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

American College of Critical Care Medicine and American Thoracic Society (Kon, Davidson, Morrison, Danis, Douglas & White, 2016).

How do we understand the problem?

37 studies used theory

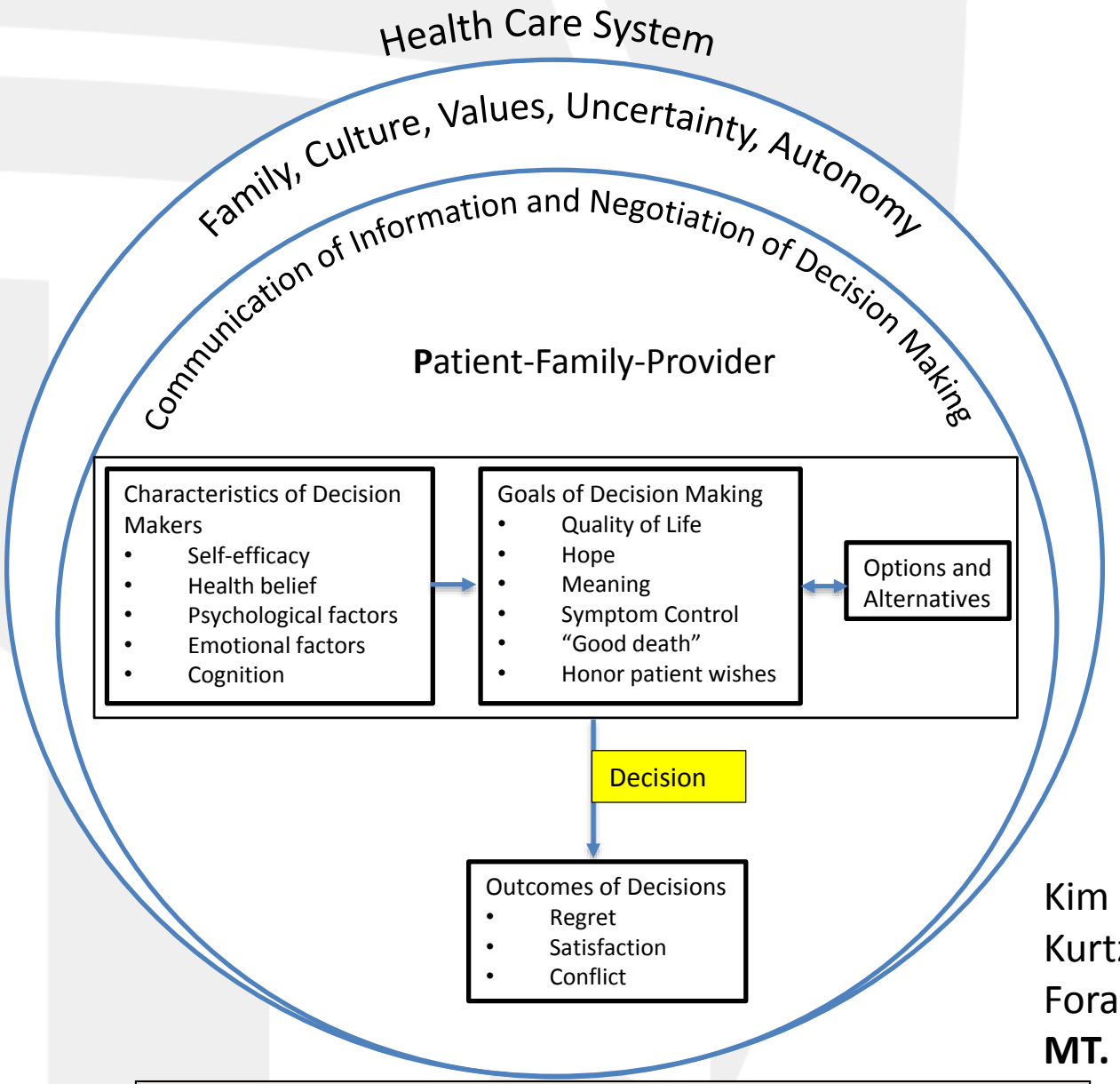
- Decision making theories (n=15)
  - Charles et al.'s (1997) shared decision making model
  - Decision making models (shared, paternalistic, consumer; Katz, 1984; Emanuel et al., 1992; Charles et al., 1999)
  - O'Connor et al.'s (1999) Ottawa decision support framework
- Family centered approaches (n=11)
  - 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

