May 16th, 10:15 AM

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Shared Decision Making in Neurocritical Care: Barriers and Facilitators

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Disclosures

Grant Support

- NIH/NICHD 5K23HD080971 (Muehlschlegel)
- NIH UL1TR000161 (UMASS Med School CTSI [Luzuriaga])

No conflicts to report.
In Medicine, including in the NeuroICU, decisions are often difficult – no right or wrong.

“"I have diabetes. Should I take insulin or pills?"

"I have Breast cancer. Should I have a mastectomy or choose breast-conserving surgery?"

Without a hemicraniectomy, this Stroke patient will die. The procedure will save the patient’s life, but will leave the patient permanently disabled. Should we offer / do it?

"My wife is on a ventilator and needs a tracheostomy/feeding tube. I’m not sure she would want that."

Value laden decisions
I will use the example of the Neuro-Intensive Care unit (NeuroICU) to explain the concept of Shared Decision Making.
In the NeuroICU, outcome prognostication may be particularly difficult. Sudden, heterogeneous, biased providers, prognosis is unknown, communication breakdown.
Critically-ill NeuroICU patients are too ill to make their own decisions.

Too ill, very suddenly
- Confused
- Sedated (to tolerate ventilator)
- Comatose

Brain injury
- Leaves them without decision-making capacity
- For weeks/months/life

?Brain surgery/hemicraniectomy?
- What’s next? Prognosis?
- Tracheostomy or not?
- Feeding tube or not?
- Rehab? Nursing home?
- Or comfort care/hospice?

Most survive first 7-10 days

“Goals-of-Care” Decisions
Self-fulfilling prophecies are ever present in the NeuroICU.

Withdrawal of support in intracerebral hemorrhage may lead to self-fulfilling prophecies

Clinical Nihilism in Neuroemergencies

Claude Hemphill III, MD, MA; Douglas B. White, MD, MA

Self-Fulfilling Prophecies Through Withdrawal of Care: Do They Exist in Traumatic Brain Injury, Too?

Saef Izzy · Rebecca Compton · Raphael Carandang · Wiley Hall · Susanne Muchlschlegel
“What would be the best possible way to present care options to families?”

- Explain the procedure/decision
- Include patient’s wishes/values
- Make sure probabilities and uncertainties are understood
- Explain what comes after hospital: NH, rehab
- Explain all options, including “doing nothing”, or “comfort care”
- Evidence Based
- Standardized

Shared Decision Making
What the heck is Shared Decision Making (SDM)?


SDM is a priority by Obama administration

*Healthy People 2020*

- Building social support networks.
- Facilitating the meaningful use of health IT
- Enabling quick and informed action to health risks
- Increasing health literacy skills.
- Provide new connections to hard-to-reach populations
- Provide sound principles for design of interventions
- Increasing Internet and mobile access.
What the heck is Shared Decision Making (SDM)?

From:  http://www.informedmedicaldecisions.org

SDM a priority by Obama administration
Healthy People 2020

SDM is a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences.
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SDM

honors both the provider’s expert knowledge and the patient’s right to be fully informed of all care options and the potential harms and benefits.

This process provides patients with the support they need to make the best individualized care decisions, while allowing providers to feel confident in the care they prescribe.
Sounds easy – let’s do it!

Number of yearly publications with search term “Shared Decision Making”
American College of Crit Care Med and American Thoracic Society call for increased SDM in the ICU:

Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement

Alexander A. Kon, MD, FCCM\textsuperscript{1,2}; Judy E. Davidson, DNP, RN, FCCM\textsuperscript{3}; Wynne Morrison, MD, MBE, FCCM\textsuperscript{4}; Marion Danis, MD, FCCM\textsuperscript{5}; Douglas B. White, MD, MAS\textsuperscript{6}
This recently published viewpoint article in JAMA discusses certification of SDM tools.
The International Patient Decision Aid Standards (IPDAS) provide an evidence-informed framework with set quality criteria.


