Shared Decision-Making
(and what to do when you disagree…)

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After the presentation, the participant will be able to:

1) Understand the models of shared decision-making

2) Identify tools for enhancing engagement

3) Identify risk management issues in relationship-centered care
Changing Field of Healthcare

• Outcomes

• Person-centered care

• Patient Satisfaction…
“Health is more than the absence of disease”
What’s it like to go in for help?
The Medical model...
In The Field of Medical Ethics

4 Principles:

- **Autonomy**- (primary)

- **Beneficence**- practitioner should act in patient’s best interest

- **Non-maleficence**- “primum non nocere”
  
  prē-muim-ˌnōn-no-ˈkā-rā (first, do no harm)

- **Justice**- fairness (as in, allocation of resources)

(Beauchamp & Childress)
Shared Decision-Making

Clinical decisions that are:

- Shared by providers and patients
- Based on the best evidence available about treatments
- Weighted according to the specific needs, preferences and values of the patient
- Thus this is also *Culturally Competent* care
Modern History of Shared Decision-Making

• First use --1970s debates and legislation about informed consent vs. informed decision-making.

• One study in particular lead to the development of the Office for Human Research Protections (OHRP) and the requirement of Institutional Review Boards to monitor research
Tuskegee Public Health Service Syphilis Study

- 600 Black sharecroppers
  - 399 with syphilis, 201 without
  - Studied: 1932-1972 with no treatment despite penicillin availability
  - Informed they had “bad blood”

Outcomes:
- Some died of syphilis
- Some wives contracted syphilis
- Some infants contracted congenital syphilis
- Did receive free medical care, meals, burial insurance
<table>
<thead>
<tr>
<th>Model</th>
<th>Paternalistic (Traditional Medical Model)</th>
<th>Shared Decision-Making</th>
<th>Informed</th>
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<tr>
<td>Role of the clinician</td>
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<td>Role of the clinician</td>
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<td>Role of the patient</td>
<td>Passive: Accepts the proposal of the clinician. Is obliged to cooperate in his/her recovery.</td>
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<td>One way (mainly): Clinician → Patient</td>
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<td>Role of the clinician</td>
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<td>Role of the patient</td>
<td>Active: Receives all information. Forms his/her own judgment on harms and benefits of treatment options. Discusses preferences with the clinician. Decides on the therapy together with the clinician.</td>
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# Treatment Decision-Making Models

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<td>Active: Receives all information. Forms own judgment. Is free to choose between all options unbiased by the clinician’s own opinion. Decides on the therapy alone.</td>
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Some arguments against Shared Decision-Making (mainly by the medical community)

- “The patient role is not conducive to objectivity.” “There is a difference between being a consumer and being a patient…”
- “Compromise or accommodation is not ‘best practice…”
- “The provider should act on behalf of the patient…”
Case by case, instance by instance

Traditional

Shared

Informed
Autonomy - self determination

- Right to decide (right to treatment, right to refuse)

- Competency - actually a legal term - though frequently used in clinical settings; what is usually being alluded to is "decision-making capacity"

- Capacity: Clinical term that is task-specific

- Context: (Emergent,/Urgent/Non-Urgent, etc… Complex vs. simple, high risk vs. low, etc…)

- Age and Issue:
Consent vs. Assent

• Consent—given by those of legal age. With those not of legal age or ability, consent must be given by a parent/legal guardian

• Assent—agreement to treatment, typically without meeting requirement of informed consent
Elements of Informed Consent (Informed Decision Making…)

- Informed consent should include:
  - Nature of the treatment (procedure/therapy/meds…)
  - Purpose of the treatment
  - Benefits
  - Risks
  - Alternative treatments (including no treatment at all)
  - Understanding of the patient’s goals.
  - Implies discussion, not just “sign here…”
• “Among the tests she had during the three days she spent there were a spinal tap, a CT scan, an EEG, a chest x-ray, and extensive blood work. Foua and Nao Kao signed ‘Authorization for and Consent to Surgery or Special Diagnostic or Therapeutic Procedures’ forms, each several hundred words long, for the first two of these. It is not known whether or not anyone attempted to translate them, or, if so, how ‘Your physician has requested a brain scan utilizing computerized tomography’ was rendered in mong.”
So, why do we have trouble with shared decision-making?

