Championing Person-Centric Advance Care Planning

Reframing Shared Decision Making at the End of Life

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Objectives

- Define Shared Decision Making (SDM)
- How do we understand EOL DM Problems?
- Review important findings from EOL DM research
- Implications for Practice
- From what and who to who and how
Definition of Shared Decision Making

A collaborative process that allows patients/surrogates and clinicians to make health care decisions together, taking into account the best scientific evidence, as well as the patient’s goals and preferences.

How do we understand the problem?

37 studies used theory

- Decision making theories (n=15)
  - Charles et al.'s (1997) shared decision making model
  - Decision making models (shared, paternalistic, consumer; Katz, 1984; Emanuel et al., 1992; Charles et al., 1999)
  - O'Connor et al.'s (1999) Ottawa decision support framework

- Family centered approaches (n=11)
  - Teno et al.'s (2001) patient-centered, family-focused model
  - Janzen's (1978; 1987) Therapy Management Group
  - Kissane et al.'s (2003) Family focused grief therapy model

- Behavioral change model (n=8) and others (n=3)
  - Health belief model
  - Self-efficacy theory
  - Transtheoretical model

8 studies developed theory

- The puzzle of pain management
- Dancing on the stairs
- Maintaining integrity in the face of death
- Contextual anatomy of a wish to die

Framework for End of Life Decision Making

Significance of Shared Decision Making at End of Life

Multiple Reports Call for improved Decision Making

1995 SUPPORT Study
2004 NIH State of the Science on Improving EOL Care
2011 NINR et al. Science of Compassion
2014 IOM Dying in America

Quality of EOL

Most people prefer to die at home but few achieve this. (Tang & Mccorkle, 2003; Fischer, Min, Cervantes & Kutner, 2013).

Cost

40% of US pts w cancer in ICU in final 180 days, compared with <18% in Belgium, Canada, England, Germany, Netherlands, Norway (Bekelman, Halpern, Blankart, Bynum et al., 2016)
Preliminary Work

1) Attitudes towards Advance Directives

Descriptive study of 34 Medical Inpatients:

Only 15% had an AD

Positive attitudes $M = 50.38$ (SD, 5.58) (possible range 17-68)

41% felt did not know enough and that their Dr. would decide

74% thought AD would help their family  \textit{Nolan, Bruder} (1997).

2) Accuracy of Surrogates in EOL Decision making

Descriptive study of 150 patients with ALS, CA, HIV, CHF

If comatose, 54% of patients would opt to have the judgements of their loved ones guide DM \textit{even if it disagreed} with a “perfect” living will.

Gap in the Decision Making Literature

  – i.e. *what* patients want

• Little is known about whether surrogates can predict *how* patients want decisions made at the end of life
Natural History of End-of-life DM

Aims

• From diagnosis to death, measure patient’s desired level of control over DM relative to their Dr. and family.
• Use two scenarios: conscious and unconscious.
• Describe DM using open-ended interviews.
Natural History of End-of-life DM

Design
Mixed methods, Descriptive Exploratory

Sample
Patients with Stage III/IV GI CA, ALS, CHF NYHA III or IV
Family Caregivers

Procedure
Patient identified important health care decision and rated decision control preference re: that decision
Family caregiver: estimated patient decision control preference re that decision
Followed Participants every 3 mos for up to two years or until death
<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent</td>
<td>Shared</td>
<td>Reliant on Physician</td>
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</tbody>
</table>
Decision Control Preferences Scale
Substituted Judgment vs. Best Interest

Independent via Previous Wishes

Shared

Reliant on Physician
Decision Control Preferences Scale
(Degner, Sloan, & Venkatesch, 1997)

- Independent
- Shared
- Reliant on Family
Decision Control Preferences Scale
Substituted Judgment vs. Best Interest

Independent via Previous Wishes

Shared

Reliant on Family
Results
N = 130 Patients

- 40% CHF
- 36% CA
- 24% ALS
- 64% white
- 63% male
- Mean age of 62.0 +/- 12.5 years.
- 65% High School or less Education
- 39% had an Advance Directive

Nolan, Hughes, Narendra, Sood, Terry, Astrow, Kub, Thompson, Sulmasy (2005). When patients lack capacity: The roles that patients with terminal illness would choose for their physicians and loved ones in making medical decisions, Journal of Pain and Symptom Management, 30(4), 342-353
While only 15% would rely on the Dr.’s judgement (D, E) while conscious, 39% chose this if they were unconscious (P < .001)
While only 6% would rely on Loved Ones judgement (D, E) while conscious, 21% chose this if they were unconscious ($P = 0.39$)
If you are unconscious, how should we weigh input of Physician and Family?

- My loved one’s input should weigh most heavily
- My doctor’s and my loved one’s input should both weigh equally
- My doctor’s input should weigh most heavily
- What if the respondents were Physicians?
Decision control preferences for physician participants in Precursors (blue bars, n = 488) and in patients reported by Nolan et al., 2005 (red bars, n = 130)
Changes over time:
If unconscious, role of family
N = 147 Patients

Decision Control Preferences (A-E) scored as 1 (independent) to 5 (reliant)

Did not change over time re: Family
2.61 (95% CI = 2.41 – 2.80) baseline to
2.25 (95% CI = 2.25 – 2.81) at 6 months

Generalized estimating equations (GEEs) used to test multivariable models

Changes over time:
If unconscious, role of physician
N = 147 Patients

Patient Decision Control Preferences Moved to 
greater independence from physician

3.27 (95% CI = 3.08 – 3.45) baseline to
2.84 (95% CI = 2.58 – 3.10) at 6 months
P < .001

Women and patients with ALS more likely to
move to greater independence from physician

