptoms of depression       | .065      |         | .786       | .779–1.460 |
| Symptoms of anxiety           | .068      |         | .587       | .837–1.368 |
| Quality-of-life score        | -.203     |         | .341       | .538–1.239 |
| Male                          | -.039     |         | .690       | .793–1.166 |
| Age = 65 years (vs. ≥65 years)| .359      | <.001   | 1.432      | 1.213–1.690 |
| ≤9 years of education (vs. >9 years) | -.296    | .001   | .743       | .627–.882  |
| Time since implantation of ICD, years | .004      |         | 1.004      | .975–1.035 |
| CRT-D (vs. ICD only)         | .347      | <.001   | 1.415      | 1.178–1.712 |
| Secondary prevention (vs. primary) | -.171     | .025   | .843       | .705–1.007 |
| Received ICD shocks          | .255      |         | .004       | 1.085–1.535 |
| Had prior generator replacement | .169     |         | .022       | .913–1.534 |

Legend: CI = Confidence Intervals; CRT-D = Cardiac Resynchronization Therapy-Defibrillator; ICD = Implantable Cardioverter Defibrillator.

Table 3

| Attitudes about preferable situations in which to discuss what ICD deactivation involves, N = 3067. | B         | P value | Odds ratio | 95% CI |
|---------------------------------------------------------------|-----------|---------|------------|--------|
| Specific situation                                            | Value a   |         |            |        |
| I don't wish to have such a conversation                      | 1204 (40.0) | .001 | .701–1.340 |
| I myself will broach the question when I feel the need to     | 2529 (84.3) | .001 | .501–.835 |
| In connection with the ICD surgery                            | 1466 (49.6) | .001 | .929–1.786 |
| If I receive a shock                                          | 1502 (50.5) | .001 | .748–1.098 |
| If I have repeated shocks                                    | 1938 (65.2) | .001 | 1.067–1.486 |
| Upon repeatedly being hospitalized due to recurring heart problems | 1870 (63.0) | .001 | .786–1.097 |
| If I should suffer from a disease with a poor prognosis (e.g., cancer) | 1912 (64.6) | .001 | .973–1.033 |
| Routinely upon return visits to the ICD clinic                | 1249 (41.7) | .001 | .770–1.131 |
| If my heart disease, which is the reason for the ICD treatment, deteriorates | 1935 (64.8) | .001 | .808–1.151 |
| Towards end-of-life, during the last days                     | 2043 (69.1) | .001 | .903–1.506 |

* Data are presented as number and percentages, with proportions of patients agreeing to each statement. Patients were asked to take a stand for each statement.

Table 4

| Logistic regression for attitude about when the patient would like clinicians to broach the subject of what is involved when turning the defibrillating shocks, N = 3067. | B         | P value | Odds ratio | 95% CI |
|-----------------------------------------------------------------------------------------------------------------|-----------|---------|------------|--------|
| Never wishes to have such a discussion, Omnibus p value < .001                                                    | -.031     | .850    | .969       | .701–1.340 |
| Symptoms of depression                                                                                           | -.435     | .001    | .647       | .501–.835 |
| Quality-of-life score                                                                                             | -.207     | .342    | 1.230      | .803–1.884 |
| Male                                                                                                              | -.098     | .315    | .906       | .748–1.098 |
| Age ≥65 years (vs. ≥65 years)                                                                                     | .230      | .125    | 1.067–1.486 |
| ≤9 years of education (vs. >9 years)                                                                             | -.074     | .853    | .929       | .786–1.097 |
| Time since implantation of ICD, years                                                                          | -.002     | .870    | 1.002      | .973–1.033 |
| CRT-D (vs. ICD only)                                                                                            | -.069     | .481    | .933       | .770–1.131 |
| Secondary prevention (vs. primary)                                                                               | -.036     | .692    | .965       | .808–1.151 |
| Received ICD shocks                                                                                               | .422      | .001    | 1.525      | 1.285–1.810 |
| Had prior generator replacement                                                                                | .154      | .239    | 1.166      | .903–1.506 |

