Oregon Health & Science University
School of Medicine

Scholarly Projects Final Report

Title *(Must match poster title; include key words in the title to improve electronic search capabilities.)*

Bridging the Gap: Integrating Family Involvement in Decision-Making for Implantable Cardioverter Defibrillators

Student Investigator's Name

Michael Mudgett

Date of Submission *(mm/dd/yyyy)*

03/20/2026

Graduation Year

2026

Project Course *(Indicate whether the project was conducted in the Scholarly Projects Curriculum; Physician Scientist Experience; Combined Degree Program [MD/MPH, MD/PhD]; or other course.)*

MD

Co-Investigators *(Names, departments; institution if not OHSU)*

William Mackie, MD and Sarah Goodlin, MD

Mentor's Name

Sarah Goodlin, MD

Mentor's Department

Geriatrics

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Concentration Lead's Name

Mark Baskerville, MD

Project/Research Question

What do family members of patients who receive ICD or CRT-D therapy believe is important for other families to know when making decisions about implanted cardiac devices, and how can their perspectives inform more effective, family-inclusive shared decision-making?

Type of Project *(Best description of your project; e.g., research study, quality improvement project, engineering project, etc.)*

Qualitative research study using Grounded Theory

Key words *(4-10 words describing key aspects of your project)*

ICD; Shared Decision Making; Family Involvment

Meeting Presentations

If your project was presented at a meeting besides the OHSU Capstone, please provide the meeting(s) name, location, date, and presentation format below (poster vs. podium presentation or other).

N/A

Publications *(Abstract, article, other)*

If your project was published, please provide reference(s) below in JAMA style.

Pending publication

Submission to Archive

Final reports will be archived in a central library to benefit other students and colleagues. Describe any restrictions below (e.g., hold until publication of article on a specific date).

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Next Steps

What are possible next steps that would build upon the results of this project? Could any data or tools resulting from the project have the potential to be used to answer new research questions by future medical students?

Would investigate both family and patient perspectives as well as investigate themes more dynamically

Please follow the link below and complete the archival process for your Project in addition to submitting your final report.

https://digitalcollections.ohsu.edu/submit/direct?ln=en&sub=SBMETD

Student's Signature/Date *(Electronic signatures on this form are acceptable.)*
This report describes work that I conducted in the Scholarly Projects Curriculum or alternative academic program at the OHSU School of Medicine. By typing my signature below, I attest to its authenticity and originality and agree to submit it to the Archive.

X

Student's full name

Mentor's Approval *(Signature/date)*

X

Mentor Name

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Report*: Information in the report should be consistent with the poster, but could include additional material. Insert text in the following sections targeting 1500-3000 words overall; include key figures and tables. Use Calibri 11-point font, single spaced and 1-inch margin; follow JAMA style conventions as detailed in the full instructions.*

Introduction *(≥250 words)*

- **Decisions about implantable cardioverter-defibrillators (ICDs) and CRT-Ds are complex, and although families often help patients navigate these choices, many report inadequate communication, limited involvement, and little awareness of key issues, highlighting gaps in shared decision-making.[1-4]**
- **Objective: Analyze family perspectives to inform the development of family-inclusive strategies for ICD care.**

Methods *(≥250 words)*

- **Qualitative study using six focus groups with family members of patients who had received ICD or CRT-D therapy**
- **Participants recruited through cardiology and heart failure programs at two medical centers in Utah and Maryland**
- **All participants provided informed consent**
- **Conducted semi-structured, facilitator-led discussions exploring what families believe others should know about device decisions**
- **Sessions were audio-recorded, transcribed verbatim, and de-identified**
- **Original data collection received institutional review board approval; secondary analysis was deemed exempt**
- **Grounded theory analysis used to iteratively code transcripts until thematic saturation**
- **Independent co-author review and consensus discussions ensured accuracy and reliability of themes**

Results *(≥500 words)*

Family members of ICD recipients reported significant gaps in communication, education, and involvement, particularly a lack of awareness about ICD deactivation and limited understanding of device function, risks, and long-term implications. Families felt unprepared to support decision-making and emphasized the need for proactive clinician engagement and inclusion of key support persons. Personalized, one-on-one communication and structured decision-support tools were consistently preferred to improve shared decision-making and understanding.

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Discussion *(≥500 words)*

- **Family members frequently misunderstood ICD function, risks, and deactivation, and often felt unprepared to support decisions, highlighting persistent gaps in shared decision-making and communication. They expressed a strong preference for early, personalized involvement, including identification of key support persons, opportunities to ask questions, and tailored discussions rather than generic educational materials.**

Conclusions *(2-3 summary sentences)*

- **Family-inclusive strategies, such as identifying key support persons, introducing deactivation discussions earlier, and using structured, tailored communication tools, may improve shared decision-making and better prepare patients and families across the course of ICD care**

References *(JAMA style format)*

1. Standing H, Exley C, Flynn D, et al. A qualitative study of decision-making about the implantation of cardioverter defibrillators and deactivation during end-of-life care. *Health Services and Delivery Research.* 2016;4(32):1-150. doi:https://doi.org/10.3310/hsdr04320

2. Lee MC, Sulmasy DP, Gallo J, et al. Decision-Making of Patients With Implantable Cardioverter-Defibrillators at End of Life: Family Members' Experiences. *American Journal of Hospice and Palliative Medicine®*. 2016;34(6):518-523. doi:https://doi.org/10.1177/1049909116641622

3. GREEN AR, JENKINS A, MASOUDI FA, et al. Decision-Making Experiences of Patients with Implantable Cardioverter Defibrillators. *Pacing and Clinical Electrophysiology*. 2016;39(10):1061-1069. doi:https://doi.org/10.1111/pace.12943

4. Lewis CL, Wallace BC, Knoepke CE, Matlock DD. 144 Cardiologists' recommendations and perceptions of shared decision making for implantable cardioverter defibrillator placement. Published online July 1, 2024:A66.2-A66. doi:https://doi.org/10.1136/bmjebm-2024-sdc.143

5. Hill LM, McIlfatrick S, Taylor B, Dixon L, Fitzsimons D. Implantable cardioverter defibrillator (ICD) functionality: patient and family information for advanced decision-making. *BMJ Supportive & Palliative Care*. 2019;12(e2):e219-e225. doi:https://doi.org/10.1136/bmjspcare-2019-001835

6. Linder J, Hidayatallah N, Stolerman M, et al. Perceptions of an Implantable Cardioverter-Defibrillator: A Qualitative Study of Families with a History of Sudden, Life-Threatening Cardiac Events, and Recommendations to Improve Care. *Einstein Journal of Biology and Medicine*. 2016;29(1):3-3. doi:https://doi.org/10.23861/ejbm20132929

7. Timonen V, Foley G, Conlon C. Grounded Theory Research. In: *The Palgrave Handbook of Qualitative Research in the Health Sciences*. Springer, Cham; 2021:147-164. doi:10.1007/978-3-030-85124-8_9