The Science of Patient Centered Decisions: An ACCORDS Seminar Series

Please sign in and be sure to fill out an evaluation before you leave.

- More in this series:

<table>
<thead>
<tr>
<th>Date</th>
<th>Title</th>
<th>Speakers</th>
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<tbody>
<tr>
<td>2/7/2019 Ed2N 1206</td>
<td>Shared Decision Making in Practice: ICDs/LVADs</td>
<td>Dan Matlock, MD &amp; Larry Allen, MD</td>
</tr>
<tr>
<td>2/26/2018 Ed2N 1202</td>
<td>Shared Decision Making in Practice: Hospice &amp; Palliative Care</td>
<td>Maija Reblin, PhD</td>
</tr>
<tr>
<td>3/19/2019 Ed2N 1206</td>
<td>Shared Decision Making in Practice: Colon Cancer &amp; Lung Cancer</td>
<td>Tanner Caverly, PhD</td>
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- Behavioral Science in Health and Health Care: An ACCORDS Seminar Series

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<tr>
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<th>Speakers</th>
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<tbody>
<tr>
<td>2/20/2019 ED2S 2305</td>
<td>Behavioral Health in Practice: How to Implement Change in the Clinic</td>
<td>Danielle Loeb, MD and Bethany Kwan, PhD, MSPH</td>
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<td>3/21/2019 ED2S 2305</td>
<td>Multi-level Model of Change Capacity</td>
<td>Georges Potworoski, PhD</td>
</tr>
<tr>
<td>4/24/2018 ED2N 2307</td>
<td>At the Intersection of Policy, Advocacy, and Behavioral Medicine</td>
<td>Jim Sallis, PhD</td>
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Recorded seminars can be found on our website [https://goo.gl/1q9nUx](https://goo.gl/1q9nUx)
Request a Planning or Support Consultation with the Education Program
The Science of Patient Centered Decisions: An ACCORDS Seminar Series

Shared Decision Making & ICDs/LVADs

Dan Matlock, MD, MPH & Larry Allen, MD, MHS

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Request a Planning or Support Consultation with the Education Program

Thank you!
Shared Decision Making and Implantable Defibrillators

Dan Matlock, MD, MPH
Associate Professor of Medicine
University of Colorado School of Medicine
Implementation Scientist - GRECC

Colorado Program for Patient Centered Decisions
Implantable Defibrillators
Example: Implantable Defibrillators

<table>
<thead>
<tr>
<th>Treatment Comparison</th>
<th>Hazard Ratio (97.5% CI)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amiodarone vs. placebo</td>
<td>1.06 (0.86–1.30)</td>
<td>0.53</td>
</tr>
<tr>
<td>ICD therapy vs. placebo</td>
<td>0.77 (0.62–0.96)</td>
<td>0.007</td>
</tr>
</tbody>
</table>

- Placebo: (244 deaths; 5-yr event rate, 0.361)
- Amiodarone: (240 deaths; 5-yr event rate, 0.340)
- ICD therapy: (182 deaths; 5-yr event rate, 0.289)
Potential Harms of ICDs

- Procedural risks (Infection, Bleeding, etc.)

Additionally:
- Increased HF admissions (Goldenberg I, Circulation. 2006)
- Anxiety/Depression/PTSD (Sears SF, Heart. 2002)
- Inappropriate shocks (Sears SF, Am. J of Card. 2006)
- Potential suffering at the end-of-life (Goldstein NE, Annals Int. Med. 2004)
- Quality of Life (Noyes K, Medical Care. 2007)
Type of Death

Lunney, JAMA. 2003
Tools: Decision Aids

International Patient Decision Aid Standards (IPDAS)

1. Provide information about options
2. Present probabilities (unbiased and understandable)
3. Provide methods for clarifying values
4. Structured guidance for deliberation and communication

http://ipdas.ohri.ca/
What is a good decision?

- Cochrane Review of 115 trials of Decision aids
  - Improved knowledge
  - Improved patient/doctor communication
  - Improved patient involvement
  - Improved Satisfaction
  - Improved value/treatment concordance
  - Lowered decision conflict
  - Lowered decision regret
  - Lowered the proportion undecided

Stacey D, Cochrane Review, 2017
Design and Testing of Tools for Shared Decision Making

Daniel D. Matlock, MD, MPH; Erica S. Spatz, MD, MHS
Implantable Cardioverter Defibrillator

A decision aid for patients considering ICD therapy for primary prevention.