Legend: CI = confidence intervals; CRT-D = Cardiac Resynchronization Therapy-Defibrillator; ICD = Implantable Cardioverter Defibrillator.
model was significant \( (p = .001) \), and of the variables entered, only gender \( (\beta = .108, p = .001) \), depressive symptoms \( (\beta = .122, p = .002) \), and experiences with the ICD \( (\beta = .077, p = .036) \) were significant predictors. Women, those without depressive symptoms, and those with worse ICD experiences were more indecisive.

### 4. Discussion

In our nationwide survey of more than 3000 patients with ICDs, we found that only a minority had discussed the implications of generator replacement at battery-end-of-service or had discussed potential ICD deactivation at the end-of-life. Moreover, many patients were unable to foresee what they might prefer to do with their ICD in an end-of-life situation. These findings suggest a number of possibilities with regard to the recommendations offered in current expert consensus statements about managing ICD patients [1,2], the effectiveness of such statements, and whether they are being followed.

As Kramer and colleagues [19] recently discussed: is it time for a new approach to ICD replacements? They point to the fact that the appropriateness of initial device placement has been closely scrutinized, but there has been little consideration as to what happens in the years after implantation when ICD battery drains sufficiently to require replacement. They suggest that the guidelines for initial ICD implantation [20] should be followed when making recommendations to patients regarding replacement, i.e., the patient should be expected to survive for at least one year with a reasonable quality-of-life. When we asked our participants, however, the majority stated that they would like to replace the battery, even if no shock therapy had been delivered, even if they had reached a very advanced age, or even if they were seriously ill with a terminal disease like cancer. This implies the importance of making battery replacement a more deliberative process where patient preferences, past experiences, and advance care planning should be explicitly included in decision making together with a comprehensive medical evaluation [19].

We found a strikingly low rate of discussions about the possibility of deactivating the device near the end-of-life suggesting a lack of concordance with the current consensus statements. Before implanting an ICD, clinicians should explain that these devices may avert sudden cardiac death, but that later in life the benefits versus the negatives of the ICDs should be re-evaluated. For example, if the patient is stricken with a fatal illness, the physician should, in accordance with existing expert consensus statements [1,2], explain that death from an arrhythmia may be a better mode of dying than that the patient faces from their terminal condition. The statements also suggest that the physician should explain that repeated ICD shocks may be distressing to the patient and family as death nears. However – and in contrast to the advice given by experts in the consensus statements [1,2] – as many as 40% of our participants stated that they never wanted the physician to initiate a discussion about deactivation in an anticipated end-of-life situation and those in favor of a discussion, preferred it to take place during the last days in life. Others have also reported that patients prefer to discuss deactivation only late in their illness trajectory [6,7]. This highlights the importance that the opinion of patients should be considered at the time of initiating a discussion on terminal conditions or delivery these types of documents. When attempting to define sub-groups of patients who had participated in discussions about withdrawal of ICD therapy, we found that anxious patients, patients younger than 65 years, and those who had received ICD shocks and prior battery replacement were more likely to have had such a discussion. These findings could be explained by the fact that relative youth may be associated with a
more proactive way of communicating with healthcare professionals and the experience of having an arrhythmia that results in ICD shocks leads to more consultations and thus more opportunities to have this discussion. Anxiety is a common factor in promoting discussions as anxious patients attempt to resolve their anxiety by gaining more information.

