

ICD Deactivation in Heart Failure: Towards a new level of understanding

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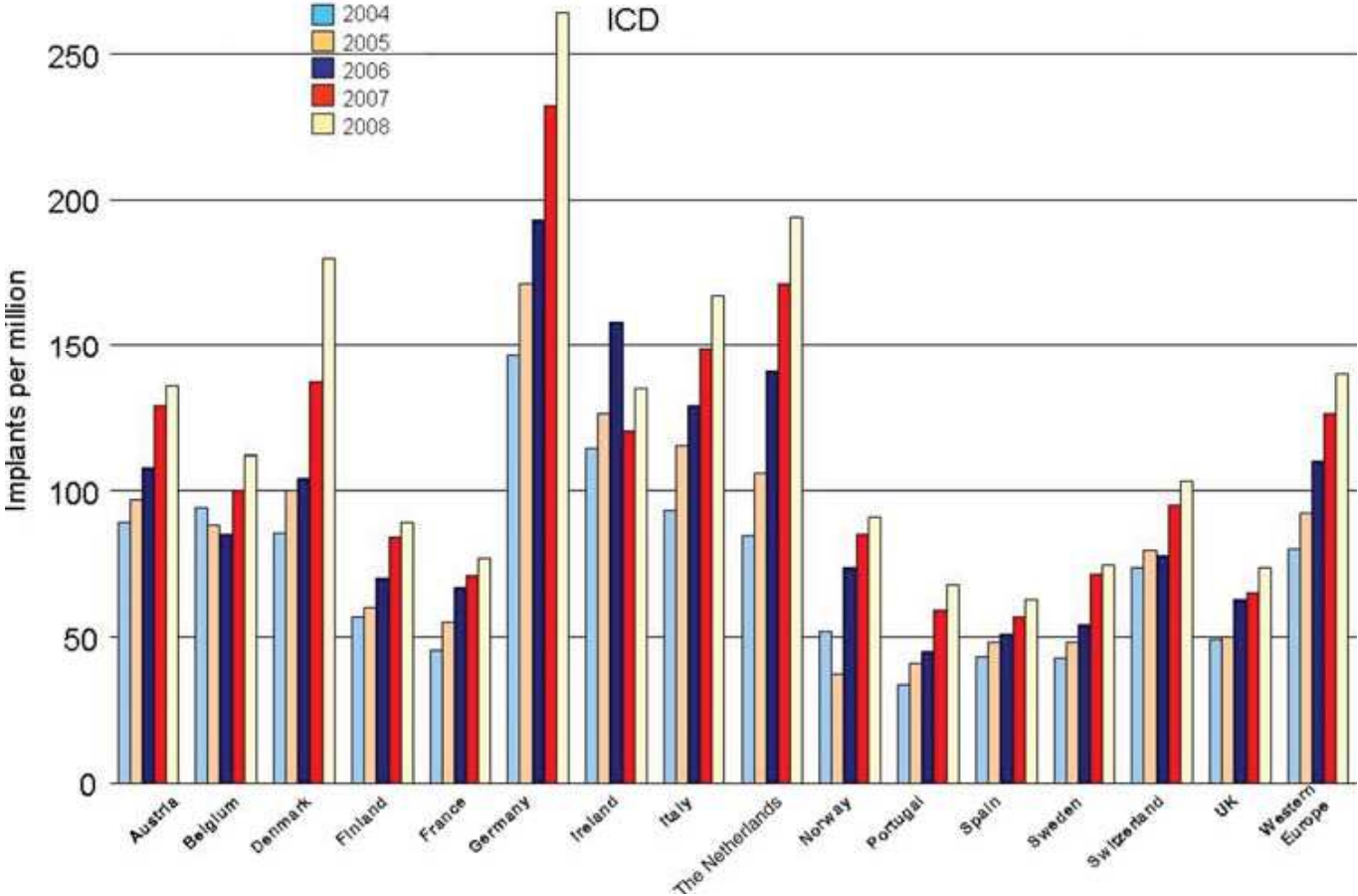
18th September 2015

Presentation overview

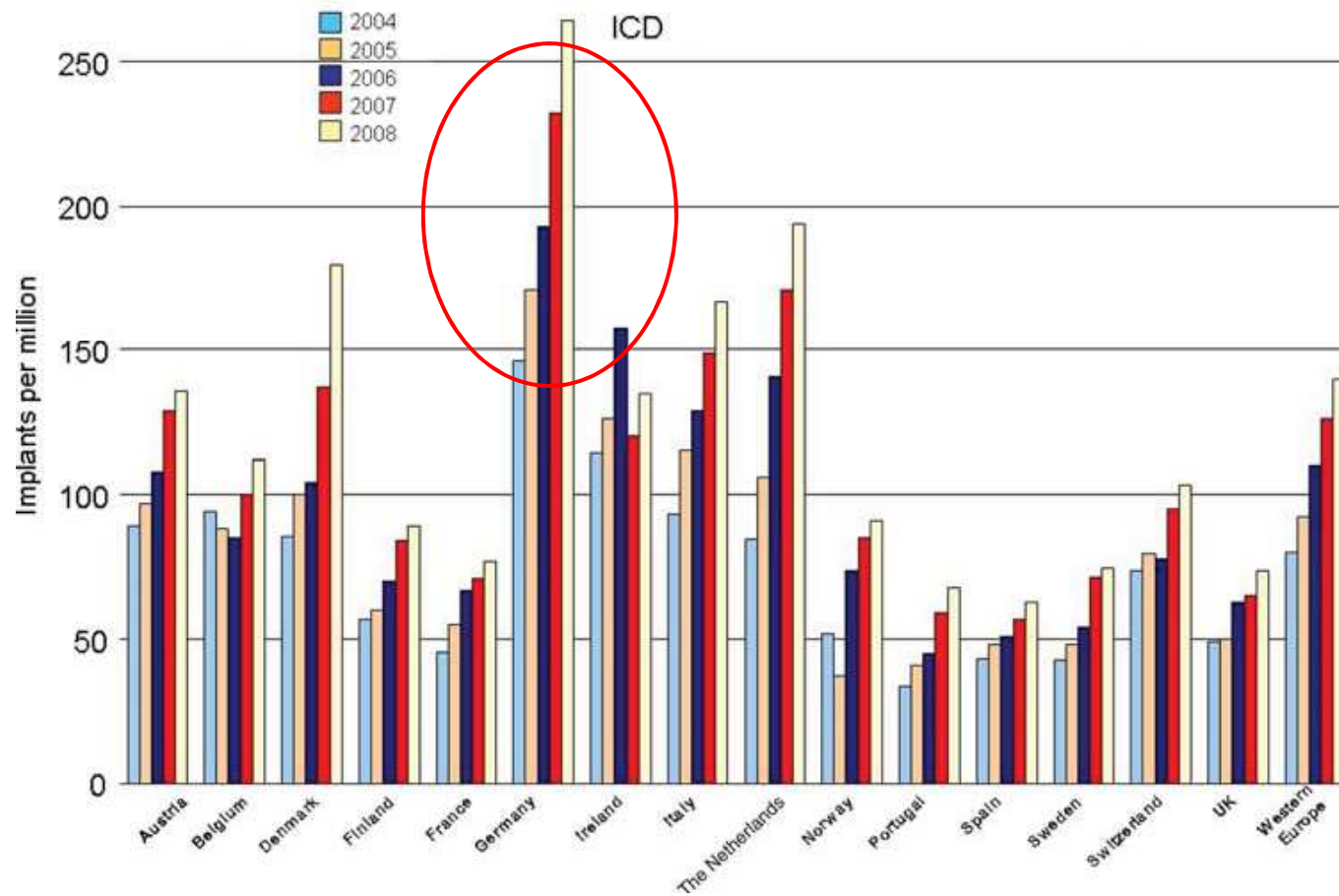
- ICD implantation & deactivation context
- 3 clinical questions that require answers
- Ethical & legal considerations
- Overview of research design & findings
- Practical implications & further work