WATCH VIDEO

DOWNLOAD BOOKLET

DESCARGAR FOLLETO ESPAÑOL
Decision Aid: Paper Tools

Path 1
You may choose to get an ICD. You may be feeling like you usually do, then a dangerous heart rhythm could happen. The ICD may help you live longer by treating a dangerous heart rhythm. You will continue to live with heart failure that may get worse over time.

Feel Healthy

Feel Sicker

Death

Last years of life

“I’m not ready to die. I have so much I’m trying to stay alive for. Even if it means getting shocked, I’m willing to do anything that can help me live longer.”

Path 2
You may choose to NOT get an ICD. You may be feeling like you usually do and then a dangerous heart rhythm could happen. You may die quickly from the dangerous heart rhythm.

Feel Healthy

Feel Sicker

Death

Last years of life

“I’ve lived a good life. The idea of dying quickly sounds like a painless way to go. I’ve always said I hope to die in my sleep. Going through surgery and getting shocked is not the kind of thing I want.”

www.patientdecisionaid.org
## Benefit: Results from a 5-year study

<table>
<thead>
<tr>
<th>With an ICD</th>
<th>Without an ICD</th>
</tr>
</thead>
<tbody>
<tr>
<td>29 die, 71 live</td>
<td>36 die, 64 live</td>
</tr>
</tbody>
</table>

![Comparison chart showing outcomes with and without an ICD.]
"I'm not ready to die. I have so much I'm trying to stay alive for. Even if it means getting shocked, I'm willing to do anything that can help me live longer."

"I've lived a good life. The idea of dying quickly sounds like a painless way to go. I've always said I hope to die in my sleep. Going through surgery and getting shocked is not the kind of thing I want."
Decision Aid Tools: Video

www.patientdecisionaid.org
Pilot Trial

- DAs were feasible within three practice settings
- Utilizing clinic staff facilitated patient identification
- Patients:
  - Felt the DAs were helpful and balanced
  - Would recommend them to other patients
  - Non significant trends in improvements in decision quality (pilot trial)
  - Patients preferred the paper and video (not website)
- Clinicians wanted decision aids related to re-implantation and biventricular pacing
Implementation is hard!

- **Who will deliver the Decision aid?**
  - Provider?
  - Staff member
    - empowered to provide DA on behalf of provider

- **How will the DA be delivered?**
  - Electronically
    - With EHR? Patient portal? Email?
  - In person or mailed
    - Print, DVD?
Medical decisions require different depths of deliberation
- Daily, reversible vs. single, irreversible decisions

When will the DA be delivered?
- Timing important for shared decision making
  - Before visit may set up SDM
  - In visit can directly support SDM interactions
Clinicians lacked confidence in the content of the DAs
- Many concerns about DAs disrupting established workflows
- Lack of incentives a major barrier
# Stepped-Wedge Design

<table>
<thead>
<tr>
<th>Site</th>
<th>Control Period 5 months</th>
<th>Phase 1 Intervention Roll-Out 5 months</th>
<th>Phase 2 Intervention Roll-Out 5 months</th>
<th>Phase 3 Intervention Roll-Out 5 months</th>
<th>Phase 4 Intervention Roll-Out 5 months</th>
<th>Phase 5 Intervention Roll-Out 5 months</th>
<th>Phase 6 Intervention Roll-Out 5 months</th>
<th>Intervention Continued 5 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>St. Luke’s/MAHI</td>
<td></td>
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<td></td>
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<tr>
<td>Denver VA</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Providence</td>
<td></td>
<td></td>
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<tr>
<td>Baptist</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UC Health/ Denver Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beth Israel</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Why not something else?
- Classic patient-level randomization difficult due to diffusion;
  intervention is largely program-based
- Cluster randomization (3 sites DA, 3 sites none)

Advantages:
- Still random
- Phased implementation over time allows study

Disadvantages:
- Other changes in ICD care over the intervention period
- Medicare mandate – a major secular trend!
## Reach

<table>
<thead>
<tr>
<th>Provider - Clinic - System</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adoption</td>
<td>Reach</td>
</tr>
<tr>
<td>Implementation</td>
<td>Effectiveness</td>
</tr>
<tr>
<td>Maintenance</td>
<td></td>
</tr>
</tbody>
</table>