Kim K, Heinze K, Xu J, Kurtz M, Park H, Foradori M, Nolan MT. (2017). Theories of health care decision making at the end of life: a Meta-ethnography, *Western Journal of Nursing Research*. 2017 Aug

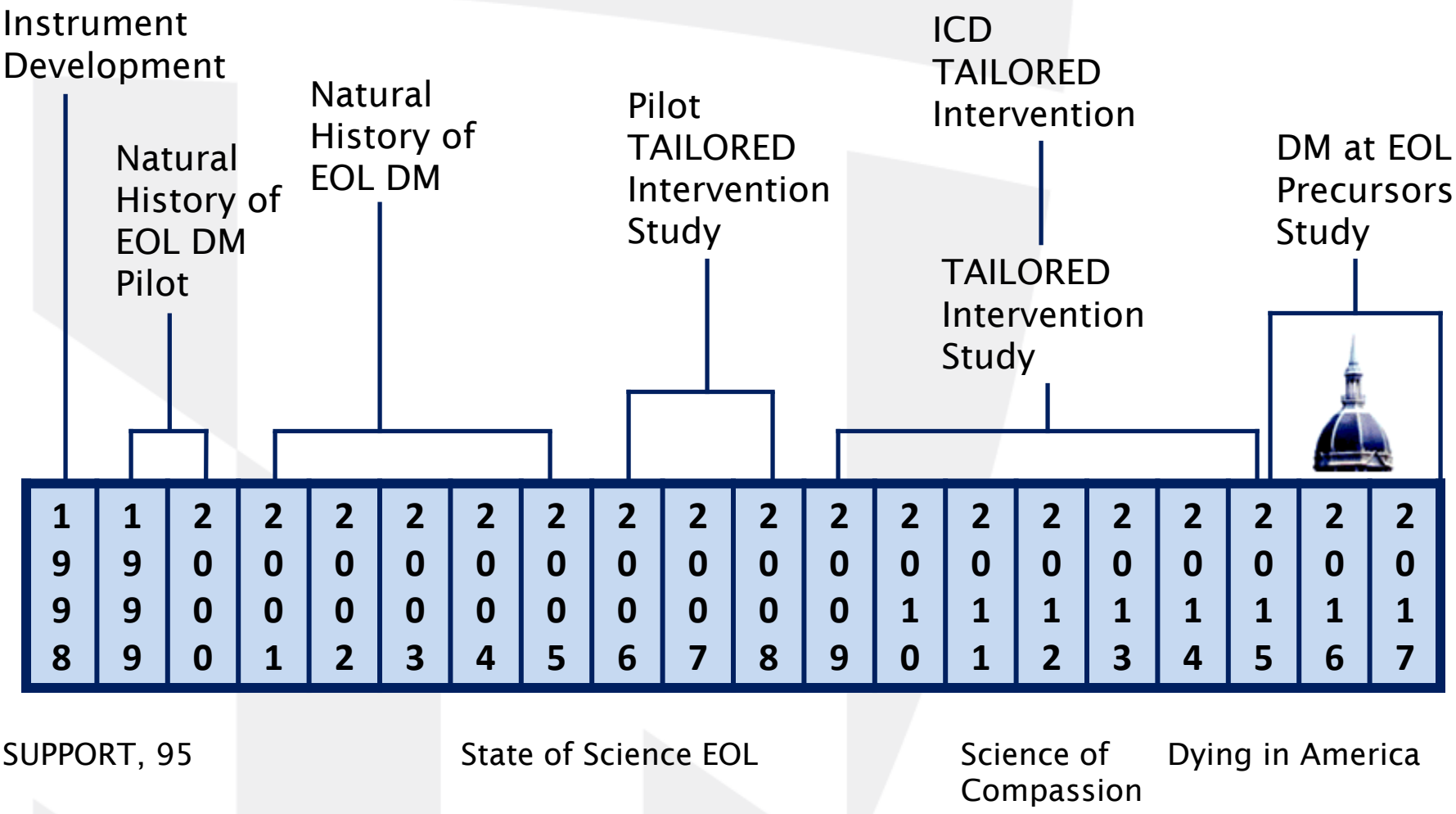
Framework for End of Life Decision Making



