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Defibrillators, Deactivation, Decisions, and Dying

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In a medical culture where death is too often viewed as failure, clinicians and patients struggle to have high-quality discussions about deactivating an implantable cardioverter-defibrillator (ICD). The implications of this inaction are not trivial. In approximately half of hospices over the course of a year, patients dying of incurable disease will be shocked by their ICDs.[1] Multiple societies have made recent calls for increased communication around ICD deactivation.[2,3] However, exactly what form those conversations should take has yet to be determined.

In this issue, Dodson et al[4] publish results from a survey of 95 patients with ICDs (70% response rate) regarding their preferences for ICD deactivation. They found that when faced with a series of 5 scenarios about deactivation, 71% of respondents answered "possibly" or "definitely yes" that they would want their ICD deactivated. The authors also report qualitative results demonstrating relatively poor understanding of the risks and benefits of the ICD.

As the authors note, this finding is in contrast with prior surveys in which most patients say that they would not want to deactivate their ICD even if they were living with an advanced illness.[4] Why were patients in this study more likely to say that they would deactivate their ICD in certain scenarios? The authors hypothesize that it may have been because their protocol involved an informational script. We agree and propose that the survey went further to create a process that helped patients consider and clarify their preferences. In effect, the survey may have become a successful decision-making intervention.

Many patients with ICDs are unaware that it is possible to deactivate an ICD. We know that knowledge influences decisions. Thus, by introducing the topic of deactivation at the beginning of the survey, by exploring patient knowledge surrounding the pros and cons of ICDs, by clarifying their knowledge about deactivation, and then by reading and asking for a response to a series of 5 specific clinical scenarios about deactivation, they may have created a situation where postsurvey respondents were in a new place philosophically regarding ICD deactivation.

The dual-process theory of decision making argues that people process decisions either "intuitively," quickly drawing on past experiences and emotion, or "reasonably," using a more thoughtful, analytic approach. This theory is foundational in the growing field of behavioral economics and is the topic of a recent book called *Thinking Fast and Slow* by Nobel laureate Dan Kahneman.[5] According to a Cochrane review of 86 randomized trials of

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decision aids, when people go through a more reasoned process, their decisions are more likely to be better informed, based on more accurate expectations, and more concordant with their stated values.[6] Patients faced with decisions regarding ICD deactivation may quickly and intuitively seize on the prevention of sudden death. However, those same patients may also prefer to die peacefully in their sleep without prolonged suffering in the face of incurable disease. Thus, for patients with ICDs, a more reasoned approach is required to allow the patient to weigh the consequences of ongoing device function vs deactivation.

Any complex decision involving life and death is nuanced, and there are likely to be multiple explanations for the unique findings found in the survey by Dodson et al.[4] First, these patients were older than those surveyed in other studies, had their ICD for an average of 4 years, and 71% had not experienced a shock. The conclusion that patients were more willing to deactivate their device and less likely to be able to explain its risks and benefits may in part reflect that for many of these participants the ICD has been of relatively minor significance in their recent lives (positively or negatively). Second, the authors found that respondents were increasingly likely to deactivate their ICD through the 5 scenarios. Perhaps this was less a function of the specific content of the individual scenarios and more a function of having just spent 4 prior scenarios imagining death. It would have been interesting to see if presenting the scenarios in a random order would have changed the responses. Finally, thinking about one’s own death can be a challenging process.[7] Perhaps 30 minutes was not enough time to imagine these potential futures.[8] It would be informative to survey these 95 participants again to explore their postsurvey reflections and to see if their preferences for deactivation have remained stable.

While the authors conclude that the findings highlight the importance of including multiple patient-centered outcomes in advance care planning, we would also argue that difficult topics like ICD deactivation should be raised when patients have the time and emotional stability to consider complex information and reason through their preferences. This discussion could be part of an annual heart failure review.[3] Recently, updated performance measures surrounding ICD implantation state that all eligible patients should receive “counseling” to determine if an ICD is right for them.[9] Dodson et al[4] give evidence that at least a portion of that “counseling” should include preparation for a possible time in the future when a person may wish to deactivate their ICD.

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