# received intervention

# eligible for intervention

Deceptively simple → denominator challenges
# Effectiveness

<table>
<thead>
<tr>
<th>Patient</th>
<th>Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reach</td>
<td></td>
</tr>
<tr>
<td>Effectiveness</td>
<td></td>
</tr>
<tr>
<td>Provider – Clinic – System</td>
<td>Adoption</td>
</tr>
<tr>
<td></td>
<td>Implementation</td>
</tr>
<tr>
<td></td>
<td>Maintenance</td>
</tr>
</tbody>
</table>

**Primary:**
1. **Knowledge** (IPDAS standard)
2. **Value-treatment concordance** (decision quality)

**Secondary:**
- Decision conflict
- Decision regret
- Control preferences
Adoption/Implementation

- Interviews with:
  - Clinical and Operational Staff involved with the Defibrillation patient education and decision making process
  - Cardiologists
  - Nurses
  - Administrators
## Maintenance at the clinic level

<table>
<thead>
<tr>
<th>Provider - Clinic - System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>- Reach</td>
</tr>
<tr>
<td>- Effectiveness</td>
</tr>
<tr>
<td>- Adoption</td>
</tr>
<tr>
<td>- Implementation</td>
</tr>
<tr>
<td>- Maintenance</td>
</tr>
</tbody>
</table>

What we will measure:
- Clinics that maintain, adapt, and discontinue use of PtDAs

How we will measure:
- Key informant interviews about why

*Measuring maintenance is easy*

*Obtaining maintenance is difficult*
## 14. Shared Decision-Making

**Recommendations for Shared Decision-Making**

References that support the recommendations are summarized in Online Data Supplement 60.

<table>
<thead>
<tr>
<th>COR</th>
<th>LOE</th>
<th>Recommendations</th>
</tr>
</thead>
</table>
| I   | B-NR| 1. In patients with 
|     |     | VA or at increased 
|     |     | risk for SCD, clinicians 
|     |     | should adopt a shared 
|     |     | decision-making approach 
|     |     | in which treatment 
|     |     | decisions are based not 
|     |     | only on the best available 
|     |     | evidence, but also on the 
|     |     | patients’ health goals, 
|     |     | preferences, and values (1-5). |
| I   | B-NR| 2. Patients considering 
|     |     | implantation of a new ICD 
|     |     | or replacement of an 
|     |     | existing ICD for a low 
|     |     | battery should be informed 
|     |     | of their individual risk of 
|     |     | SCD and nonsudden death 
|     |     | from HF or noncardiac 
|     |     | conditions and the 
|     |     | effectiveness, safety, 
|     |     | and potential complications 
|     |     | of the ICD in light of 
|     |     | their health goals, 
|     |     | preferences and values (1-5). |
“For these patients identified in B4, a **formal shared decision making encounter must occur between the patient and a physician (as defined in Section 1861(r)(1)) or qualified non-physician practitioner (meaning a physician assistant, nurse practitioner, or clinical nurse specialist as defined in §1861(aa)(5)) using an evidence-based decision tool on ICDs prior to initial ICD implantation. The shared decision making encounter may occur at a separate visit.”
www.patientdecisionaid.org

Tuesday, March 20, 2018
Users: 199

Friday, February 16, 2018
Users: 66

Jan 2018

April 2018

ICD Booklet
ICD Video
Our Program
Rep. Evident
Spanish ICD DA
LVAD DA
LVAD Systematic Review
Supporting Evidence
Medicare

- Requirements for Shared Decision Making
  - Lung Cancer Screening
  - Left Atrial Appendage Closure Devices
  - Implantable Defibrillators
Thank You

- Bryan Wallace
- Paul Varosy
- Jocelyn Thompson
- Channing Tate
- Colleen McIlvennan
- Fred Masoudi
- Carmen Lewis
- Jean Kutner
- Chris Knoepke
- Russ Glasgow
- Pilar Ingle
- Gracie Finnigan-Fox
- Monica Edwards
- Larry Allen

daniel.matlock@ucdenver.edu
www.patientdecisionaid.org
Shared Decision Making
For **LVAD** in End-Stage Heart Failure

Larry A. Allen, MD, MHS
ACCORDS Conference
February 2019
The Artificial Heart is Becoming Mainstream

