Difficult conversations about ICDs:

When is the right time and how can we make those conversations easier?

Miriam Johnson

What's the issue for people with heart failure?

- Treatment of
- They incr
- They h
- They n
  distress
- ICDs used
  still do not h
- **HRS Expert Consens** **et al Heart Rhythm 2011**
- **Palliative Care and Cardiovascular Disease and Stroke: A Policy Statement From the AHA/ASA. Braun LT et al 2016**

"However this communication simply must take place. Instead of serving as a reason to avoid conversation, uncertainty should be a trigger for exploration."

Complications during life

- Trial data - 9.1%
  - related to:
    - Access
    - Lead
    - Generator
    - Infection
  - excludes inappropriate shocks
  - excludes psychological morbidity
- Registry data – 3% to 9.5%
  - Lowest in US register
  - Highest in Danish
  - Depends on method of detection
  - Same exclusions

openheart

2015

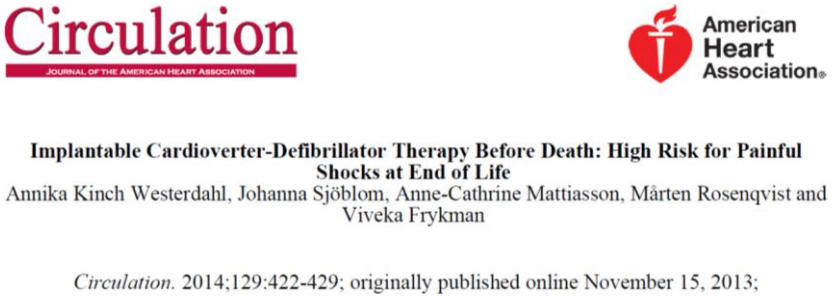
A systematic review of ICD complications in randomised controlled trials versus registries: is our 'real-world' data an underestimation?

Vivienne A Ezzat, Victor Lee, Syed Ahsan, Anthony W Chow, Oliver Segal, Edward Rowland, Martin D Lowe, Pier D Lambiase

Complications surrounding death

"Death and defibrillation: a shocking experience"

- PM device interrogation and chart review
- N =130
- 35% ventricular arrhythmias in the last hour before death,
- 31% received a shock in their last 24 hours, including many with arrhythmia storms,
- some receiving >10 shocks in their final hours.



- 52% of the group had a DNAR order but of these 65% had the device "on" at 24 hours preceding death, and 51% were still "on" 1 hour before death.

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So why don't we talk about it?

Clinicians:

- Most think conversations should happen
- Ethical misunderstandings
- Fear of taking away "hope"
- Belief can predict shocks and manage them
- Belief that patients understand about their device
- Belief that patients should initiate the conversation
- No time
- Insufficient training re communication skills

Circulation: Heart Failure

Lost in Translation
Examining Patient and Physician Perceptions of Implantable Cardioverter-Defibrillator Deactivation Discussions

Michael Mitar, Ana C. Alba, Jane MacIver, Heather Ross, 2012:5: 660-666

Barriers to Conversations About Deactivation of Implantable Defibrillators in Seriously Ill Patients Results of a Nationwide Survey Comparing Cardiology Specialists to Primary Care Physicians. Nathan Goldstein, Elizabeth Bradley, Jessica Zeidman, Davendra Mehta, R. Sean Morrison. *J Am Coll Cardiol*. 2009;54(4):371-373.

So why don't we talk about it?

Patients

- don't want to talk about it but don't understand it
- …cause instantaneous death "committing suicide"
- …it will always keep them alive
- … "exclusively benevolent"
- preferred to defer deactivation decisions to their physicians
- conversation unexpected
- as part of an overall conversation about prognosis and treatment planning with clinical team – more likely to consider and agree to "turn off"

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ICD Recipients' Understanding of Ethical Issues, ICD Function, and Practical Consequences of Withdrawing the ICD in the End-of-Life
ANNA STRO¨MBERG, CHRISTINA FLUUR, JENNIFER MILLER, MISOOK L. CHUNG, DEBRA K. MOSER, and INGELA THYL´EN. *PACE 2014; 00:1–9*

End-of-life decisions in ICD patients with malignant tumors. Kobza R, Erne P. *Pacing Clin Electrophysiol*. 2007;30:845–849.

When and how?

American Heart Association. life is why™

- Is there anything I need to know about an ICD regarding end-stage heart failure or death?