Kim K, Heinze K, Xu J, Kurtz M, Park H, Foradori M, **Nolan MT.** (2017).

Care Transitions - Death - Bereavement

Timeline of End of Life Decision Making Studies



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 *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 even if it disagreed with a "perfect" living will.

Terry, Vettese, Song, Forman, Haller, Miller, Stallings, Sulmasy (1999).

Gap in the Decision Making Literature

- Multiple studies have examined the accuracy of surrogates in predicting patient treatment preferences.
  Shalowitz, D. I. et al. Arch Intern Med 2006;166:493-497 (61-72% accuracy).
  - 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.

R55 NR00 5224; R01 NR005224;

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

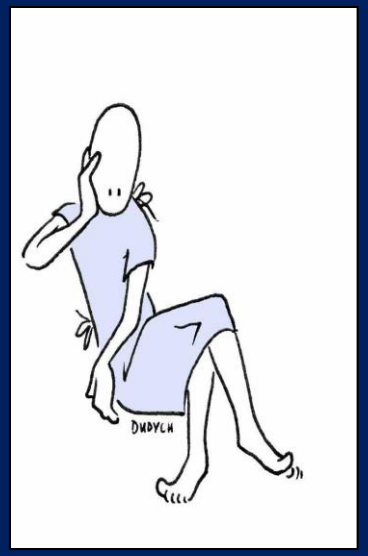
Patient identified important health care decision and rated decision control preference re: that decision

Family caregiver: estimated patient decision control preference re that decision

Followed Participants every 3 mos for up to two years or until death

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

A



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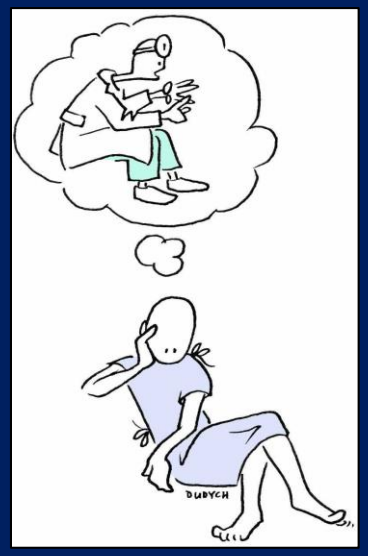


