Shared Decision Making in Clinical Practice

November 20, 2017

Karen Sepucha, PhD; Leigh Simmons, MD;
Lauren Leavitt, MA; Felisha Marques, MPH

MGH Health Decision Sciences Center
www.massgeneral.org/decisionsciences/
Support conversations that draw on expertise of patients and families, care team, and clinical evidence to ensure informed, patient-centered decisions.
Shared Decision Making in 6 Steps
Introductions from You

• Tell us about you
  – Your role in health care
  – Heard of shared decision making?
  – Observed a conversation about a significant health decision?
  – Seen a decision aid used to help with making a decision?
Some challenging decisions for patients (and families)

• When should I start having a mammogram?
• Should I have an MRI to evaluate my acute low back pain?
• Should I try medication or counseling for my depression?
• Is it time to get my knee replaced?
• Should I join a clinical trial for cancer therapy or have standard care?
• Would my loved one want to have a feeding tube?
And for providers

• How far should I push this older patient with diabetes, but also many other illnesses, to lower their A1c?

• Should this patient with chest pain be admitted for observation or can they go home and f/u with specialist in a few days?

• I disagree with this patient’s preferred treatment (e.g. contralateral mastectomy), should I just do it anyway?
Shared Decision Making (SDM)

• Interactive process between patient (and family) and clinician(s):
  – Engages patient in decision making
  – Gives accurate information about options and outcomes
  – Tailors treatments to patient’s goals and concerns

• SDM is means to ensuring informed decisions that reflect patients’ goals

Six Steps to SDM

1. Invite patient to participate
2. Present options (+/- using a decision aid)
3. Provide information on benefits and risks
4. Elicit patient preferences
5. Facilitate deliberation and decision making
6. Assist with implementation

Credits: R. Wexler, FIMDM, and K. Clay, Center for Shared Decision Making, Dartmouth-Hitchcock Medical Center
What can help?
Patient Decision Aids
Decision Aids

• Tools designed to help people participate in decision-making

• Available in different media (online, DVD, booklets)

• Provide information on the options

• Help patients clarify and communicate their goals and treatment preferences
Evidence for Decision Aids

2017 Cochrane Systematic Review contains 105 RCTs:

Decision aids increase decision quality:
→ increase in knowledge
→ increase accuracy of risk perceptions
→ increase in value-choice concordance

Decision aids engage patients
→ less passive (RR 0.68)
→ fewer who remain undecided
→ Reduced decisional conflict due to feeling uninformed (MD -9.28/100) and indecision about personal values (MD -8.81/100)

Decision aids address over- and under-use
→ reduction in major invasive elective surgery (RR 0.86)
→ reduction in PSA testing (RR 0.88)
→ increase in medication use for diabetes (RR 1.65)

Stacey et al. Cochrane Database of Systematic Reviews, 2017
Overview of decision aid use

By the numbers:
- ~10,000 distributed annually
- ~75% of orders from primary care (vs. 25% specialty)
- >1000 unique clinicians and staff have prescribed programs

Top Titles:
1. Insomnia
2. Anxiety
3. Chronic Low Back Pain
4. Knee Osteoarthritis
5. PSA Testing
Some limitations of decision aids

- Limited number of clinical topics available
- Decisions may come up that need to be dealt with in the visit
What can help?
Decision Coaching
What is coaching?

• Non directive
• Structured elicitation of needs, elicitation of preferences, preparation for communication, and facilitation of deliberation
• Trained health professionals or lay people
Ottawa Personal Decision Guide

You will be guided through four steps:

1. Clarify the decision.
2. Identify your decision making requirements.
3. Explore your needs.
4. Plan the next steps.

- Generic tool
- 4 steps
- Clinicians or trained students

http://decisionaid.ohri.ca/index.html
### Step 1: Clarify the Decision

<table>
<thead>
<tr>
<th>What decision do you face?</th>
<th>Should I have hormone replacement?</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your reason for making this decision?</td>
<td>Hot flashes and night sweats are really impacting life</td>
</tr>
<tr>
<td>When do you need to make a choice?</td>
<td>Not sure, but would like to get some help soon</td>
</tr>
<tr>
<td>How far along are you with making a choice?</td>
<td>🔴 I am thinking about the options</td>
</tr>
<tr>
<td>Are you leaning toward one option?</td>
<td>🔴 I am nervous about hormone therapy</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Step 2: Explore your decision

**Knowledge**
In the balance scale below, list the options and main benefits and risks you already know. Underline the benefits and risks that you think are most likely to happen.