Increasing implantation rates



Increasing implantation rates



An increasing elderly population

- **By 2050:** 25% of the population in Europe will be over 65 yrs.
Largest increase will be in over 85 age group.
- **By 2030:** Prevalence of HF will ↑ 46% compared to 2012
20% of all over 80 yrs have HF (Go et al. 2013)
- 20% of ICDs are implanted in patients over the age of 80 years
(Kaufman et al. 2011)
- Multiple debilitating diseases are more frequent among elderly, i.e. dementia
1/4 of people over 85 years have dementia (WHO 2011)





Impact on clinical practice

- Increasing number of elderly people with multiple co-morbidities
- Complex decisions required as the patient approaches end-of-life
- Counter-intuitively despite dire symptoms many patients with an ICD remain optimistic ([Stewart et al. 2010](#))
- Challenge: integration of palliative care & cardiology

Decision-making: the questions...

- When should ICD deactivation be discussed?
- Who should initiate the discussion?
- Who makes the final decision?



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European Guidance: Ambiguous

ESC 2009 (Palliative care position statement)

A discussion about deactivation should be **conducted early in the follow-up of end-stage HF** patients, ideally before the end of life. Patients should be considered when it is clinically **obvious that they are about to die**, when a DNR order is in force, and when the impairment of quality of life is such that a sudden cardiac death might be considered a relief.

EHRA Expert Consensus Statement 2010 (CIEDs Guidelines)

Pre-implantation informed consent.

At the time of implantation of an ICD/CRT-D

In the event of the patient having a DNR order or receiving palliative care (the deactivation of shock therapy should be suggested).

At each clinic visit significant changes in the patients' health should be asked and the physician informed of significant new diagnoses

ESC Acute & Chronic HF Guidelines 2012

If **Heart Failure deteriorates**, deactivation of a patient's ICD may be considered after appropriate discussion with patient and caregiver



European Heart Journal (2012), 33, 1787–1847
doi:10.1093/eurheartj/ehs104

ESC GUIDELINES



ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012

The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC

Table 28 Patients in whom palliative care should be considered

• Frequent admission to hospital or other serious episodes of decompensation despite optimized treatment
• Heart transplantation and mechanical circulatory support ruled out
• Chronic poor quality of life with NYHA class IV symptoms
• Cardiac cachexia/low serum albumin
• Dependence in most activities of daily living
• Clinically judged to be close to the end of life

NYHA = New York Heart Association.

Table 29 Key components of palliative care service

• Frequent assessment of patient's physical, psychological, and spiritual needs
• Focus on complete symptom relief from both HF and other co-morbidities
• Advanced care planning, taking account of preferences for place of death and resuscitation (which may include deactivating ICD)

American Guidance: Conflicting

HRS expert consensus statement 2010 (CIEDS Guidelines)

Prior to implantation

After episode of increased or repeated firing from ICD

Progression of cardiac disease including repeated hospitalisations for Heart Failure and /or arrhythmias

Patient / surrogate chooses a DNR order

Patient is at end of life

ACCF/AHA 2013 (Heart Failure Guidelines)

Information should be provided about the efficacy, safety, and potential complications of an ICD and the potential for defibrillation to be inactivated if desired in the future, notably when a patient is **approaching end of life**

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Implementation into practice?