C

D

E

Independent

Shared

Reliant on Physician

Decision Control Preferences Scale

Substituted Judgment vs. Best Interest

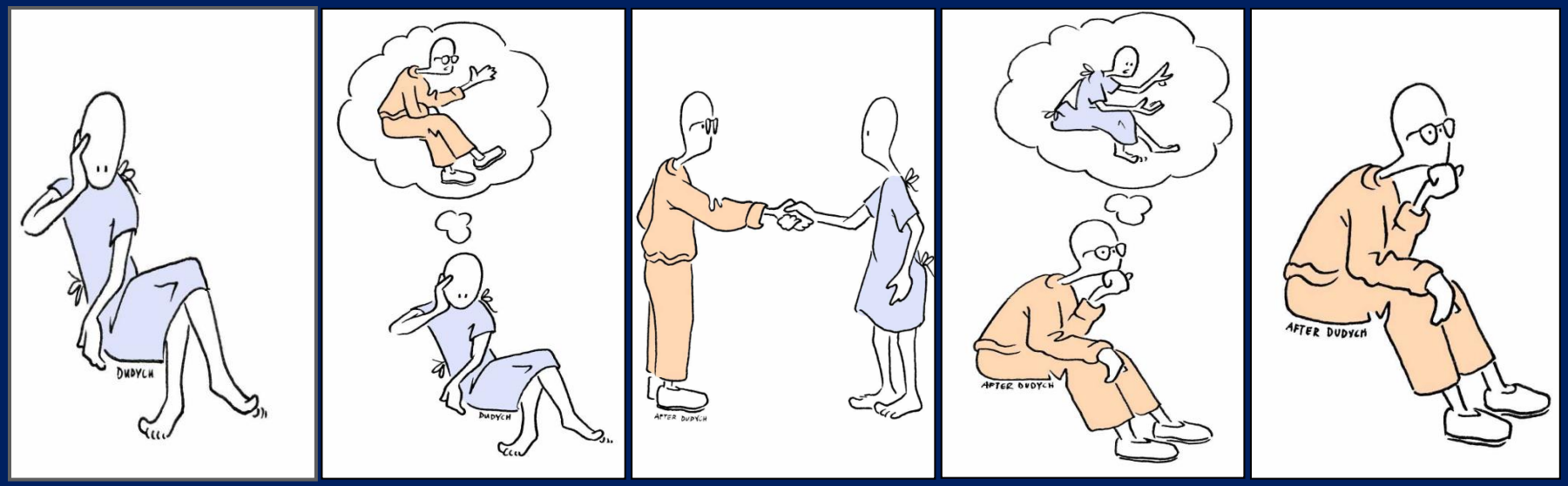
Independent via Previous Wishes

Shared

Reliant on Physician

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

A B C D E



Independent

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Decision Control Preferences Scale

Substituted Judgment vs. Best Interest

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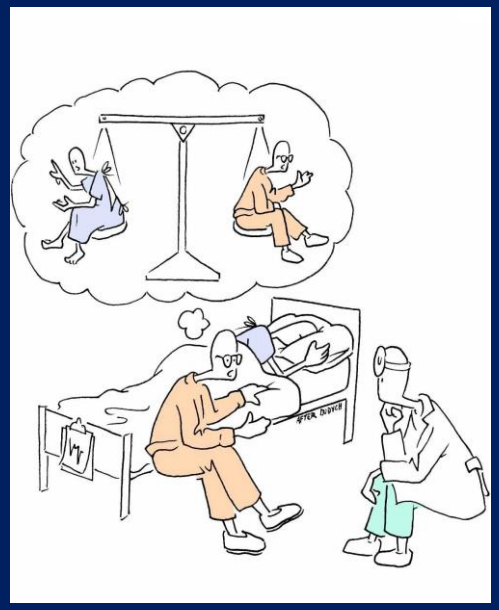