Continuous Flow Technology: Centrifugal Design

HeartMate III

FDA Approved
BTT 2016
DT 2018

Continuous Flow Technology: Axial Design

HeartMate II

FDA Approved
BTT 2008
DT 2010

Pulsatile Technology

HeartMate XVE

FDA Approved
BTT 1998
DT 2002

Kirklin et al. Second IMACS Report

Table 4 Device Strategy, IMACS, January 1, 2013 to December 31, 2016 (n = 14,062)

<table>
<thead>
<tr>
<th>Device strategy</th>
<th>N</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Listed for transplant</td>
<td>3,984</td>
<td>28%</td>
</tr>
<tr>
<td>Bridge to candidacy</td>
<td>4,072</td>
<td>29%</td>
</tr>
<tr>
<td>Destination therapy</td>
<td>5,724</td>
<td>41%</td>
</tr>
<tr>
<td>Other</td>
<td>382</td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>14,062</td>
<td>100%</td>
</tr>
</tbody>
</table>

J Heart Lung Transplant, June 2018
DT LVADs Involve Complex Tradeoffs

High Risk
and Burdens
and Cost

High Reward
DT LVADs Involve Complex Tradeoffs

Benefits

Risks/Burdens
DT LVADs Involve Complex Tradeoffs

**Benefits**
- Continuous-flow LVAD (2009)
- Pulsatile-flow LVAD (2009)
- Medical therapy (2001)

**Probability of Survival**
- P = 0.008 (2009)
- P = 0.09 (2001)

**Months since Randomization**
- 0
- 12
- 18
- 24

**Risks/Burdens**
- 1 in 10 have a disabling stroke (10%)
- 2 in 10 have a serious bleed that requires medical attention (20%)

**Driveline care, power source management**
Quality v. Quantity

Aggressive v. Nonaggressive

$1000 bet
DT LVADs Involve Complex Tradeoffs

Benefits

- Driveline care
- Power source management

Risks/Burdens

- 1 in 10 have a disabling stroke
- 10%

Preference-Sensitive Decision

80% Alive 17% Alive

Driveline care, power source management
Informing Patients about LVAD has been Deferred to Marketing

In 2014, identified 77 LVAD educational materials...

- 97% discussed **benefits**
- 53% mentioned any **risks**
- 36% mentioned **lifestyle** considerations
- 1% mentioned **palliative care** or hospice as an option
- 0% met majority International Patient Decision Aid Standards

Development and Alpha Testing
Iterative changes with patient, caregiver and clinician feedback

Emotion and Fear of Death

Decision Framing

Paper
8 pages

Palliative and Hospice Care

Burdens Emphasized

Controlled Testimonials

Video
26 minutes

Caregiver Integration

What might my life look like with each OPTION?
The numbers below are a summary of information collected from recent medical studies. However, no one can know what will happen to an individual person.

Life with an LVAD
- How long might I live?
- Patients who receive an LVAD after just 2 months and a quarter of a year after their LVAD are alive.
- 80% are alive

Life without an LVAD
- How long might I live?
- Patients who receive an LVAD after 2 months and a quarter of a year after their LVAD are alive.
- 17% are alive

With or without an LVAD, there are services available to help with SYMPTOMS and suffering of advanced illness.

What is palliative care?
Palliative care is medical care for people with serious illness. It helps provide relief from symptoms, pain, and stress. It also provides emotional and spiritual support. The goal of palliative care is to improve the quality of life for patients and their caregivers.

What is hospice?
Hospice care is given by health professionals for patients near the end of their lives.

Patient Perspectives:
- Patients who quit LVAD
  - It was one of the best things you can do for me.
  - I never thought I would see my grandchildren.

Ruth
Wife

Dale
Patient
Whether patient decision aids help real people should be U
DECIDE-LVAD Trial

Test the **effectiveness** of a shared decision support intervention for patients considering DT LVAD consisting of:

1. Site-based training
2. Implementation of patient decision aids
Design: 6-Site, Stepped Wedge Trial


<table>
<thead>
<tr>
<th>Site</th>
<th>Pre 4 months</th>
<th>Phase 1 4 months</th>
<th>Phase 2 4 months</th>
<th>Phase 3 4 months</th>
<th>Phase 4 4 months</th>
<th>Post 4 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordinating Site</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Random Sites</td>
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<tr>
<td>2 Random Sites</td>
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<tr>
<td>1 Random Site</td>
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</table>

- Control Period
- Roll-Out
- Intervention Period
Patients, Caregivers and Data Collection

Initiation of formal DT LVAD evaluation

Enrollment, Baseline 1 Survey

Formal DT LVAD education

Baseline 2 Survey

1-Month Follow-Up Survey

6-Month Follow-Up Survey

INTERVENTION: Incorporate Patient Decision Aids
Patients, Caregivers and Data Collection

Majority of patients undergo open-heart surgery with a 1-5% risk of death

Enrollment, Baseline 1 Survey
Baseline 2 Survey
1-Month Follow-Up Survey
6-Month Follow-Up Survey

Time 0 1 month 6 months
Intrusive Research?