Cochrane Review: updated 2014:
Includes 115 studies involving 34,444 participants. Evaluate which decision aids meet IPDAS criteria.
The current IPDAS Checklist consists of 12 Quality Dimensions.

1) Using A Systematic Development Process
2) Providing Information About Options
3) Presenting Probabilities
4) Clarifying And Expressing Values
5) Using Personal Stories
6) Guiding / Coaching In Deliberation And Communication
7) Disclosing Conflicts Of Interest
8) Delivering Decision Aids On The Internet
9) Balancing The Presentation of Information and Options
10) Addressing Health Literacy
11) Basing Information On Comprehensive, Critically Appraised, And Up-To-Date Syntheses Of The Scientific Evidence
12) Establishing The Effectiveness
The Ottawa Research Institute Decision Aid Library hosts 666 (+) decision aids.

https://decisionaid.ohri.ca/

Examples:

Atrial Fibrillation: Which Anticoagulant Should I Take to Prevent Stroke?

A Decision Aid to Prepare Patients And Their Families For Shared Decision-Making About Cardio-Pulmonary Resuscitation (CPR)
Decision Aids have been shown to have important effects on decisions and decision-making.

- **Knowledge**
  - DAs improved knowledge of options and outcomes; lead to more realistic expectations

- **Decision processes**
  - DAs help match their values to their choices; reduce decisional conflict and passivity; help the undecided to decide

- **Adherence to treatment**
  - DAs do not improve adherence to medication

- **Treatment decisions**
  - Impact on treatment choice is modest and variable

- **Impact on major elective surgeries**
  - Reduction in the choice of major elective surgery in the DA group, compared to usual care
  - No effect on minor elective surgeries

From: Stacey et al, Cochrane Review Decision aids, 2014; Col: Chapter 17: Shared Decision Making, from Communicating Risks and Benefits: An Evidence-Based User’s Guide (FDA)
There are some barriers to SDM making it difficult to implement decision aids into health care settings.

**Patient barriers**
- Unaware that there is a decision to make
- Believing that clinicians prescribe the only available treatment
- Discomfort, inexperience with SDM
- Preconceptions about care

**Physician barriers**
- Concerns about time
- Lack of training
- Pessimism about pt's ability to assume a more active role
- Believing it's not applicable to their patients
- Clinical situation
- Clinical care pattern
- Difficulty reconciling patient preferences
- Concerns that DA could bias patients to choose less expensive options
Decision aid development activities at UMASS
Example: Goals of Care Decision in Critically-ill TBI patients

NIH/NICHD 5K23HD080971 (PI Muehlschlegel)
Mentors: Mazor, Goldberg, Col (UNE) Shutter (UPMC)
In TBI, “Goals-of-Care” decisions may be better supported using Shared Decision Making.

In order to create a decision aid for “Goals-of-Care” decisions for surrogate decision-makers, we move through stages:

**First Stage**

- Determine stakeholder practices + preferences
- Develop decision aid prototype
- Feasibility trial
- Randomized trial (multi-center)

Qualitative study of surrogate decision-makers and physicians caring for critically ill TBI patients
For methods and results, please view our posters this afternoon.

Posters 54 and 65
These findings inform our pilot decision aid for goals-of-care discussions

Consider both key stakeholders’ positions

Determine stakeholder practices + preferences

Develop decision aid prototype

Feasibility trial

Randomized trial (multi-center)

Key is to create a decision aid which is acceptable to surrogate-decision makers and physicians.

Otherwise: poor acceptability & issues with implementation
These findings inform our pilot decision aid for goals-of-care discussions

Planning Stage: 2-3 centers

Determine stakeholder practices + preferences

Develop decision aid prototype

Feasibility trial

Randomized trial (multi-center)

Determine feasibility of DA, outcome measures, recruitment

R01 NIH PCORI
"You want to speak to the head of the household? There is no head of the household. My parents are into shared decision making."
Thank you.
susanne.muehlschlegel@umassmemorial.org