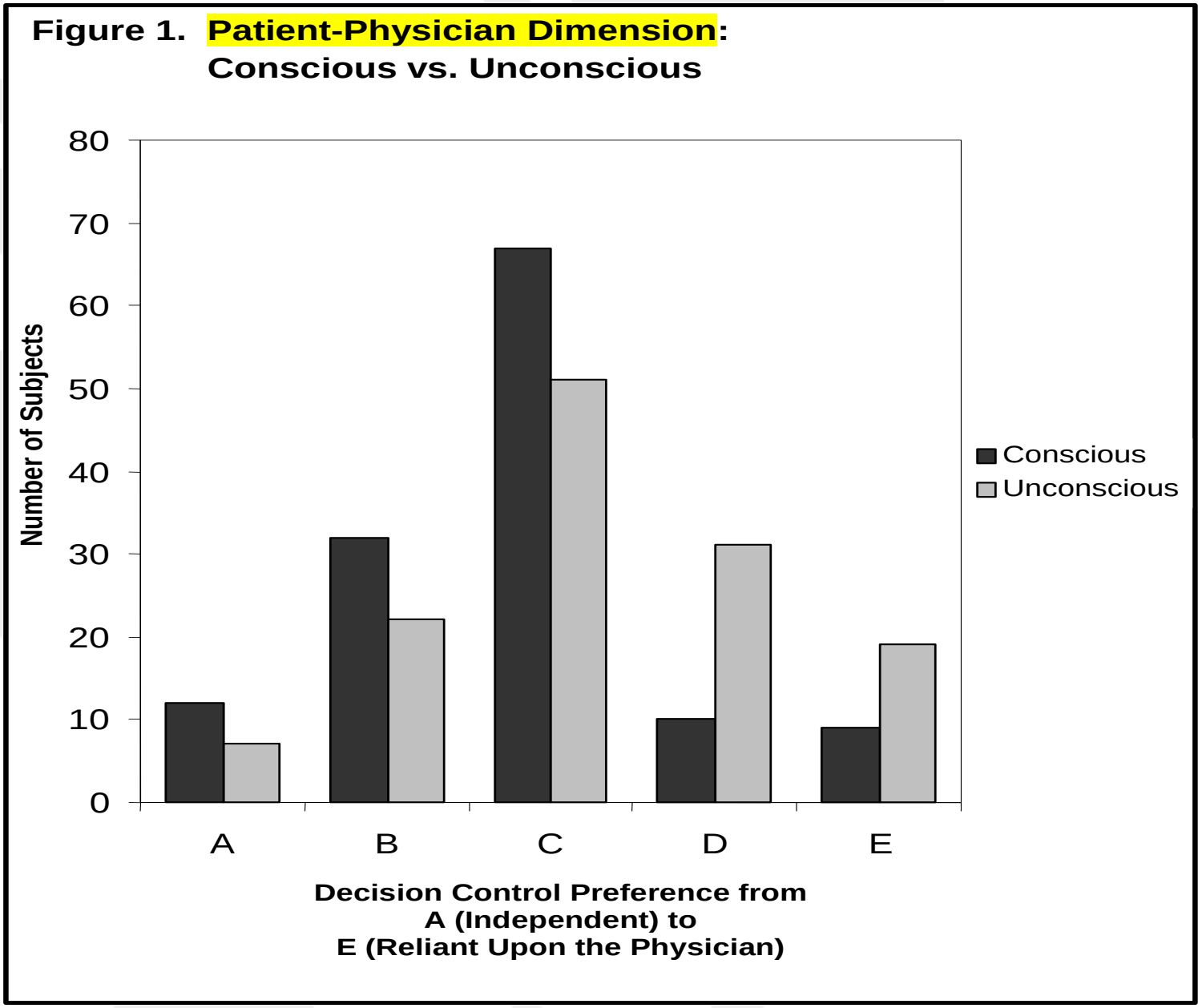
Shared

Reliant on Family

Results
N = 130 Patients

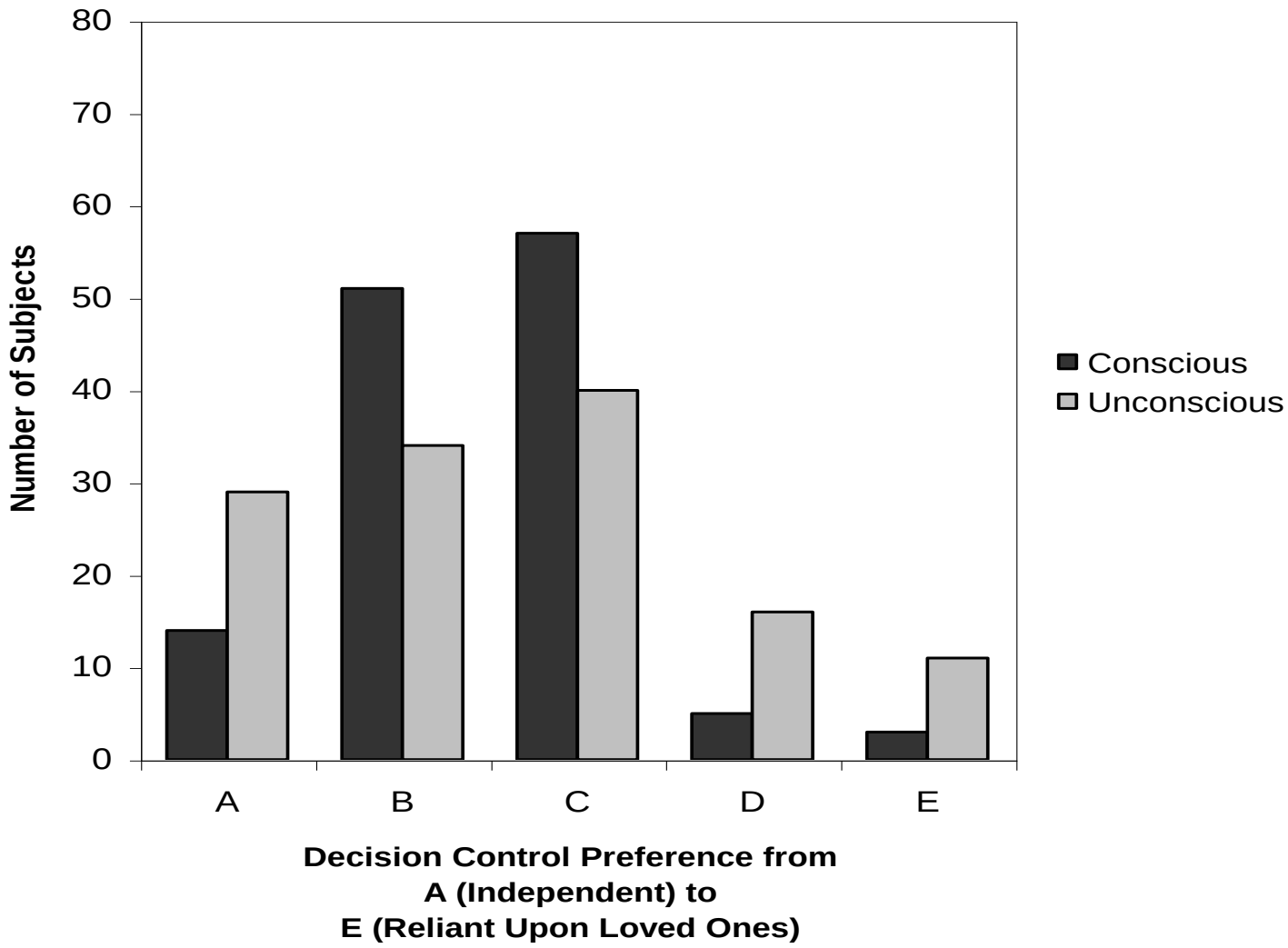
- 40% CHF
- 36% CA
- 24% ALS
- 64% white
- 63% male
- Mean age of 62.0 +/- 12.5 years.
- 65% High School or less Education
- 39% had an Advance Directive

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 ($P < .001$)