**Values**
Use stars (★) to show how much each benefit and risk matters to you. 5 stars means that it matters “a lot”. No star means “not at all”.

**Certainty**
Circle the option with the benefits that matter most to you and are most likely to happen. Avoid the option with the risks that are most important to avoid.

<table>
<thead>
<tr>
<th>☀️ BENEFITS</th>
<th>How much it matters</th>
</tr>
</thead>
<tbody>
<tr>
<td>☀️ RISKS</td>
<td>How much it matters</td>
</tr>
<tr>
<td>☀️ RISKS</td>
<td>How much it matters</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option #1</th>
<th>Relieve hot flashes</th>
<th>Help sleep</th>
<th>****</th>
<th>*****</th>
<th>Breast cancer</th>
<th>Blood clots</th>
<th>****</th>
<th>***</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hormone therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Option #2</td>
<td>Avoid hormones</td>
<td>Relieve hot flashes</td>
<td>***</td>
<td>****</td>
<td>Difficulty sleeping?</td>
<td>***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-depressants</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Option #3</td>
<td>Avoid medicines</td>
<td></td>
<td></td>
<td></td>
<td>Don’t seem to work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle changes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

**Note:**
- Breast cancer and blood clots are potential risks associated with hormone therapy.
- Difficulty sleeping is a possible side effect of anti-depressants.
- Avoid medicines is a benefit of lifestyle changes.

**Sources:**
- Massachusetts General Hospital
- Health Decision Sciences
Step 2: Explore your decision

Support

<table>
<thead>
<tr>
<th>Who else is involved?</th>
<th>Name: Husband</th>
<th>Name:</th>
<th>Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which option does this person prefer?</td>
<td>anything that stops night sweats</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is this person pressuring you?</td>
<td>X Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>How can this person support you?</td>
<td>he can’t sleep when I am up each night so impacting both of us</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What role do you prefer in making your choice?</td>
<td>□ I prefer to share the decision with</td>
<td>X I prefer to decide myself after hearing the views of Health care team</td>
<td>□ I prefer that someone else decides. Who?</td>
</tr>
</tbody>
</table>
## Step 3: Identify decision making needs

1. **Identify your decision making needs.**

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>Do you know the benefits and risks of each option?</td>
<td>![Yes]</td>
<td>![No]</td>
</tr>
<tr>
<td>Values</td>
<td>Are you clear about which benefits and risks matter most to you?</td>
<td>![Yes]</td>
<td>![No]</td>
</tr>
<tr>
<td>Support</td>
<td>Do you have enough support and advice to make a choice?</td>
<td>![Yes]</td>
<td>![No]</td>
</tr>
<tr>
<td>Certainty</td>
<td>Do you feel sure about the best choice for you?</td>
<td>![Yes]</td>
<td>![No]</td>
</tr>
</tbody>
</table>

People who answer “No” to one or several questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps two ☉ and four ☉ that focus on your needs.
# Step 4: Plan next steps

Plan the next steps based on your needs.