- American study found 77% (n=430) physicians felt that it should be discussed pre-implantation (Kelley, et al. 2009)
- 4% of European cardiologists or electrophysiologists would discuss ICD deactivation at pre-implantation (Marinskis & van Erven. 2010)
- 40% of patients never wanted to discuss deactivation with their doctor (Thylen, et al. 2013)
- Retrospective case note review found no patients had a pre-implantation discussion (Hill, et al. 2015)

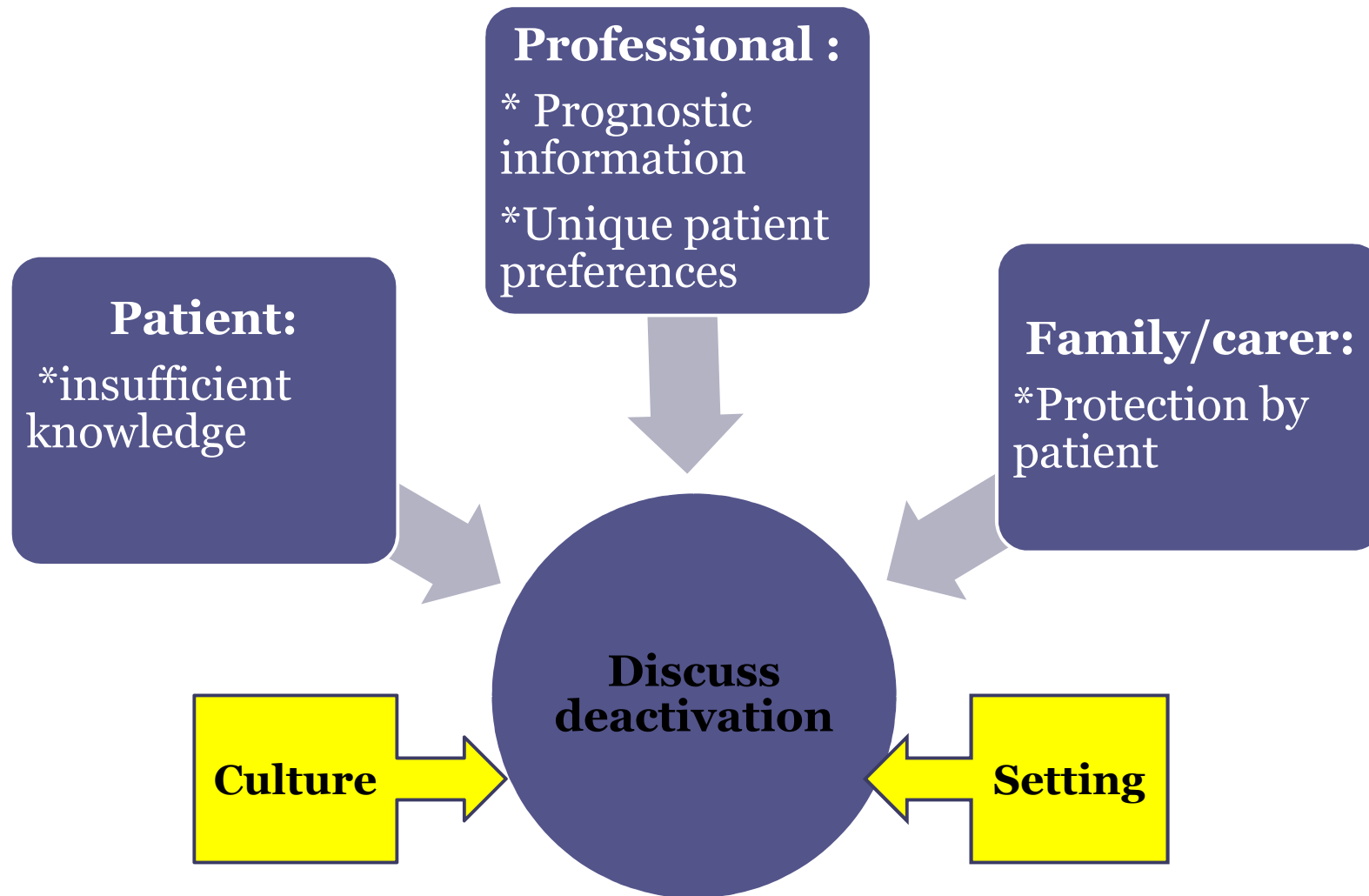


Decision-making: the questions..

- When should ICD deactivation be discussed?
- Who should initiate the discussion?
- Who makes the final decision?

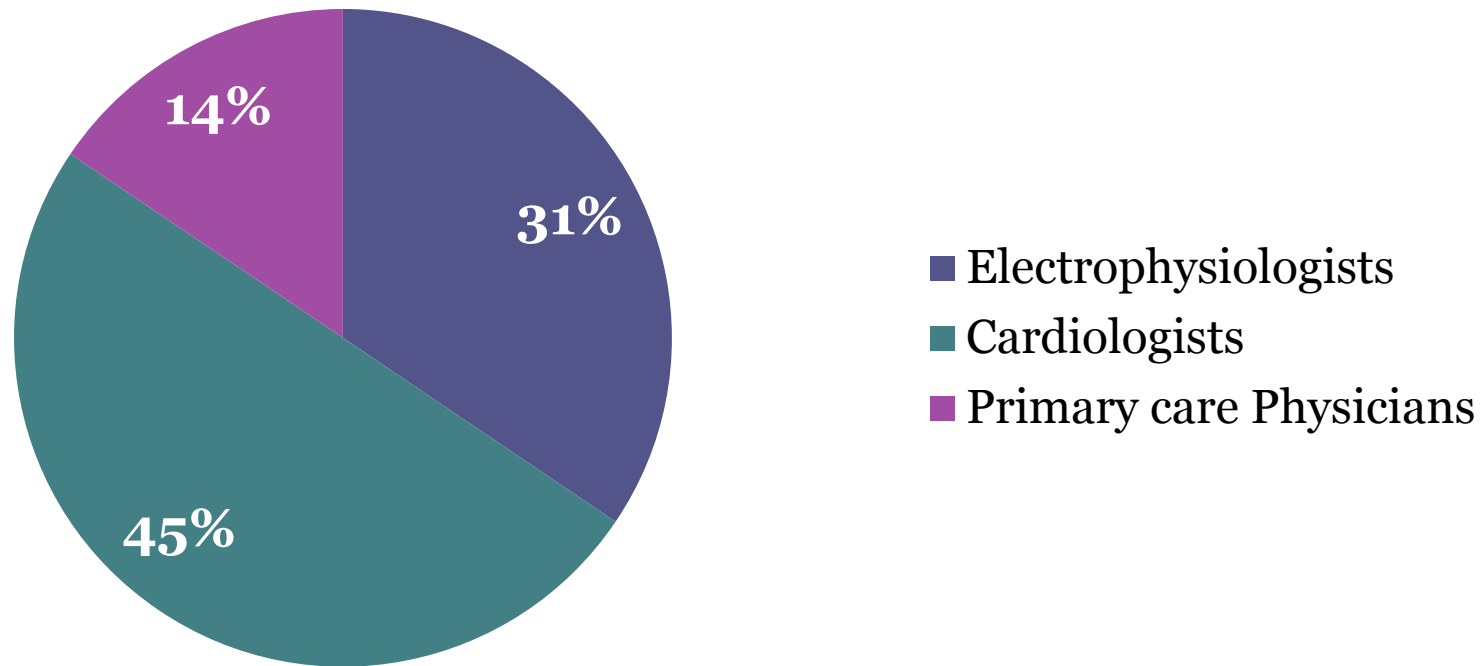


Challenges to initiating a discussion



Patients' Preferences

Responsible for initiating the discussion



Diverse perspectives

Patient:

1. *Systematic narrative review:* ([Hill, et al. 2014](#))

- Diverse preferences regarding discussion and deactivation
- Ethical & legal considerations
- “Living in the now”

2. *End-of life ICD questionnaire:* ([Thylen, et al. 2013](#))

- 69% of patients preferred discussion about deactivation during the last few days of life
- 40% - did not want to discuss deactivation:
- 1/10 discussed deactivation with family members

Professional:

3. *Physician survey :* ([Kelley, et al. 2009](#))

- Most physicians would initiate a discussion with Geriatricians & Electrophysiologists most willing
- Prior deactivation discussion was independent predictor
- 77% believed informed consent for implantation should include a discussion

Carer:

4. *Qualitative study:* ([Fluur, et al. 2013](#))

- Dealing with changes in life
- Handling an uncertain future

Decision-making: the questions...

- When should ICD deactivation be discussed?
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Who should make the final decision



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Patient

Cardiologist

Who should make the final decision



**C
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Cardiologist

Family/carer

Ethical & Legal Considerations

- Limited European use of Advance Directives
- Increasing use of advance care planning
- Mental capacity of the patient to decide
- Family's knowledge of the patient's wishes
- Legally permissible (UK) as viewed as the withdrawal of a life-sustaining intervention.



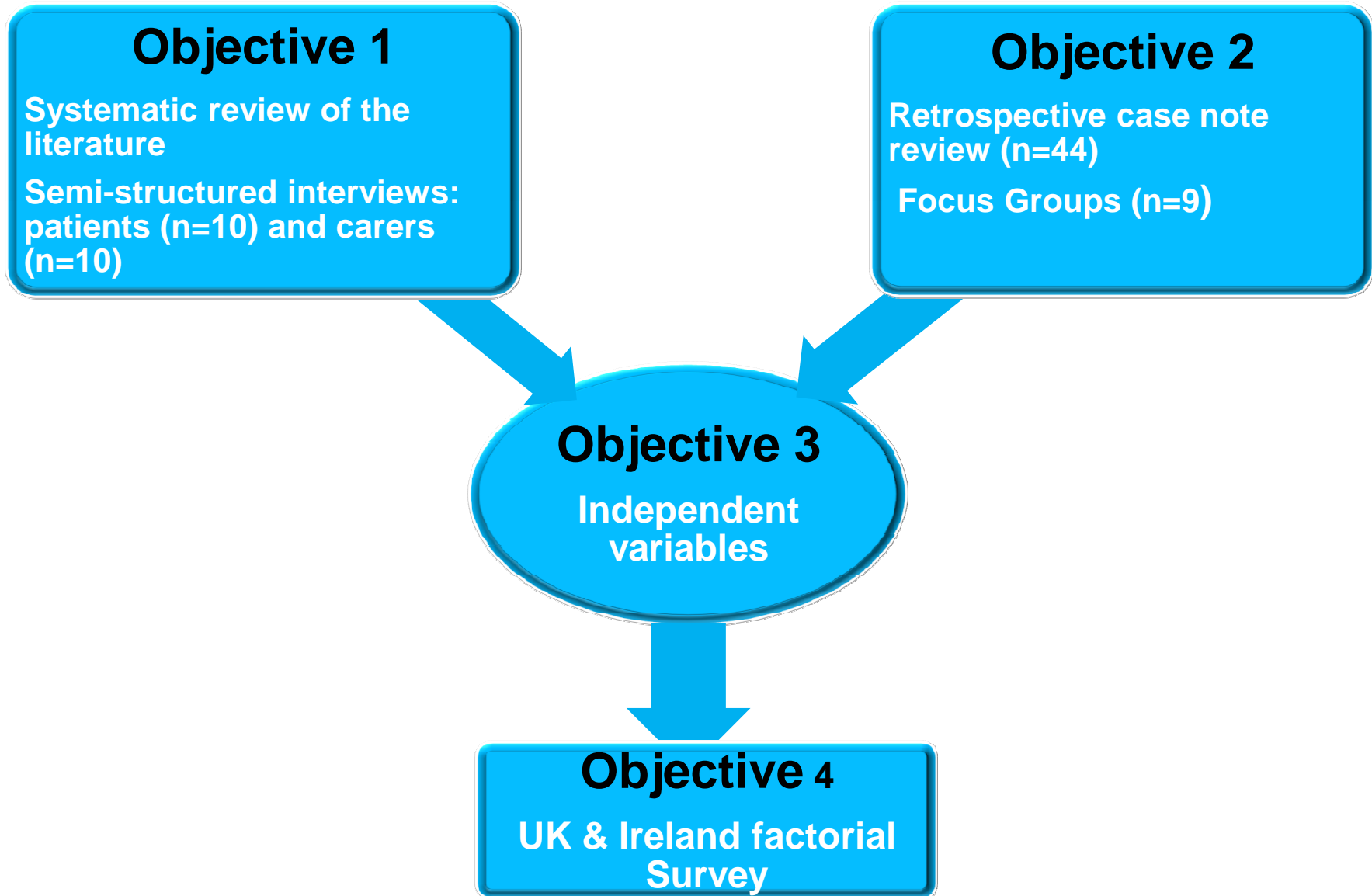
Management of Implantable Cardioverter Defibrillators in Advanced Heart failure: An exploratory study of heart failure patients', carers' and healthcare professionals' perspectives.

