SHARED DECISION-MAKING: IT’S NOT WHAT YOU THINK

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Disclosures

- Dina Tom, MD, MSc, has no relationships with commercial companies to disclose relevant to this presentation.

Learning Objectives

1. Define shared decision-making (SDM) and contrast it to family-centered rounds, motivational interviewing, parent education, and informed consent.
2. Discuss the benefits of SDM to the patient, parent, and physician.
3. Understand parent preferences for SDM and how uncertainty may change parents’ preference for SDM.
4. Identify barriers and opportunities to improve SDM in your day-to-day practice.

What is Shared Decision-Making?

- 1982: Informed Consent is an "ethical obligation that involves a process of shared decision-making based upon the mutual respect and participation of patients and health professionals."
- Model: Both parties contribute their own knowledge and preferences, discuss available treatment options, and reach a treatment plan together.
- Tool to increase parent participation in their child’s healthcare

"Giving people the power to choose between alternatives"

- Glyn Elwyn, BA, MD, MSc, PhD

Shared Decision-Making: It is NOT...

- Family Centered Rounds
- Motivational Interviewing
- Patient Education
- Informed Consent
1. Why is Shared Decision-Making important?

2. Learning Objectives

   At the end of this presentation the participant will be able to:

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3. Benefits of Shared Decision-Making

   - Patient satisfaction
   - Patient/parent education
   - Compliance
   - Special health care needs
   - Asthma
   - Diabetes
   - Acute otitis media

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5. Evaluation for Patient/Parent Communication

   1. How much effort was made to help you understand your health issues?

   2. How much effort was made to listen to the things that matter most to you about your health issues?

   3. How much effort was made to include what matters most to you in choosing what to do next?
1. How much effort was made to help you understand your health issues?

0 1 2 3 4 5 6 7 8 9
No effort was made

2. How much effort was made to listen to the things that matter most to you about your health issues?

0 1 2 3 4 5 6 7 8 9
No effort was made

3. How much effort was made to include what matters most to you in choosing what to do next?

0 1 2 3 4 5 6 7 8 9
No effort was made

What role do you typically play in your patients’ health care decisions?

A. You keep your patients and their families informed, but in general, make health care decisions for them on the basis of what you think is best. *Paternalistic*

B. You discuss options with your patients and their families and then come to a decision together. *Shared Decision-Making*

C. You tell your patients and their families the options, giving the pros and cons of each option, and allow them to choose their treatment option. *Consumerism*

Murray et al. BMC Fam Practice. 2007

Physician Preference for SDM

- 75% preferred to share the decision-making with their patients
- 14% preferred to make the decisions themselves on the basis of what they thought best for the patient (paternalism)
- 11% preferred patients/families to make the decisions (consumerism)

<table>
<thead>
<tr>
<th>Physician Preference</th>
<th>N</th>
<th>Paternalism N (%)</th>
<th>Shared decision-making N (%)</th>
<th>Consumerism N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paternalism</td>
<td>142</td>
<td>108 (76)</td>
<td>30 (21)</td>
<td>4 (3)</td>
</tr>
<tr>
<td>Shared decision-making</td>
<td>780</td>
<td>39 (5)</td>
<td>710 (91)</td>
<td>31 (4)</td>
</tr>
<tr>
<td>Consumerism</td>
<td>118</td>
<td>7 (6)</td>
<td>25 (21)</td>
<td>86 (73)</td>
</tr>
</tbody>
</table>

87% of physicians perceived themselves as practicing their preferred style of decision-making.

Parent Preferences for SDM

- Most parents want to be actively involved in their child’s medical decisions
- Outpatient (Asthma, ADHD, Special needs), NICU, PICU, Anesthesia, EMT
- Inpatient literature lacking
- MY STUDY
  - October 2015 - March 2016
  - Cross-sectional survey
  - 200 parent respondents
  - Inpatient units (PICU, IMC, ACU, Heme/Onc, ED, Trauma)
  - 24-question survey

Parent Preferences for SDM in Acute vs. Chronic Illness

- 81% Hispanic ethnicity
- 78% mothers
- 38% ages 30-30 years
- 77% less than college degree
- 55% some financial hardship
- 73% English
- Mean age of child 8.1 yrs
- 46% chronic medical condition
- 64% hospitalized before
- Top reasons for admission:
  - Complication of chronic problem (31.5%)
  - New problem (28%)
  - Trauma (28%)
Parent SDM Preference

- Most parents prefer active (42.5%) or collaborative role (41%)
- No difference in SDM preference by parent/child demographic, prior exposure to inpatient setting or perceived severity of illness.

Parent Perception of Uncertainty

- Merle Mishel, PhD, RN Uncertainty in Illness Scale
- Parental uncertainty was not significantly associated with SDM preference...
- Except among parents of chronically ill children
- When uncertainty was HIGH, these parents preferred a PASSIVE role in SDM.

What does this all mean?

- Hospitalization does not change parent preference for SDM
- Consistent with other outpatient and PICU studies
- 20% of children in the US have a chronic condition
- Parents of chronically ill children perceive greater severity of illness and uncertainty
- Addressing uncertainty clinically may have significant impact for parents
- More research is needed in this parent/patient population

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Physician-Reported Barriers to SDM

- TIME CONSTRAINTS
  Most frequently cited barrier to any change in clinical practice.
- PATIENT CHARACTERISTICS
  Equity in healthcare.
- CLINICAL SITUATION
  Improves with practice.
**Opportunities for SDM**

A step process to SDM
1. Determine if decision is appropriate for SDM
2. Offer choice
3. Provide options
4. Click patient preferences & decide

- The parent should not be asked to make decisions for which they are insufficiently informed.

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**Choose the most appropriate situation for shared decision-making:**

A. Any patient interaction involving a potential for treatment
B. Physician-parent discussion of recommended vaccines
C. Asking the parent to make the decision regarding treatment when the diagnosis/prognosis is unknown
D. Discussing more than one medically acceptable option when the physician is certain of the diagnosis/prognosis

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**Ripe for SDM**

- R, Pea for chronic effusions/speech delay
- Language in deaf children with ear tube implants
- Ambulation in a child with Down syndrome
- Tobacco vs. conservative management for tennis elbow
- ADHD management
- ADHD medication initiation, behavioral therapies
- Mental health disorders: therapy +/- medication management
- Withholding/withdrawing hydration in kidney disease
- PPI/H2 blockers for GERD
- Ambulation for seniors
- Decision to be or not to be on a clinical trial in oncologic disorders
- Tonsil management and when to discontinue or change therapy
- NSCLC/PD-L1 treatment decisions: progression vs. palliative care
- Palliative care discussions

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**Resources for SDM**

- Dartmouth Center for Shared Decision-Making
- LessIsMoreMedicine.com
- Effective Healthcare Program at the AHRQ
  - [https://www.ahrq.gov/clinic/189tmd.html](https://www.ahrq.gov/clinic/189tmd.html)
- Minnesota Shared Decision-Making Collaborative
- Agency for Healthcare Research and Quality

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**Thank you!**

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- Alex Foster, MD, MPH
- Christian Aquino, BS
- Anthony Arredondo, MD
References


QUESTIONS?