Majority of patients undergo open-heart surgery with a 1-5% risk of death

Enrollment, Baseline 1 Survey

Baseline 2 Survey

1-Month Follow-Up Survey

6-Month Follow-Up Survey

“The last thing I’d like to do the day before a life-threatening surgery is to fill out 90-minutes of questionnaires.”

Time 0

1 month

6 months
Patient Participants

248 patients enrolled (from n=385 eligible; power/planned n=168)
- Enrolled patients more likely to be white non-Hispanic than non-enrolled (75% vs. 64%)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Control (n=135)</th>
<th>Intervention (n=113)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean years (SD)</td>
<td>63.5 (9.7)</td>
<td>63.2 (10.2)</td>
</tr>
<tr>
<td>Male</td>
<td>82.2%</td>
<td>86.7%</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>79.1%</td>
<td>82.7%</td>
</tr>
<tr>
<td>Some college or more</td>
<td>56.4%</td>
<td>69.2%</td>
</tr>
<tr>
<td>On Disability</td>
<td>27.6%</td>
<td>32.0%</td>
</tr>
<tr>
<td>Married</td>
<td>72.5%</td>
<td>65.4%</td>
</tr>
<tr>
<td>Diagnosed &lt; 2 years</td>
<td>11.9%</td>
<td>12.4%</td>
</tr>
<tr>
<td>Enrolled in ICU</td>
<td>21.5%</td>
<td>26.5%</td>
</tr>
<tr>
<td>INTERMACS 4-7 (p&lt;0.01)</td>
<td>18.3%</td>
<td>44.6%</td>
</tr>
</tbody>
</table>

And, I’m lying on my back in the ICU near death.
Intervention Delivery

• Training
  • All sites participated: 31-72 staff per site

• Patient decision aid exposure
  • 88% received pamphlet decision aid
  • 92% received video decision aid

• “Educational materials” felt to be biased in favor of LVAD
  • 54% of control patients
  • 43% of intervention patients (p=0.13)
Primary Outcome: DECISION QUALITY

“The extent to which medical decision making reflects the considered preferences of a well-informed patient.”

Values-Choice Concordance

Knowledge

Lower-Quality LVAD Decision

Option chosen optimizes values, goals, and preferences

An informed patient

Higher-Quality LVAD Decision
Knowledge

- Control: 59.5%→64.9%
- Intervention: 59.1%→70.0%
- Adjusted difference of difference: 5.5%

Higher-Quality LVAD Decision

P=0.030

Control
Intervention

Staff Education and Patient Decision Aid

Lower-Quality LVAD Decision
Usual Care

Percent difference, mean (baseline 1 to baseline 2)
Values

- Do everything I can to live longer, even if that means having major surgery and being dependent on a machine.

Choice

- LVAD
- No LVAD

Concordant

- Live with whatever time I have left, without going through major surgery or being dependent on a machine.
Values - Choice Concordance

Values

Do everything I can to live longer, even if that means having major surgery and being dependent on a machine.

Live with whatever time I have left, without going through major surgery or being dependent on a machine.

Choice

LVAD

No LVAD

Discordant
Values-Choice Concordance

- Control: 0.17 correlation coefficient
- Intervention: 0.48 correlation coefficient
- Adjusted difference of difference: 0.28

Higher-Quality LVAD Decision

Knowledge Improvement

Percent difference, mean (baseline 1 to baseline 2)
Secondary Outcomes: 6-month implant

Adjusted for Site and Time Period

P=0.008

26% decrease in patient going on to LVAD

Control: 80%
Intervention: 54%
Maybe?

Time trends not adequately captured by step wedge?

26% of people scared out of potentially life-saving therapy?

Decrease profitable care?