Figure 2. Patient-Loved Ones Dimension: Conscious vs. Unconscious

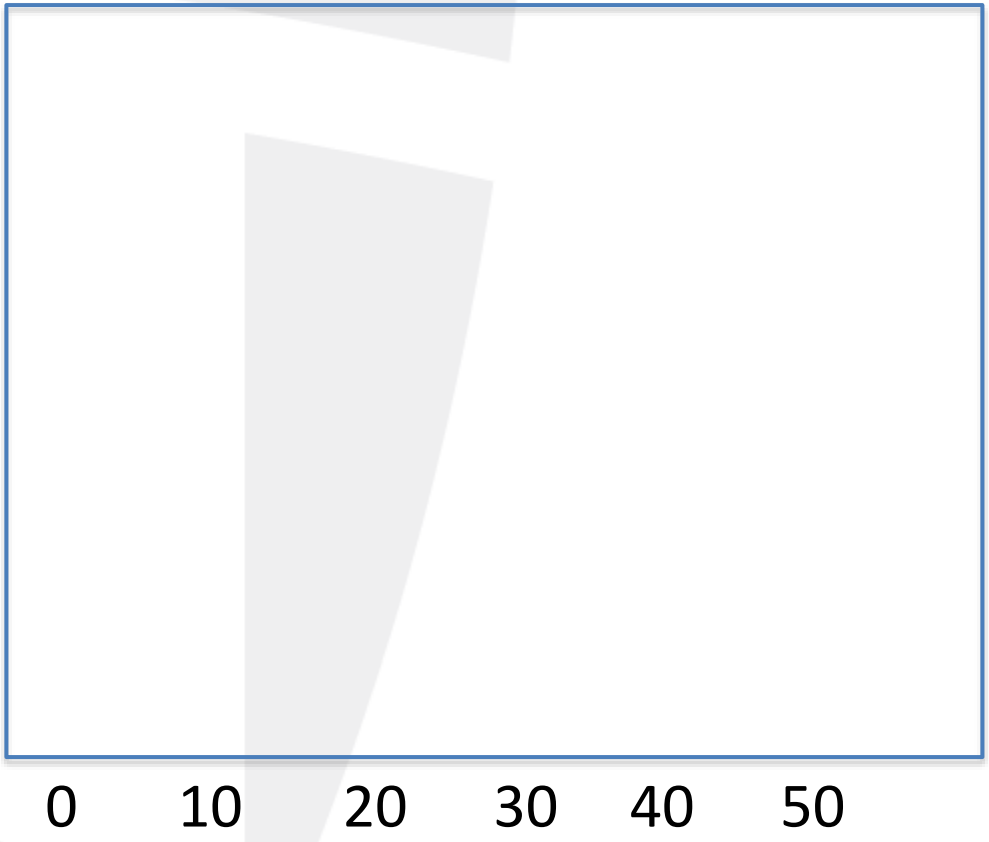


While only 6% would rely on Loved Ones judgement (D, E) while conscious, 21% chose this if they were unconscious (P = 0.39)