Older patients more likely to shift to greater
reliance on physician
Accuracy of Family Estimates of Patient Decision Control Preferences

• 52 patient-family member dyads
  – 27 ALS
  – 25 CA

• Family members
  – 65% female
  – Mean age of 55.9 +/- 11.5 years
  – 81% were spouses
  – 29% previously helped family member with decision-making
Results Unconscious Scenario

• 24/52 (46%) dyads concordant : kappa 0.15

• Preference for independent decision-making NOT associated with higher odds of agreement
  – OR 1.5, 95% CI 0.44-5.10
  – AOR 1.5, 95% CI 0.39-5.54

• CA dyads had higher odds of agreement than ALS dyads
  – AOR 3.79; 95% CI 1.09-13.16

Implications for Practice

- Elderly rely more on physician over time
- Reliance on family remains stable
- Physicians should check in to see if more help in DM is needed as disease progresses in elderly
- Physicians may ask patient how family should be involved in DM early in disease process
- One cannot assume decision control preferences based on education, race, health status
Aims

At 8 weeks after intervention

Test effect of TAILORED Intervention on family:

• Decision self-efficacy
• Decision making distress, caregiver burden, depression
• And patient satisfaction with family decision involvement

TAILORED EOL Decision Making Intervention Study

Design
RCT

Sample
163 patient (41% ALS, 59% GI CA)-surrogate dyads
Patient-identified family member who might be involved in decisions

Intervention
- Intensive nurse directed discussion of patient EOL decision control preferences vs. control discussion of nutrition
- Take-home handout
- Baseline paper and pencil surveys then intervention
- 4 week “booster” phone call
- 8 week outcome measure

Sulmasy, Hughes, Yenokyan, Kub, Terry, Astrow, Johnson, Ho, Nolan (under review). The TAILORED study: A randomized controlled trial to improve surrogate decision making.
TAILORED EOL Decision Making Intervention Study

Findings

Race: 68% White, 24% Black
Sex: 58% male
Age: 62.7 (+/- 11.0)
Education: 38% HS, 31% college

Sulmasy, Hughes, Yenokyan, Kub, Terry, Astrow, Johnson, Ho, Nolan (under review). The TAILORED study: A randomized controlled trial to improve surrogate decision making.
Findings: Preferences for shared decision making

Patients:

- Baseline
  - I: 40% and C: 52%
- Post intervention:
  - I: odds of shared decision making increased (AOR: 1.78, p .04)
  - C: odds of shared decision making decreased (AOR: 0.59, p .08)

Sulmasy, Hughes, Yenokyan, Kub, Terry, Astrow, Johnson, Ho, Nolan (under review). The TAILORED study: A randomized controlled trial to improve surrogate decision making.
Findings: Preferences for shared decision making

Family:

- Baseline
  - I: 38% and C: 40%
- Post intervention:
  - I: odds of shared decision making increased (AOR: 2.05, p .03)
  - C: odds of shared decision making did not change (AOR: 1.44, p .28)

Sulmasy, Hughes, Yenokyan, Kub, Terry, Astrow, Johnson, Ho, Nolan (under review). The TAILORED study: A randomized controlled trial to improve surrogate decision making.
Findings: Satisfaction with decision involvement

Family:
Post Intervention:
C: 52% completely satisfied on 5-pt scale
I: 71% completely satisfied on 5-pt scale

Family Confidence in decision making (self-efficacy)
High at baseline and 8 weeks in both groups

Sulmasy, Hughes, Yenokyan, Kub, Terry, Astrow, Johnson, Ho, Nolan (under review). The TAILORED study: A randomized controlled trial to improve surrogate decision making.
Discussion
TAILORED Intervention

- Increases in preference for shared decision making,
- Increases in surrogate-patient congruence
- Increase in surrogate decision satisfaction
- Decrease in surrogate decision distress
- Increase in caregiver burden

While changes were modest, improvements in these outcomes at the EOL are rare
Open-ended family interviews after patient death

- Treatment decision making very painful
- Family cohesion about decisions important
- Desire that loved one be respected for who he/she is as a person at EOL
- Need for affirmation that they (family member(s)) were doing a good job in caregiving
Implications for Practice

• The TAILORED intervention is brief and acceptable
• Decision making at EOL is complex
• Address who is the preferred decision maker and how decisions will be made rather than simply what decisions may be faced.
• Ask family about who the patient is even when unconscious
• Affirm the role of the family caregiver
TAILORED ICD Pilot Study of Decision Making about Deactivation at EOL

Design
Pilot Study of RCT

Sample
Convenience sample of 50 dyads of clinic patients with advanced CHF and ICD
Patient-identified family member who might be involved in decisions

Intervention
• Intensive nurse directed discussion of patient EOL decision control preferences vs. control discussion of nutrition
• Take-home handout
• Baseline paper and pencil surveys then intervention
• 4 week “booster” phone call
• 8 week outcome measure
TAILORED ICD Pilot Study of Decision Making about Deactivation at EOL

Findings

Plan for Deactivation by Group at Baseline and 8 weeks

<table>
<thead>
<tr>
<th>Study Arm</th>
<th>Time 1</th>
<th>Time 3</th>
<th>Time3 vs. Time 1</th>
<th>Interventio n vs. Control at time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>3 (12%)</td>
<td>7 (33%)</td>
<td>0.074</td>
<td>0.076</td>
</tr>
<tr>
<td>Intervention</td>
<td>6 (24%)</td>
<td>11 (65%)</td>
<td>0.013</td>
<td></td>
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At 8 weeks: Family Members Asked if they could make a decision re: Deactivation

Control: 33.3% certain that they could make decision
TAILORED 58.8% certain that they could make


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Thank you