We also found that the majority of the participants had not discussed their illness trajectory with their physician or a family member. While advanced directives are considered an essential part of care for the ICD population, this was not a reality in our study where only 7% had advanced directives are considered an essential part of care for the ICD population, this was not a reality in our study where only 7% had advanced directives

| Age ** | <65 years | N (%) | ≥65 years | N (%) |
|--------|-----------|-------|-----------|-------|
| Yes    | 609 (57.9)|       | 1267 (65.1)|       |
| No     | 131 (12.5)*** | 174 (8.9)| 207 (8.7)*** | 98 (15.8)*** |
| Can't take a stand | 311 (29.6) | 504 (25.9) | 599 (25.2) | 216 (34.9)*** |

| Implantation indication and device | ICD indication | CRT ** |
|----------------------------------|---------------|-------|
| Primary                          | Yes           | No    |
| Secondary                        | Yes           | No    |
| No                               | 670 (62.2)    | 1205 (62.8) | 459 (65.8) | 1414 (61.6) |
| Can't take a stand               | 108 (10.0)    | 197 (10.3) | 55 (7.9) | 290 (10.9) |
| Shock experience **              | 300 (27.6)    | 515 (26.9) | 183 (26.3) | 631 (27.5) |
| Time since implant               | 685 (63.3)    | 1175 (60.9) | 477 (62.9) | 1399 (62.5) |
| Shock                            | No            | 95 (9.2) | 204 (10.6) | 89 (11.7) | 216 (9.7) |
| No                               | 593 (28.1)    | 222 (25.1) | 253 (24.5) | 549 (28.5) | 192 (25.4) | 623 (27.8) |

| Psychological factors           | Symptoms of anxiety | Symptoms of depression |
|---------------------------------|---------------------|-----------------------|
| Yes                             | 276 (58.9)          | 1568 (63.3)           | 148 (58.3) | 1698 (63.0) |
| No                              | 56 (11.9)           | 243 (9.8)             | 34 (13.4) | 265 (9.8) |
| Can't take a stand              | 137 (29.2)          | 665 (26.9)            | 72 (28.3) | 734 (27.2) |

| End of life discussions with ICD | Battery replacement *** | Illness trajectory | Deactivation |
|---------------------------------|------------------------|-------------------|-------------|
| Yes                             | 865 (67.3)***          | 722 (65.3)        | 1135 (61.1) | 282 (66.0) | 1578 (62.1) |
| No                              | 210 (9.9)             | 179 (10.6)        | 110 (9.9) | 191 (10.3) | 49 (11.5) | 252 (9.9) |
| Can't take a stand              | 299 (23.3)***         | 274 (24.8)        | 530 (28.6) | 96 (22.5) | 712 (28.0) |

Legend: * Of the total, yes, n = 1876 (62.6%); no, n = 305 (10.2%); can't take a stand, n = 815 (27.2%); ** = overall chi-square significance at p < .05; *** = post-hoc examination of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with p < .05.

Table 6
Prevalence of attitudes regarding ICD battery replacement even if at an advanced age, N = 3067*.

because ICD patients and their families cannot make appropriate decisions without a clear understanding of available options, which may lead to a prolonged and uncomfortable death [22]. Although a large number of our patients could not take a stand about ICD deactivation if confronted with a terminal illness, of those who could take a stand in advance, the majority stated that they would prefer deactivation. Every fifth patient, however, believed that they would like the shock therapies to remain active. These results support findings from previous, small scale studies demonstrating that the majority of patients prefer to keep their ICD active [5,7,10] while some favor device deactivation at end-of-life [6,9]. Together these data demonstrate that ICD recipients form a heterogeneous group.