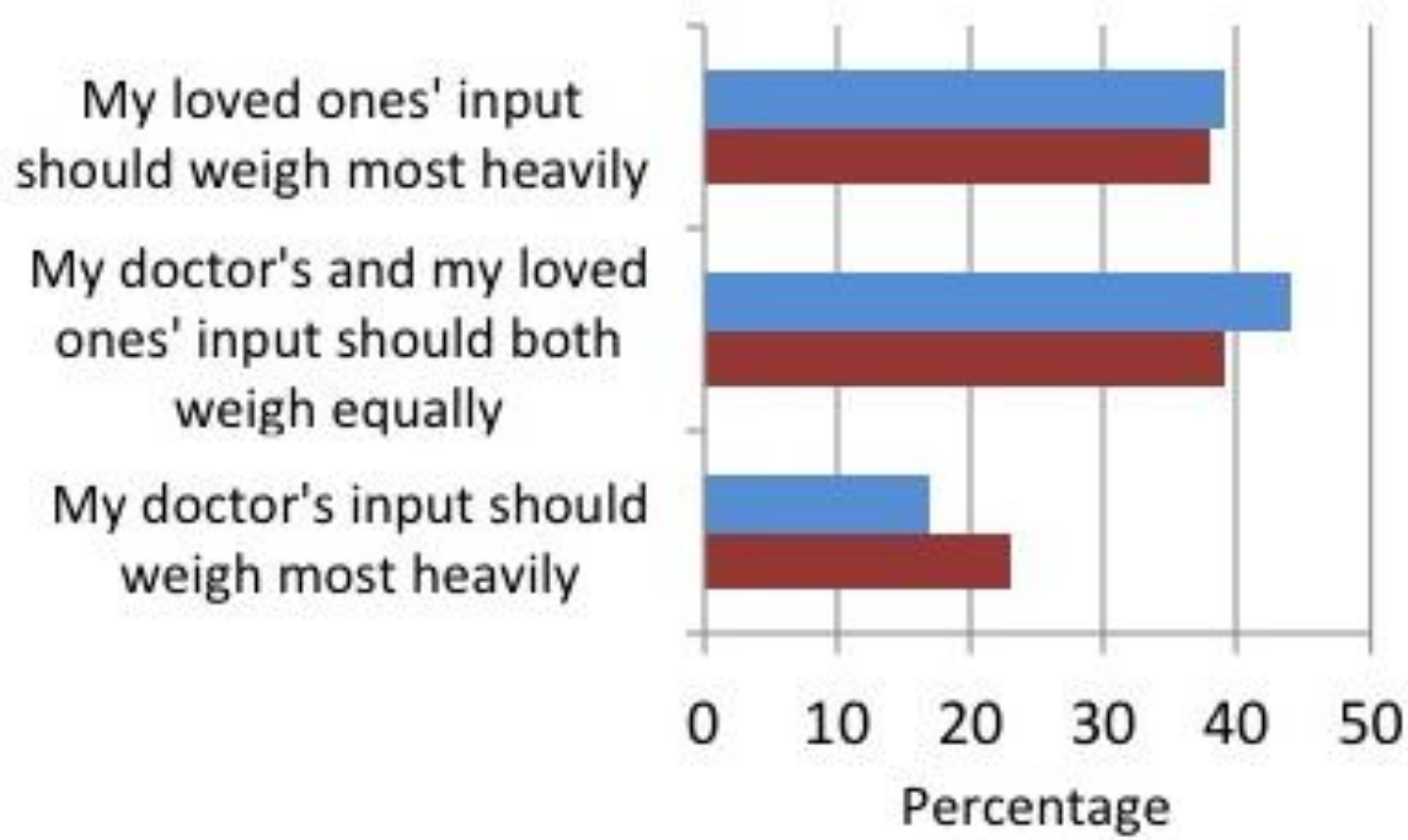
If you are unconscious, how should we weigh input of Physician and Family?

- 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)



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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

Sulmasy, Hughes, Thompson, Astrow, Tery, Kub, Nolan (2007). How would terminally ill patients have others make decisions for them in the event of decisional incapacity? A longitudinal study, JAGS, 55:1981-1988

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

Sharma, Hughes, Nolan, Tudor, Kub, Terry, Sulmasy (2011). Family understanding of seriously-ill patient preferences for family involvement in healthcare decision making, JGIM, 26(8), 881-886.

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

TAILORED EOL Decision Making Intervention Study

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

Sharma, Hughes, Nolan, Tudor, Kub, Terry, Sulmasy (2011). Family understanding of seriously-ill patient preferences for family involvement in healthcare decision making, JGIM, 26(8), 881-886.

1R01 NR010733

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.

TAILORED EOL Decision Making Intervention Study

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.

TAILORED EOL Decision Making Intervention Study

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.

TAILORED EOL Decision Making Intervention Study

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

			p-value*	
Study Arm	**Time 1**	**Time 3**	**Time3 vs. Time 1**	**Intervention vs. Control at time 3**
Control	3 (12%)	7 (33%)	0.074	0.076
Intervention	6 (24%)	11 (65%)	0.013	

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