Supervisors: Prof Donna Fitzsimons
Prof Sonja McIlfratrick
Prof Brian Taylor

Submission for PhD: 2nd October 2015



Outline of the study



Results from Systematic Literature Review

Diverse preferences regarding discussion & deactivation

- Infrequently discussed prior to implantation
- Unique preferences
- Reluctance by UK & Irish patients to discuss or deactivate their ICD

Ethical & legal considerations

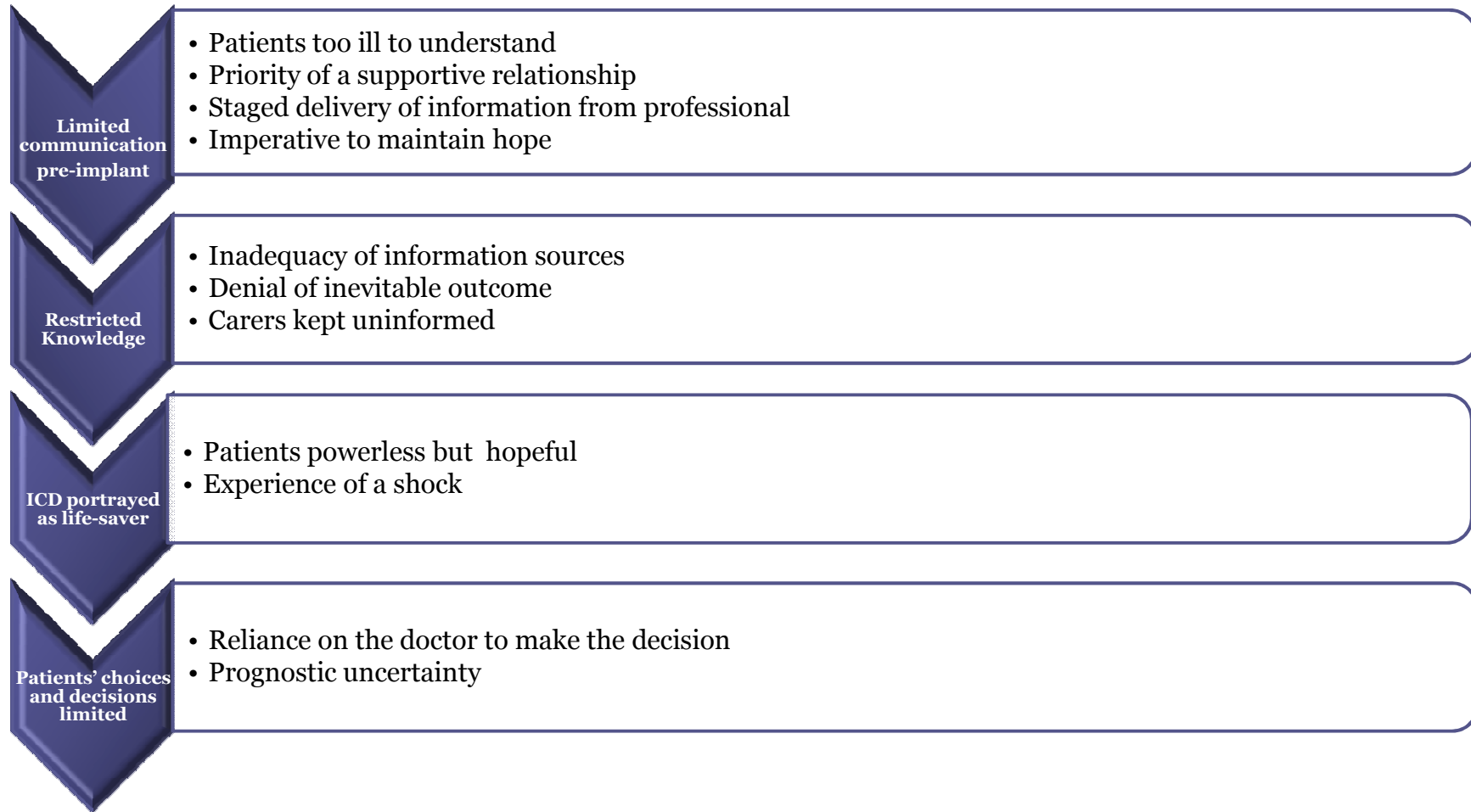
- Patients wanted involvement but physician should make the final decision
- Advance directives uncommon or did not mention ICD

'Living in the now'

- Positive outlook
- Quantity more important than quality of life

Qualitative data

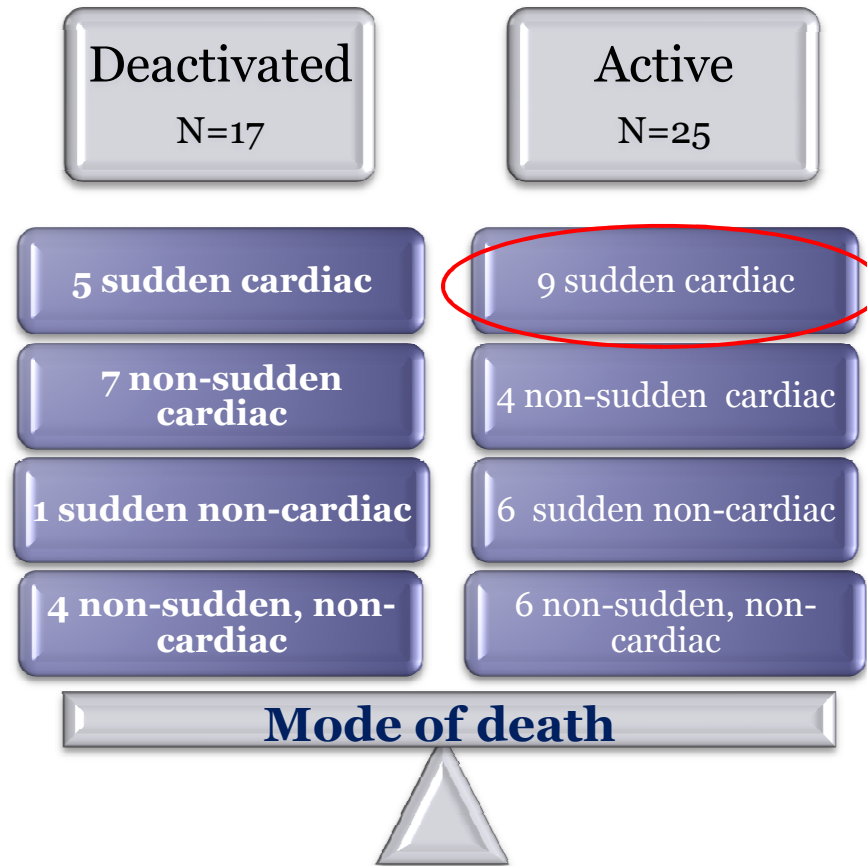
Four key themes:



Retrospective Case Note Review

Table 2: End of Life Discussion, N=23	
Characteristics	Median (25th, 75th percentile or N (%))
Incidence	23 (52)
Professional involved in the discussion	
Cardiologist	9 (20.4)
Physician	10 (22.7)
Specialist heart failure nurse	1 (2.3)
Cardiac Physiologist	1 (2.3)
Unspecified	2 (4.6)
Next of kin present	14 (31.8)
Topics discussed	
Technicalities of device only	1 (2.3)
Technicalities of device, prognosis & future treatment options	16 (36.4)
Prognosis only	5 (11.4)
Time from discussion to death, days	7.0 (1, 16.5)
Consequential Actions	
Specialist Palliative care referral	2 (4.5)
Do not resuscitate order	7 (15.9)
Specialist palliative care referral and Do Not Resuscitate order	7 (15.9)
Anticipatory planning	1 (2.3)
Hospice admission	1 (2.3)
Median (25 th , 75 th percentiles): Time from discussion to death. All additional results displayed as N	

Results on the mode of death

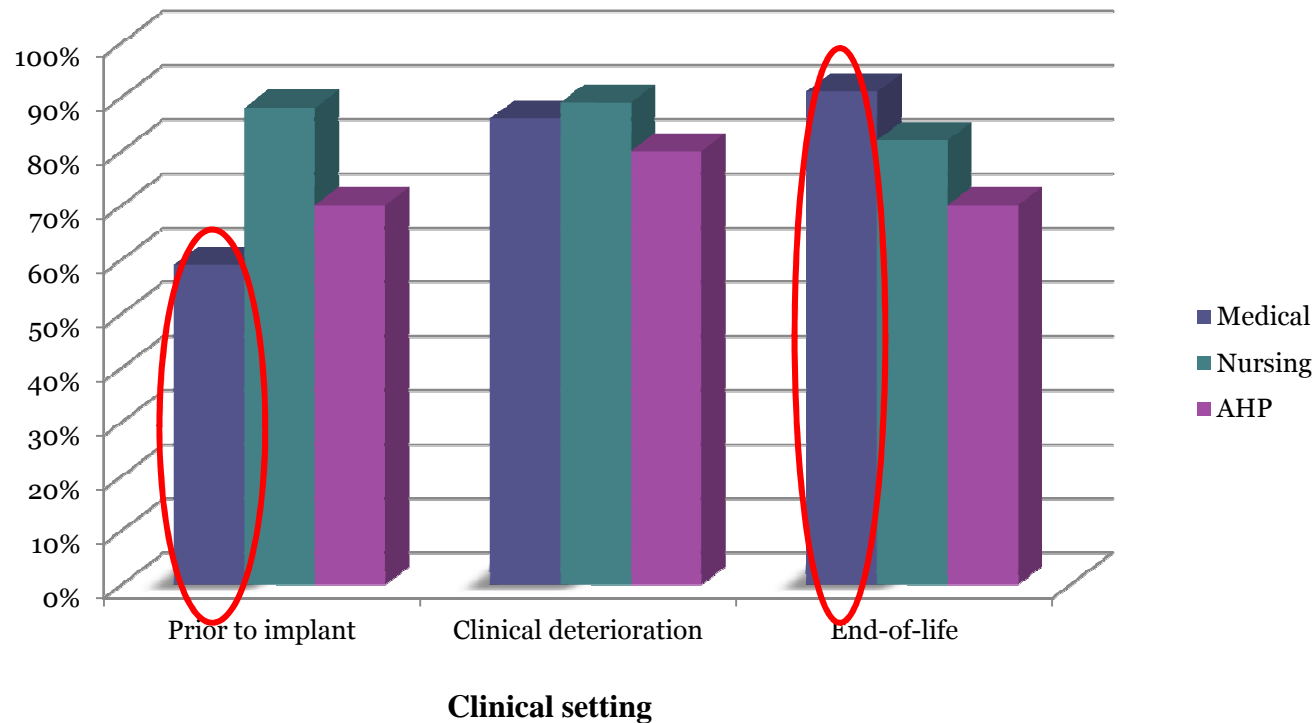


Clinical Implications

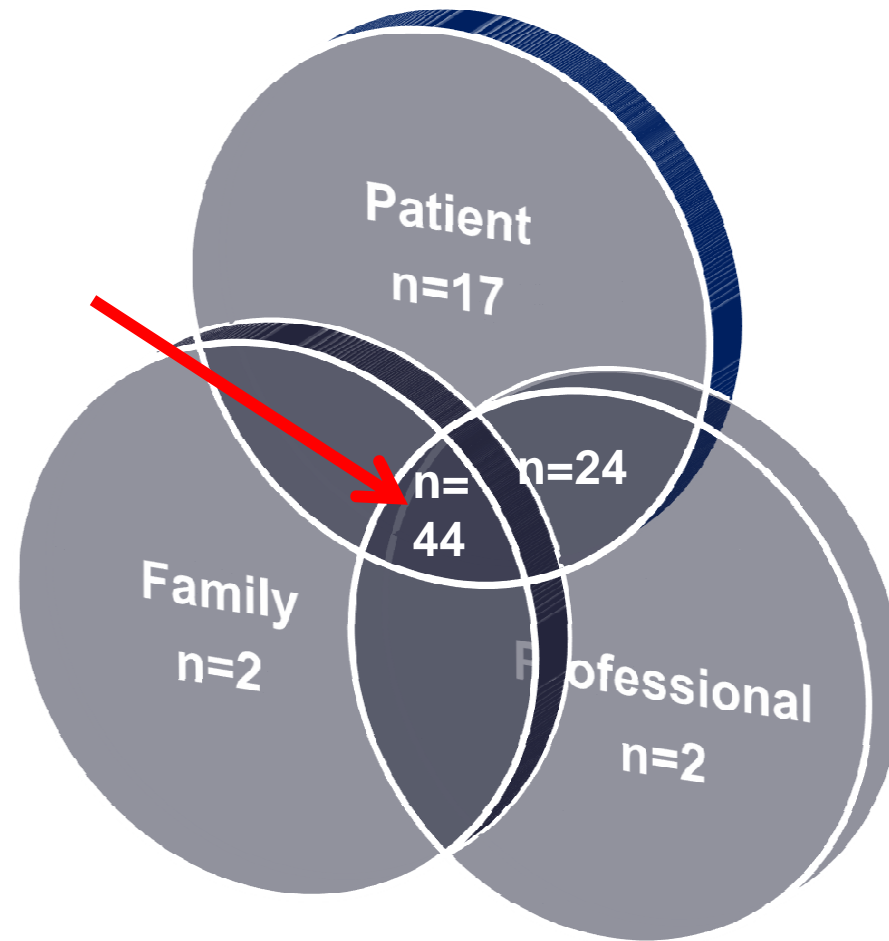
- 62.5% had an active ICD at death
- 94% who had their ICD deactivated never had a previous shock ($p = 0.003$)

Professional Preferences

- All medical, specialist nurses and cardiac physiologists felt the cardiologist should initiate discussion
- Consensus the discussion should take place when patient deteriorates
- No difference if organisational deactivation policy ($p=0.34$)

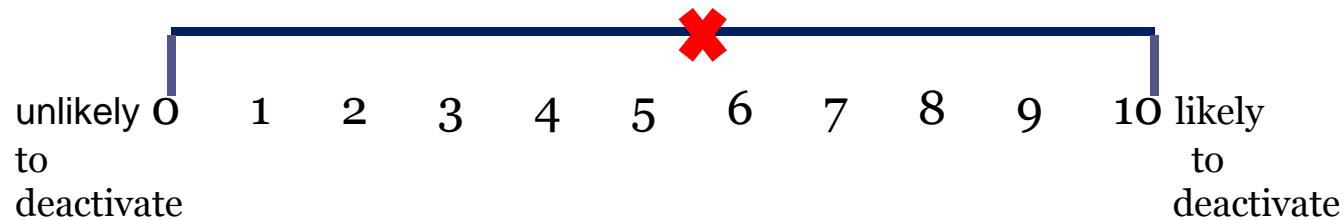


Professionals' Opinion: Who should make the decision?