What clinical conclusions can be drawn from these results? One of the most striking finding in our study is the unwillingness in certain groups to have a discussion about deactivation. This, however, cannot be taken as a pretext for failing to provide patients with their options in an end-of-life situation. Rather this finding highlights the importance of being aware of patients’ ambivalence, understanding that preferences are unique among individuals, and that patients with different characteristics have different needs. Thus, the timing of every discussion with the patient must be decided on an individual basis. This is particularly important because illness trajectory and terminal deterioration of health often is unpredictable [23–27]. However, continuity of care for patients with an ICD in the end-of-life is complex [28]. One reason for this is the lack of collaboration among healthcare providers which may lead to fragmented care for the ICD patient [22] and this should also be acknowledged in future guidelines. Because previous research [29] has suggested that patients may be too anxious when diagnosed and thus are not receptive to having
such discussions at that stage, perhaps end-of-life issues should be discussed at follow-up visits but not pre-implantation as suggested in expert consensus statements [1,2]. Further supporting this suggestion is the finding that many patients change their minds regarding deactivation over the course of their illness [29]. Half of our participants, however, favored receiving information about deactivation while in the hospital. Together this and related data suggest that frequent attempts at discussion starting from the first consultation prior to implantation – as suggested in consensus statements – and continuing on through the post-implantation period and as patients’ conditions change, seem reasonable and is also in line with Dunbar and colleagues’ recommendations about educational and psychological interventions to improve ICD recipient outcomes [21]. When such discussions are done with sensitivity to patient preferences, they likely will not be viewed as offensive, but presumed to be in every patient’s best interest.

It is also possible that resistance to discussing deactivation partly can be explained by lack of actual knowledge and true understanding of the ICD and its functions. Many patients do not understand the specifics of their device with regard to their medical condition [13,30,31]. By openly discussing the illness trajectory and option of deactivating an ICD, after providing patients with sufficient knowledge to process these discussions, clinicians encourage shared decision making and provide patients control over their healthcare choices. A better understanding of patients’ actual insights in their disease and the role of the ICD could be reached with the help of specific questionnaires in addition to discussions throughout the illness trajectory and make it possible to design an individual scheme for education and support. This way to optimize follow-up and patient support has to be further investigated, however.

### 4.1. Limitations

This study is limited by the fact that the most psychologically distressed patients and those with poor physical and mental functioning may not have agreed to participate. Although there were no differences in age, gender, time since implantation and indication for the ICD between those who participated in the study and those who did not, we were unable to collect further data from those who did not participate. Furthermore, persons responding may want to be perceived as “good patients” by not reporting problems, although our consent process insured that patients were informed about the standardization of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with p < .05.

### 5. Conclusions

In this study, we examined experiences of discussion, and attitudes about end-of-life among patients with an ICD while controlling for levels of psychological distress and quality-of-life. The vast majority of the patients had not discussed deactivation with the ICD team and a large minority of younger and healthier patients did not want this discussion at all. Many patients, above all women, those with recent implant and those with good quality-of-life or those with worse ICD

### Table 7

Prevalence of attitudes regarding ICD battery replacement even if seriously ill with another disease, N = 3067 *.

| Socio-demographics | Age | Sex | Education level |
|--------------------|-----|-----|----------------|
|                    | ≤65 | ≥65 | Male | Female | ≤9 | >9 |
| Yes                | 564 | 1070| 1354 | 280 | 542 | 1079 |
| No                 | 123 | 206 | 240 | 89 | 120 | 208 |
| Can’t take a stand | 364 | 667 | 782 | 249 | 315 | 706 |

| Implantation indication and device | ICD indication | CRT** |
|-----------------------------------|----------------|-------|
| Primary                           | Secondary      |       |
| Yes                               | 574 (53.4)     | 1060 (55.3) |
| No                                | 122 (11.3)     | 207 (10.8) |
| Can’t take a stand                 | 380 (35.3)     | 650 (33.9) |

| Post-implantation experiences     | Time since implant | Shock experience | Generator replacement |
|-----------------------------------|---------------------|------------------|-----------------------|
| ≤5 years                          | 1128 (53.4)         | 506 (57.3)       | 584 (56.7)           |
| >5 years                          | 506 (57.3)          | 102 (11.6)       | 123 (11.9)           |
| Can’t take a stand                | 756 (35.8)          | 275 (31.1)       | 323 (31.4)           |