<table>
<thead>
<tr>
<th>Things making the decision difficult</th>
<th>Things you are willing to try</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge</strong></td>
<td></td>
</tr>
<tr>
<td>- You feel you do NOT have enough facts</td>
<td>- Find out about the chances of benefits and risks.</td>
</tr>
<tr>
<td></td>
<td>- List your questions and note where to find the answers (e.g. library, health professionals, counsellors):</td>
</tr>
<tr>
<td><strong>Values</strong></td>
<td></td>
</tr>
<tr>
<td>- You are NOT sure which benefits and risks matter most to you</td>
<td>- Review the stars in the balance scale to see what matters most to you.</td>
</tr>
<tr>
<td></td>
<td>- Find people who know what it is like to experience the benefits and risks.</td>
</tr>
<tr>
<td></td>
<td>- Talk to others who have made the decision.</td>
</tr>
<tr>
<td></td>
<td>- Read stories of what mattered most to others.</td>
</tr>
<tr>
<td></td>
<td>- Discuss with others what mattered most to you.</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
</tr>
<tr>
<td>- You feel you do NOT have enough support</td>
<td>- Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends)</td>
</tr>
<tr>
<td>- You feel PRESSURE from others to make a specific choice</td>
<td>- Find out what help is on hand to support your choice (e.g. funds, transport, child care)</td>
</tr>
<tr>
<td></td>
<td>- Focus on the opinions of others who matter most.</td>
</tr>
<tr>
<td></td>
<td>- Share your guide with others.</td>
</tr>
<tr>
<td></td>
<td>- Ask others to complete this guide. Find areas of agreement. When you disagree on facts, agree to get information. When you disagree on what matters most, respect the other’s opinion. Take turns to listen, mirror back what the other has said matters most to him or her.</td>
</tr>
<tr>
<td>- Other factors making the decision DIFFICULT</td>
<td>- Find a neutral person to help you and others involved.</td>
</tr>
</tbody>
</table>

List anything else you need:
Using the Decision Guide

1. Form groups of two
   - ‘Client’ making a difficult decision
   - ‘Practitioner’ interview/coach

2. ‘Client’ choose a real decision
   (career, education, move, buy a car)

3. ‘Practitioner’ interviews patient & documents on the Ottawa Guide

4. Discussion
Discussion

• Reflections on using a decision guide

• As the ‘patient’ making a decision?

• As the coach?
Choosing a Medicine for Your Port Placement

Welcome to Interventional Radiology. You are having a brief procedure done today where a small device called a port will be placed under your skin. We would like to know what type of medicine you would prefer to keep you comfortable during the procedure. Your input is important to us.

Part 1: What is Important to You
Here are statements that will help you decide which medicine is best for you. Please circle the number on the scale below to show how important each statement is to you as you are thinking about your options.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don’t want to feel “groggy” or “out of it.”</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I want to be awake as long as I don’t feel pain.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I don’t want a long recovery time.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I want to be drowsy and wake up when the procedure is over</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I want to be able to drive or work today.</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Part 2: Your Sedation Options
There are 3 sedation options available to keep you comfortable during the procedure. Each option has different benefits, risks, side effects, and recovery time. In general, patients do well with all options, but the choice is up to you depending on what is important to you. Please read the options below. Circle the option(s) you want to talk more about. Your care team member will go over them with you.

<table>
<thead>
<tr>
<th>Sedation option</th>
<th>Reasons to choose this option</th>
<th>Reasons not to choose this option</th>
</tr>
</thead>
<tbody>
<tr>
<td>No sedation: Medicine to numb the area called local anesthetic is given.</td>
<td>No recovery time.</td>
<td>You will be awake, feel some pressure but no pain.</td>
</tr>
<tr>
<td></td>
<td>No affect on thinking, coordination, lungs, and heart functions.</td>
<td>You are very anxious about the procedure.</td>
</tr>
</tbody>
</table>
Summary

• SDM is important part of clinical care, skills can be learned

• High quality, patient-centered care requires that we inform patients, involve them in decisions and tailor treatments to their goals and preferences
Contact us

• Visit our website:  
  www.massgeneral.org/decisionsciences

• Contact us: decisions@partners.org
  Karen Sepucha, PhD, Director HDSC
  Leigh Simmons, MD, Medical Director HDSC
  Lauren Leavitt, MA, Project Manager HDSC
  Felisha Marques, MPH, Sr. Research Coordinator HDSC

@mghsdm