

A qualitative study of decision-making about the implantation of cardioverter defibrillators and deactivation during end-of-life care

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Declared competing interests of authors: none

Published October 2016

DOI: 10.3310/hsdr04320

Scientific summary

Cardioverter defibrillators at end of life

Health Services and Delivery Research 2016; Vol. 4: No. 32

DOI: 10.3310/hsdr04320

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Scientific summary

Background

In the UK there are 100,000 sudden cardiac deaths per year. Implantable cardioverter defibrillators (ICDs) are recommended for patients at high risk of sudden cardiac death [primary prevention (PP)] and for survivors of cardiac arrest (secondary prevention). All ICDs combine both a shock function (to treat fast heart rhythms) with a pacing function (to treat slow heart rhythms). In some cases, the pacing function may be very sophisticated and can provide so-called cardiac resynchronisation therapy (CRT) for the treatment of heart failure. CRT itself may be provided by a pacemaker (cardiac resynchronisation therapy with pacemaker) or in conjunction with an ICD (cardiac resynchronisation therapy with defibrillator). The majority of ICDs are used for PP and in people with chronic heart failure. They increase life expectancy but may be associated with adverse effects (unnecessary or inappropriate shocks, device complications, increased hospitalisation and anxiety and depression). Consequently, decision-making about an ICD for an individual should consider the benefit of averting sudden death alongside possible future harms, including adverse effects and the potential need for deactivation towards the end of life. We aimed to critically explore patients'/relatives' and professionals' views about, and experiences of, ICD implantation and deactivation, and to examine how this information could support better shared decision-making (SDM).

Objectives

Our objectives were to explore patients', relatives' and clinicians' views and experiences of decision-making about ICD implantation and deactivation; to establish how and when ICD risks, benefits and consequences (including deactivation) are communicated to patients; to determine patients'/relatives' and clinicians' information and decision-support needs in the context of SDM; and to identify the individual and organisational facilitators and barriers to discussions about implantation and timely decision-making about deactivation.

Methods

Qualitative methods (observations, interviews and workshops) were used. To reflect a diversity of patients' experiences, we recruited people before and after ICD implantation, as well as people who declined ICD therapy, people considering prospective deactivation and bereaved relatives. Phase 1 involved observation of 38 consultations with patients being considered for ICD at three different settings: one specialist implanting centre and two district general hospitals. These observations facilitated 'context setting' (the nature of ICD consultations and decision-making interactions, including the patient's journey through different referral and care pathways) to inform our purposive sampling strategy and the content of interview guides for in-depth interviews with patients, relatives and clinicians (phase 2). Patient participants in phase 2 were recruited following an initial approach by a member of the clinical team. Bereaved relatives (up to 18 months post bereavement) were identified via the physiologists at one tertiary care centre and contacted via letter. Following return of a consent form, they were contacted by the research team. Observations were recorded in field notes and all interviews were audio-recorded and transcribed verbatim. Data collection and analysis occurred concurrently. Interactive workshops with clinicians and patients/relatives were used to validate our findings and to explore their ideas on how the findings could be used to support better SDM.

Findings

In total, 38 consultations were observed across three sites (July 2013 to January 2015) and 80 interviews were conducted with 44 patients/relatives (33 men and 11 women, aged 47–85 years), seven bereaved relatives of ICD patients and 29 clinicians (implanting and non-implanting cardiologists, palliative care clinicians, physiologists, psychologists and specialist nurses). Workshops with 11 clinicians and 11 patients/relatives were subsequently facilitated.

Patients and relatives want to be offered a choice and to be given balanced information about the available options relating to ICD therapy, in particular the potential impact on psychological well-being and quality of life in the short and long term. There was a lack of standardised methods used to convey information about the nature of ICDs (and other options) and associated risks, benefits and consequences, including a lack of tools to support an understanding of the information on benefits and adverse events in the short and long term. Clinicians' values about patients' preferences for information and involvement in decision-making and patients' stated preferences were often discordant.

Patients and relatives want to know about deactivation in advance of implantation and to be actively involved in decision-making. We found a lack of consensus/ownership among clinicians about who should take responsibility for discussing deactivation with patients and relatives and when such discussions should happen. Potential trigger points for deactivation discussions within the care pathway were suggested, in alignment with the need for regular monitoring and review over time in terms of the clinical effectiveness and appropriateness of continued ICD therapy.

Limitations

It was possible to recruit only two patients who were prospectively considering deactivation and seven bereaved relatives. Consequently, the views and experiences of these groups may be under-represented. With regard to bereaved relatives, the length of time post bereavement may have compromised accurate recollection. This study also lacks the perspectives of primary care clinicians.

Conclusions

Patients and relatives want information about the surgical procedure to implant ICDs, balanced information on the benefits, risks and consequences of ICD therapy, including involvement in decision-making about implantation and deactivation, with a preference for these issues to be addressed at the time of implantation. In particular, they want to know about the risk of adverse effects (including potential psychological problems and negative effects of ICDs on body image), which is often not conveyed to patients and may inhibit informed values-based decisions about ICD therapy.

The clinical rationale for offering ICD therapy should be clearly communicated to patients and their relatives as early as possible in the patient pathway, potentially using codesigned information and tools, including the live demonstration and manipulation of devices. There is a need for increased access to, and a greater role for, psychological support from appropriately qualified mental health professionals, including signposting to peer support groups. Patient/family member preparation for SDM with cardiologists provided by clinicians with frequent patient contact (e.g. heart failure nurses) may be of value.

The issue of deactivation could be introduced early in the care pathway and raised again at subsequent specific trigger points for more detailed and timely discussions with patients and their relatives. There is a pressing need for evidence-based strategies to foster interprofessional learning and collaboration between cardiology and palliative care teams in the context of ICD therapy.

Future work

Multifaceted SDM interventions are warranted that also include a focus on skills development for SDM (patients/relatives and clinicians), appropriate use of updated/revised decision-support tools, an exploration of a central role of heart failure nurses and physiologists in supporting patients/relatives and defining the role of primary care clinicians in providing ongoing care and initiating deactivation issues.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

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The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 11/2004/29. The contractual start date was in May 2013. The final report began editorial review in December 2015 and was accepted for publication in July 2016. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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