The decision should not be "…reactive based on an overdue response to suffering immediately before death." (Mitar et al)

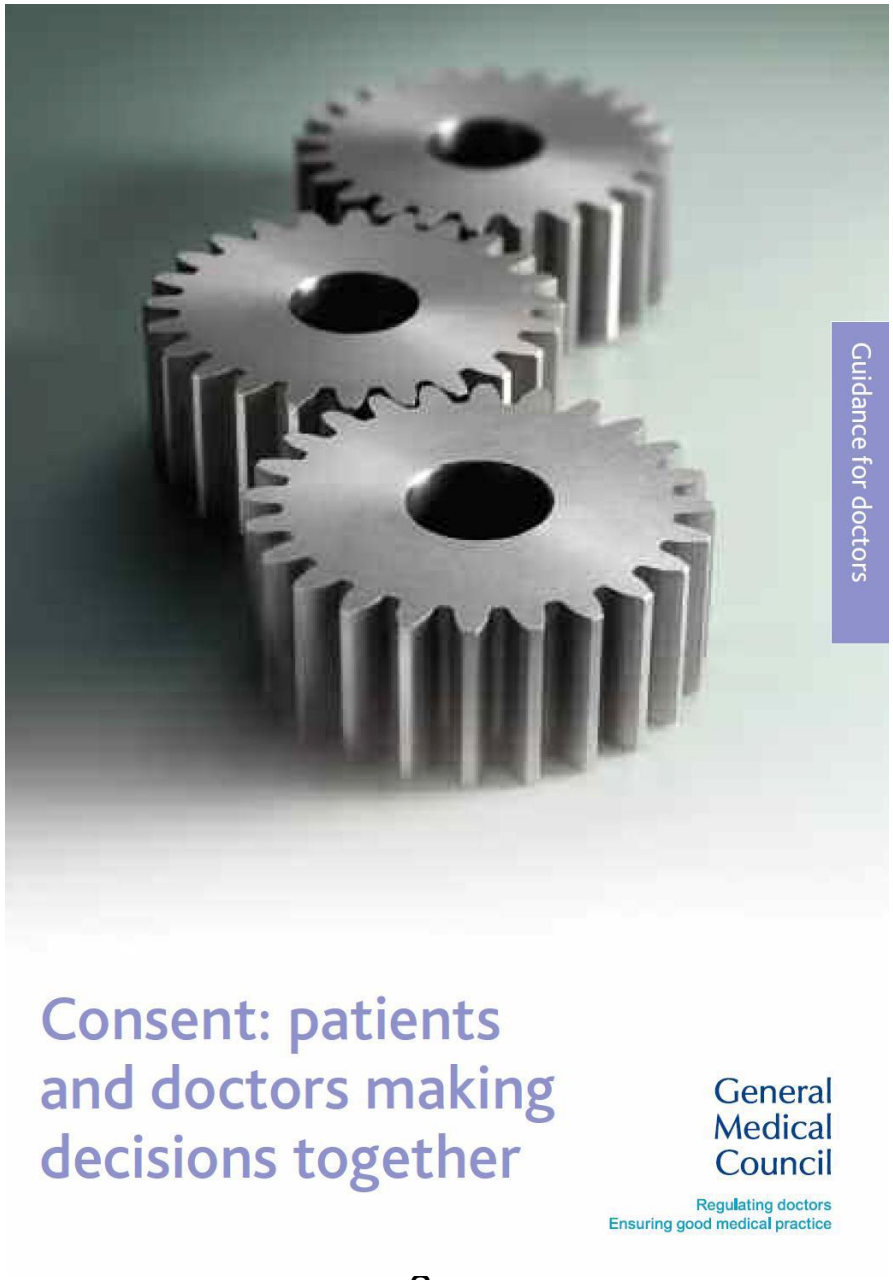
At implantation - explain

- Honestly about complications during life
- What the ICD can and cannot do
- There is a risk-benefit balance
- This will change as the disease changes
- There will come a time when the balance is about risk without benefit
- This will be regularly reviewed
- Review the risk-benefit balance regularly

- DO NOT LET THE CONVERSATION ABOUT DEACTIVATION BE A SHOCK

"You must give patients the information they want or need about:

the potential benefits, risks and burdens, and the likelihood of success, for each option;"



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How?

- Be clear about the ethical principles – this is the clinicians' job
  - Legal and morally acceptable
  - Principle of beneficence; dispel misinformation and ensure best risk-benefit balance for the patient
- Take responsibility
- Education and training
  - Develop and implement a conversational protocol for ICD deactivation discussions
- Discuss as part of an overall management plan, including anticipatory care planning, not in isolation
- Take time to identify misinformation and erroneous beliefs of patient and family
- Approach as a series of conversations which start at implantation

Take home messages

- Physicians over-estimate benefit and underestimate harms
- Patients have serious misconceptions including i) universal benefit, and ii) immediate death on “switching off”
- Harms are significant and common both during life and surrounding death
- It is the clinician’s responsibility to have the conversation(s)
- Conversations should be an *ongoing* part of an overall discussion of disease and management and start at implantation
- Training, education and systems should be in place

The final word

Questions: When i… …w can we make those conve…

When?

Start as… …e but the appr…

How to make it ea…

It should never be easy. But there are ways to make it happen.

"…this communication simply must take place. Instead of serving as a reason to avoid conversation, uncertainty should be a trigger for exploration." AHA 2016