Slide 1: What is shared in shared decision-making? Eliciting and constructing patients' preferences when the evidence is unclear

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Slide 2: Patient Centered Care

"…a partnership among practitioners, patients and their families (where appropriate) to ensure that decisions respect patients' wants, needs and preferences, and solicit patients' input…"

—Institute of Medicine

Slide 3: Patient-Centered Care

graphic representation of the interactions between and among these components:

- Informed, activated, participatory patient and family
- Accessible, well-organized, responsive health care system
- Patient-centered communicative clinician

That result in:

- Improved Communication
- Improved Health Outcomes

Slide 4: Simple, complicated, and complex situations

table 3 columns, titled: Simple, Complicated, Complex

Simple:

- Following recipe
- Uncomplicated urinary tract infrection
- Requires little knowledge
- Recipes are essential
- Good recipes give good results every time

Complicated:

- Sending rocket to the moon
- Mastectomy vs lumpectomy/radiation for breast cancer
- Requires expertise
- Formulae necessary

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

- Outcomes fairly certain

Complex:

- Raising a child
- Relieving chronic pain; third-line chemotherapy for colon cancer
- Requires practical wisdom, self-awareness
- Formulae necessary but insufficient
- Some uncertainty of outcome

Slide 5: In complex situations, evidence is rarely sufficient

- Evidence must be mapped onto the current context
- Equipoise is rare
- Goal is practical wisdom
    - …knowing exactly which rule to break, and exactly in what way and how much to break it to accommodate to the situation before you.
- Evidence as a 'middle-range theory of practice'

Slide 6: Social networks

- Patients rarely make important decisions alone
- The majority of visits for serious illness are accompanied
- Clinicians and patients construct (often tacit) "communities of care"

Slide 7: Social Networks of Relatively Healthy People

An image of intersecting circles labeled, "the patient's family/social network" and "The network of health care professionals."

Slide 8: Social networks of people with serious and chronic illnesses

An image of intersecting circles labeled, "the patient's family/social network" and " "The network of health care professionals."

Slide 9: A clinical dilemma

- "What would you do i you were me?"

Slide 10: A clinical dilemma (2)

- What else do you want to know about the patient?
- What would you say to him at your next visit?

Slide 11: Deliberating

- "This is the approach that I'd recommend – it gives you the best chance for success…"

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

- "Given what I know about you, I'd suggest you consider XYZ…"
- "Go home, think about it and let me know…"
- "I really can't tell you what to do. Everyone's different..."
- "Let's explore what' most important to you…"
- "I really know exactly how you feel…"
- "Other patients have found some additional information useful…"

Slide 12: Two views of decision-making

- Individual view
    - Decisions are made and negotiated by individuals
    - Patients want individual autonomy
    - Patients anticipate difficult choices
    - Preferences are stable and intrinsic to the individual
    - Patients balance logic and affect against known values
- Distributed view
    - Decisions are made within social networks
    - Autonomy depends on and emerges in relationships
    - Decisions don't appear real until the situation presents itself
    - Preferences are constructed as a result of interactions
    - Patients use the full range of human experience – logic, affect, intuition, relationships – to make decisions

Slide 13: Eliciting values and constructing preferences are not straightforward

- Structure, process and outcome preferences
- Mismatch between means and ends
- Unclear referents
    - "Doing everything"
- Open list of options
- Instability of preferences
- Cognitive alibi

Slide 14: Shared mind

….situations in which new ideas and perspectives emerge through the sharing of thoughts, feelings, perceptions, meanings and intentions among 2 or more people.

- state that is achieved (e.g. consensus)
- An interpersonal process (e.g. becoming attuned)

Slide 15: Shared mind is…

- Cognitive

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

    - Naturally-occurring distributed cognition – and intentional collaborative cognition
    - Regarding values, goals, perspectives, preferences
- Affective
    - Naturally-occurring attunement/resonance ("the same wavelength") – and intentional promotion of connection, trust, empathy
- Motor
    - Naturally-occurring mirroring ("in stride with") – and intentional use of non-verbal communication
- Organizational
    - Naturally-occurring groups – and intentional sense-making

Slide 16: Approaching complex situations

- "Muddling through"[1]
- Intermediate steps and goals
- Incremental change, periodic reassessment
- Awareness of affect and gut feelings
- Attending to context
- Limitations of complexity theory

Slide 17: Is it hopeless?

- Heuristics and gut feelings can clarify
- Social construction of preferences can enhance autonomy[1]
- Provisional/evolving preferences can allow for flexibility, correct for poor affective forecasts

Slide 18: Patient engagement in complex situations

- Dynamic, iterative and provisional
- Often no true sense of closure
- More information is not always better
- The medium and the messenger are important

Slide 19: Principles

- Share attentional focus – agree what you're talking about
- Inform preferences – just enough, just the right information, just in time
- Monitor cognitive load and pace accordingly
- Foster distributed/collaborative cognition

Slide 20: Principles (II)

- Mindful practice

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

    - Use the whole mind – deliberative/intuitive
    - Self-monitoring, self-questioning = interoception
    - Help patients use their whole mind = interactivity
- Promote relational autonomy
- Focus on intermediate goals and reassess

Slide 21: Information technology

- Tailor and target information; parse into useable bits
- Promote affective forecasts and reflection
- Support relationships in which dialogue and deliberation can occur

Slide 22: Re-orienting health systems

- Teams
- Patients as subjects, not mere objects of care
- Spaces in which listening can occur
- Incentives for interpersonal care
- Valuing "sharpening the saw"

Slide 23: Perils

- Self-deception
- Power
- Passivity
- Charisma
- Anxiety
- Tacit disagreements
- Mindless enactment of uninformed preferences
- Abandonment

Slide 24: An approach

"[Sometimes an] acquaintance with particulars… makes us wiser than the possession of abstract formulas, no matter how deep."—William James (ca.1890.)

Slide 25: An approach (2)

- Clinician interoception, attentiveness, self-monitoring, situational responsiveness
- Patient activation, enablement, navigation, training
- Systems that direct clinicians' gaze toward patient-as-person and promote collaborative cognition

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