![Bar chart showing comparison between Control and Intervention groups.](image)
Caregivers

182 caregivers enrolled (from n=217 eligible; power/planned n=168)

- No significant differences between enrolled/non-enrolled and control/intervention

<table>
<thead>
<tr>
<th></th>
<th>Control (n=111)</th>
<th>Intervention (n=71)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean years (SD)</td>
<td>60.2 (11.2)</td>
<td>11.5</td>
</tr>
<tr>
<td>Female</td>
<td>82.9%</td>
<td>92.5%</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>81.8%</td>
<td>86.4%</td>
</tr>
<tr>
<td>Some college or more</td>
<td>66.4%</td>
<td>63.6%</td>
</tr>
<tr>
<td>Employed</td>
<td>41.7%</td>
<td>43.9%</td>
</tr>
<tr>
<td>Married</td>
<td>86.4%</td>
<td>82.1%</td>
</tr>
<tr>
<td>Relationship to patient, spouse</td>
<td>73.9%</td>
<td>79.1%</td>
</tr>
<tr>
<td>Caregiver lives with patient</td>
<td>82.9%</td>
<td>83.8%</td>
</tr>
</tbody>
</table>
Knowledge

Non-significant
• Control: 64.2%→73.3%
• Intervention: 62.6%→76.4%
• Adjusted difference of difference: 4.8%
Values-Choice Concordance

Significant
- Control: 0.12 correlation coefficient
- Intervention: 0.49 correlation coefficient
- Adjusted difference of difference: 0.36

Knowledge Improvement
Percent difference, mean (baseline 1 to baseline 2)
Do You Have the Stomach for Results?

- **Decision Conflict** scores decreased significantly less after viewing decision aids compared to control period materials
  - Baseline 1: control 19.0, intervention 21.4
  - Baseline 2: control 2.6, intervention 9.3 (p=0.009)
    - Higher score=higer decision conflict

Are we just raising people’s anxiety?
Bereaved Caregivers...

20% of subjects **dead** by
6-month data collection
Original Investigation

Bereaved Caregiver Perspectives on the End-of-Life Experience of Patients With a Left Ventricular Assist Device

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IMPORTANCE For patients and their loved ones, decisions regarding the end of life in the setting of chronic progressive illness are among the most complex in health care. Complicating these decisions are increasingly available, invasive, and potentially life-prolonging technologies such as the left ventricular assist device (LVAD).

OBJECTIVE To understand the experience of bereaved caregivers and patients at the end of life who have an LVAD.

DESIGN, SETTING, AND PARTICIPANTS Semistructured, in-depth interviews were conducted between September 10 and November 21, 2014, with 8 bereaved caregivers of patients with an LVAD who were recruited from a single institution. Data were analyzed from December 13, 2014, to February 18, 2015, using a mixed inductive and deductive approach.

MAIN OUTCOMES AND MEASURES Themes from semistructured interviews.

RESULTS The 8 caregivers (6 females) described 3 main themes that coalesced around confusion in the final weeks with their loved ones: (1) the process of death with an LVAD approaching death, and (2) the legal and ethically permissible care of patients with an LVAD and (3) fragmented integration of palliative and hospice care.

CONCLUSIONS AND RELEVANCE Despite increasing use of LVADs in patients with advanced heart failure, bereaved caregivers of patients with an LVAD describe a high level of confusion at the end of life. There remains a need for the health care community to develop clear guidance on the management of patients with an LVAD at the end of life. Future work will focus on the educational process and the ideal timing and reiteration of such information to patients and families.

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Considerations

Strengths
- Real-world look through a hybrid effectiveness-implementation design
- Rare upstream capture of patients *considering* for DT LVAD (not just LVAD recipients)

Concerns
- Stepped-wedge is a quasi-experimental design
- Missing data due to death and withdrawal of patients not implanted
Next Steps

• Updated decision aids

• PCORI Dissemination and Implementation
  • Disseminate decision aids to all 173 LVAD programs across the U.S.
  • Targeted implementation strategies based on level of adopters at program
Thank You!  Larry.Allen@ucdenver.edu

- Collaborators:
  - Dan Matlock
  - Colleen McIlvennan
  - Jocelyn Thompson
  - And many more! (It takes a village)

- Patients and Caregivers

- Clinicians and clinical programs

Decision aids available for free at: http://patientdecisionaid.org/LVAD/