| Psychological factors             | Symptoms of anxiety | | Symptoms of depression |
|-----------------------------------|---------------------|---|-----------------------|
| Yes                               | 247 (52.3)          |   | 1357 (54.9)           |
| No                                | 56 (11.9)           |   | 270 (10.9)            |
| Can’t take a stand                | 169 (35.8)          |   | 845 (34.2)            |

| End of life discussions with ICD team | Battery replacement | Illness trajectory ** | Deactivation |
|---------------------------------------|---------------------|----------------------|-------------|
| Yes                                   | 748 (58.3)          | 874 (51.8)           | 639 (57.7) |
| No                                    | 133 (10.4)          | 193 (11.4)           | 108 (9.8)  |
| Can’t take a stand                    | 401 (31.3)          | 621 (36.8)           | 360 (32.5) |

Legend: * Of the total, yes, n = 1634 (54.6%); no, n = 329 (11%); can’t take a stand, n = 1031 (34.4%); ** = overall chi-square significant at p < .05; *** = post-hoc examination of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with p < .05.
experiences were indecisive about deactivation or ICD replacement. Irrespective of shock experiences, those who could take a stand regarding deactivation chose to keep shock therapies active in many cases. The divergence in attitudes we found in our study regarding deactivation chose to keep shock therapies active in many cases. The experiences were indecisive about deactivation or ICD replacement.

| Table 8 |
| --- |
| Prevalence of attitudes regarding the maintenance of ICD therapy in the context of terminal illness (keep shocks even if dying of cancer or other serious disease), N = 3067.* |

| Socio-demographics | Age | Sex | Education level |
| --- | --- | --- | --- |
| | <65 years | ≥65 years | Male | Female | ≤9 years | >9 years |
| Yes | 216 (20.5) | 455 (23.4) | 576 (24.3) | 95 (15.3) *** | 241 (24.7) | 424 (21.2) |
| No | 433 (41.1) | 719 (37.1) | 882 (37.2) | 270 (43.5) *** | 362 (37.1) | 783 (39.3) |
| Can’t take a stand | 404 (38.4) | 766 (39.5) | 914 (38.5) | 256 (41.2) | 372 (38.2) | 787 (39.5) |

| Implantation indication and device | ICD indication | CRT ** | ** | ** |
| --- | --- | --- | --- | --- |
| Yes | 256 (23.8) | 415 (21.7) | 184 (26.5) *** | 486 (21.2) |
| No | 431 (38.4) | 738 (38.5) | 244 (35.1) | 906 (39.5) |
| Can’t take a stand | 407 (37.8) | 763 (39.8) | 267 (38.4) | 902 (39.3) |

| Psychological factors | Symptoms of anxiety | Symptoms of depression |
| --- | --- | --- |
| Yes | 111 (23.6) | 546 (22.1) | 55 (21.7) | 605 (22.4) |
| No | 174 (37.0) | 961 (38.9) | 106 (41.7) | 1028 (38.2) |
| Can’t take a stand | 185 (39.4) | 964 (39.0) | 93 (36.6) | 1061 (39.4) |

| End-of-life discussions with ICD team | Battery replacement | Illness trajectory | Deactivation ** |
| --- | --- | --- | --- |
| Yes | 292 (22.8) | 374 (22.2) | 267 (24.1) | 396 (21.4) | 113 (26.3) | 549 (21.6) |
| No | 508 (35.6) | 632 (37.6) | 422 (38.1) | 719 (38.8) | 174 (40.4) | 966 (38.1) |
| Can’t take a stand | 483 (37.6) | 677 (40.2) | 419 (37.8) | 738 (39.8) | 143 (33.3) *** | 1021 (40.3) |

Legend: * Of the total, Yes, n = 671 (22.4%); No, n = 1152 (38.5%); Can’t take a stand, n = 1170 (39.1%); ** = overall chi-square significant at p < .05; *** = post-hoc examination of the standardized residuals was used to determine which cell or cells contributed to the significant difference and those cells marked with a *** exceeded the critical value associated with p < .05.

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