- Recognizing “our stuff…” (both individually and system-wide)

- Recognizing “their stuff…”
Their stuff-including “transference”         Our stuff-including “counter-transference”

• The unconscious directing of the patient/client’s feelings onto the practitioner

• The unconscious directing of our feelings onto the patient/client; can also be a reaction to the transference...
Confirmation Bias

“I will look at any additional evidence to confirm the opinion to which I have already come”

(Lord Molson, British Politician, 1903-1991)
What works?

• An appropriate opening encounter

• Compassionate, empathic providers (relationships matter)

• Understanding that information is necessary, but not sufficient

• Motivating people towards change and adherence
• Why is understanding an individual’s readiness for change useful for clinicians?
• Some people are not ready to accept your sage advice
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<td>Maintenance</td>
<td>Committed to healthy behavior long-term</td>
<td>Encouragement/support</td>
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A Reminder: Motivational Interviewing

- It is based on 4 core principles:
  
  - Express empathy (i.e., lecturing/shame doesn’t work…)
  
  - Develop discrepancy (between current and desired behavior)
    - change takes time
  
  - Roll with resistance (everyone is ambivalent)
  
  - Support self-efficacy (individual autonomy)
Compliance, Adherence and Labels

• Compliance is an older term used to describe how well or poorly a patient follows the provider’s recommendations for evaluation and treatment. It is provider directed...

• The more appropriate term is “adherence” which reflects the change in the relationship between providers and patients as equitable partners in health maintenance.

• “Adherence” emphasizes the individual’s autonomy and choice in the matter.

• Label the illness, not the patient i.e.,

• A person has an eating disorder, they are not “an anorexic.”

• A person has schizophrenia, they are not “a schizophrenic”
A Helpful Concept (though perhaps not in strength-based language…)

• **Defense**
  
  • Is the person simply choosing to make bad decisions?

• **Deficit**
  
  • Is the person’s illness or circumstance such that it is significantly impairing their ability to adhere to treatment recommendations?

How does this impact your care decisions?
To be able to work with him or her, you need to be able to find something that you admire about your patient…

(I said admire, not necessarily like…)
Communication

- Language Matters
- And so do non-verbals
4 Cs of Risk Management

• Compassion

• Communication (both patients/colleagues)

• Competence

• Charting
When you are not meeting eye-to-eye:

Is the patient feeling heard?

- Are you providing reasonable care/advice in an understandable manner?

- Is it context appropriate?

- Where is the patient in terms of “defense/deficit”?

- Where is the patient re: stages of change? Can you utilize motivational interviewing?

- Can you (should you) compromise, particularly as an opportunity for engagement? (would you rather be “right”, or “effective”?)

Is this issue a “relationship-breaker”?
Self-reflection

• When/when not to take things personally

• Expand the field
So, For Better or For Worse:

• Ending a provider-patient relationship:
  • Mutual consent
  • Dismissal of provider by patient
  • Patient’s improved condition*
  • Proper withdrawal by provider
    • Written notice
    • Time to seek new provider (assist-continuity of care)
    • Instruction to obtain records
    • Cannot abandon

*Note: Patient’s improved condition is a valid reason for ending a provider-patient relationship, but it must be documented and agreed upon by both parties.
A practitioner may refuse to accept/treat/advise a patient:

- If it is not an arbitrary decision
- If it is not based on discrimination (i.e., race, religion, sexual orientation, etc…)
- Cannot Abandon

- For claims of conscience:
  a) if they inform the patient of treatment options and make appropriate referrals
  b) if it is not an emergent situation, where delay in referral would cause harm
Case reports (maintaining confidentiality)

- Mine

- Audience
Connecting to Selves and Others: (for your later viewing pleasure)

- Video: Empathy: The Human Connection to Patient Care-Cleveland Clinic

- https://www.youtube.com/watch?v=cDDWvj_q-o8
What did we just talk about again?

- Our stuff (individual and system)
- Their stuff (autonomy, context and stages of change)
- Mitigation of risk
Questions/comments?