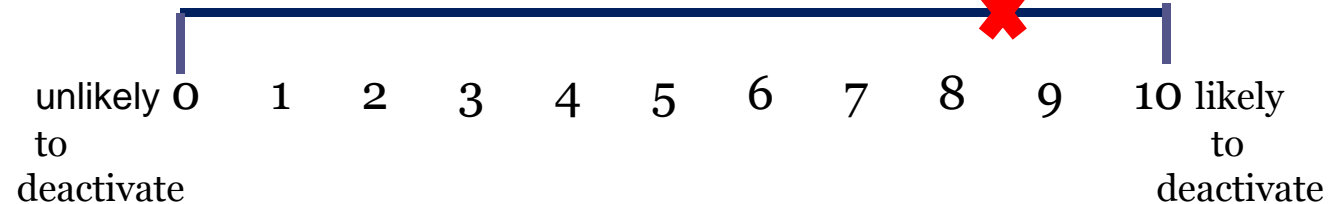


Decision-making Regarding Deactivation

- Patient sustained more than 10 shocks



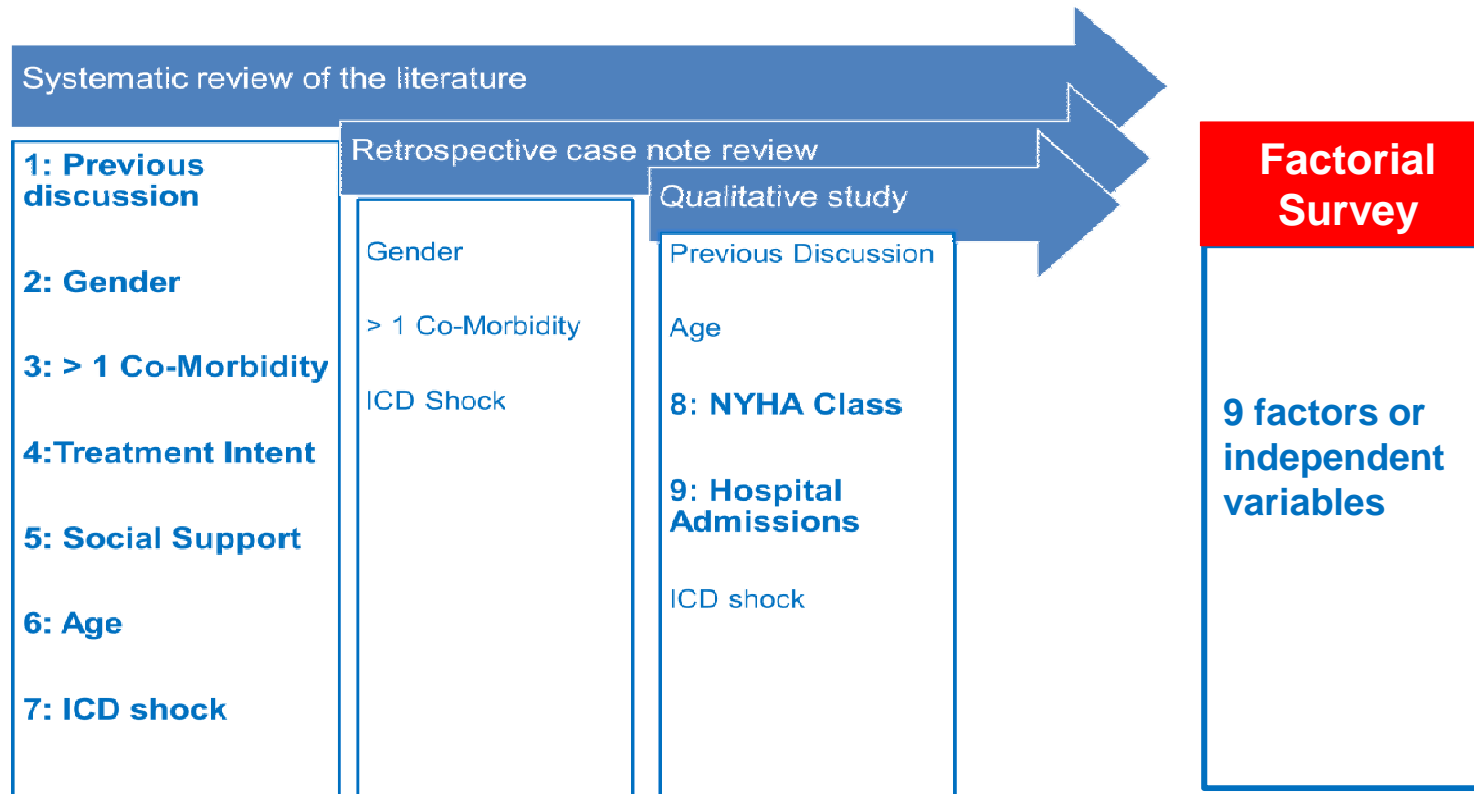
- Patient requests comfort care



- DNR being actioned



Developing Survey For Professionals: Which factors influence decision making?



Factorial Survey

- **Background:**

Advantage of combining randomisation with a survey to investigate professional decision-making (Rossi & Nock 1982).

- **Project Implicit:**

Complete anonymity with vignettes generated in 'real time'.

- **Supported by HFA (ESC):**

All cardiologists, electrophysiologists, specialist nurses and healthcare professionals throughout Europe who manage patients with an ICD.

- **Study Instrument:**

Demographic questionnaire, 1 standardised vignette & 6 unique vignettes.

Typical Vignette

You review a **59** year old **female** with **moderate heart failure (NYHA III)**, **advanced renal failure**. She has had **1 admission** over the past year and **has experienced more than 1 shock**. Medical records show **no previous discussion about deactivation** with documented management plan to be **continue present treatment**. The patient **lives alone with no family or friends**.

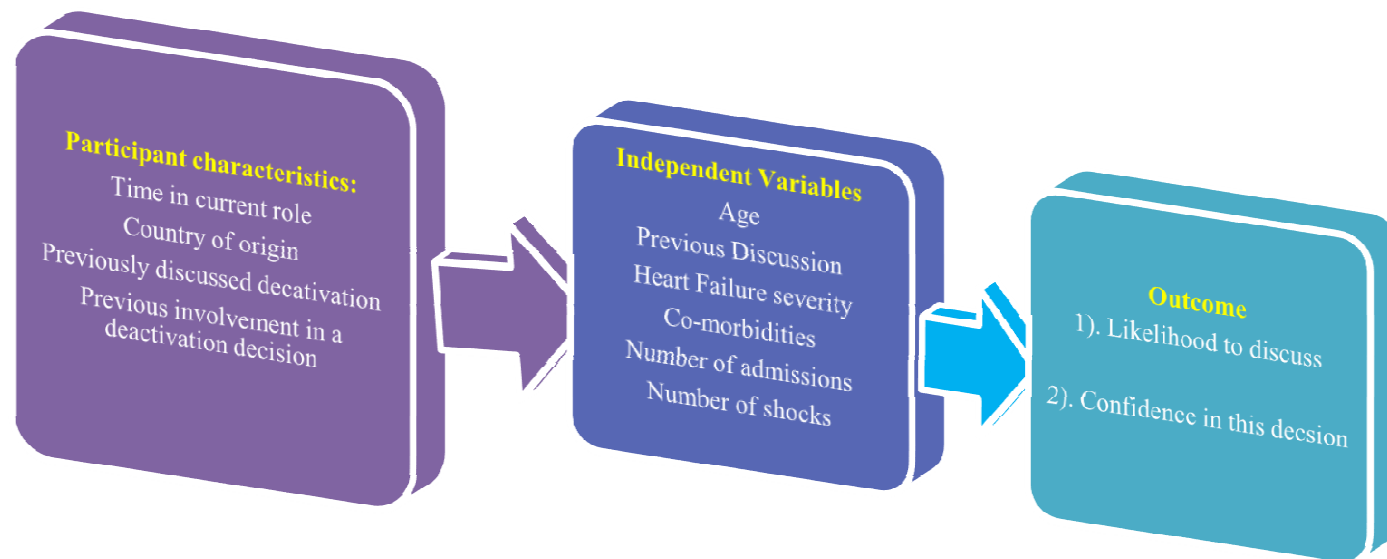
1. What is the likelihood that you would discuss ICD deactivation with this patient?

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

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

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

Summary of Findings





Clinical Implications

- Planned and open discussion preferably pre-implantation
- Increased awareness of patients' unique information needs
 - what they want to know & discuss
 - when to have discussion
 - what patients want their carers to know
- Documented advanced planning/ anticipatory care planning
- More involvement of specialist nurses in the discussion about deactivation
- Decision to deactivate an ICD does not solely reside around DNR order

Future Directions

- Qualitative exploration on factors which patient considered prior to deactivating their device
- European factorial survey on the factors which impact on professional judgement regarding an ICD at the end-of-life
<https://implicit.harvard.edu/implicit/Launch?study=/user/emily/clients/hill/hill.expt.xml&refresh=true>
- Increased understanding on the carer's role
- User friendly methods which translate guidelines to practice



Thank you for listening so attentively



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