Shared Decision Making
New Challenges for Health Literacy

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When can SDM happen?
Informed information about their condition and treatment options.

Shared also asks about goals, values and preferences, and then helps them think about what option is best for them.

Why SDM?

- Not aware of options
- Hard to understand risks, effectiveness & tradeoffs
- Patients afraid to disagree
- QOL
- Practitioners bad at predicting what people want
Preference Misdiagnosis

Physicians Thought
- Conserving Breast Important
- Not a Top Treatment Goal

Women's Preferences
- Conserving Breast Important
- Not a Top Treatment Goal

Physicians Thought
- 0% important to avoid prosthetic
- Not a big concern

Women’s Preferences
- Important to avoid prosthetic
- Not great importance

Preference Misdiagnosis

“The patient may or may not be the ultimate decision maker, but is ALWAYS the person who must live with the consequences of the decision.”

Kate Clay, RN, MA
Director, Shared Decision Making Education & Outreach
The Dartmouth Institute
Emotionally-Charged Challenges
INFORMATION OVERLOAD

Stay Up To Date on All Treatment Options
Decide How Much Information
Explain Dx & Condition
Clinician Needs to Address
Clear, Unbiased Explanation
Address Misconceptions
Describe Complex Risk Info
Elicit Values & Preferences

New concepts
New vocabulary
Strong emotions
Attentional narrowing
Quantitative risk info

TOGETHER: Map Patient Preferences Treatment Options

New Med Terms & Info
Cope with Emotions & Anxiety
Learn About Options
Understand Risks & Tradeoffs
Contemplate Preferences

INFORMATION OVERLOAD
CHALLENGING TOPICS

SURGERY  RADIATION  CHEMOTHERAPY

KEEP CALM AND CHOOSE HOSPICE
Experiences of Family or Friends
Personal Clinician Experience
Suspicion of Benefitting Others
SDM & Low Health Literacy

- Less desire for involvement
- Less question-asking
- Higher decisional uncertainty
- More decisional regret
- Less patient-centered communication

McMaffery MJ, Holmes-Rovner M, Smith SK et al, Addressing health literacy in patient decision aids. 2013 13(S2)
DECISION AIDS
A HEALTH LITERACY TOOL
DA’s Help Patients

- Understand condition
- Understand options
- Understand risks, benefits & tradeoffs
- Consider goals and preferences
- Find treatment consistent with values
DA’s Help Clinicians

- Cover all options, limit bias
- Stay up to date on treatments
- Elicit patient goals & preferences
- Explain complex info (risk)
- Help explain tradeoffs
What matters most...

Sciatica from a Slipped (herniated) Disc
This grid is designed to help you and your healthcare provider select the treatment option that is best for you. It is for people diagnosed with a herniated disc who have experienced sciatica pain for at least six weeks and is not for people with bowel and urine problems due to the disc pressing on their nerves. Ask your healthcare provider if there are other treatment options available to you. Use the back of this page to write down any other questions you have.

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Managing without Injections or Surgery</th>
<th>Injections (epidural steroids)</th>
<th>Surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What does the treatment involve?</strong></td>
<td>Taking pain relievers that reduce inflammation around the nerve and attempting to be as active as possible. Physical therapy may also help.</td>
<td>A needle is used to inject local anaesthetic and steroid where the nerve is under pressure near the spine. An injection is normally performed at a special clinic and takes around 20 minutes.</td>
<td>The slipped disc that puts pressure on the nerve is removed during an operation on the back. The operation takes approximately 2 hours. Most people stay in hospital for a night or two but some go home the day of the surgery.</td>
</tr>
<tr>
<td><strong>How soon will I feel better?</strong></td>
<td>6 weeks after diagnosis, roughly 20 in 100 people say they are very or somewhat satisfied with their symptoms.</td>
<td>Most people who experience relief feel better within the first week or so after the injection.</td>
<td>6 weeks after surgery, roughly 60 in 100 people say they are very or somewhat satisfied with their symptoms.</td>
</tr>
<tr>
<td><strong>Which treatment gives the best long term results?</strong></td>
<td>1 year after diagnosis, around 45 people who manage without surgery or injections say they are very or somewhat satisfied with their symptoms.</td>
<td>It is hard to say: some studies have shown benefits from steroid injections but others have not.</td>
<td>1 year after surgery, around 70 in 100 people say they are very or somewhat satisfied with their symptoms.</td>
</tr>
<tr>
<td><strong>What are the main risks/side effects associated with this treatment?</strong></td>
<td>All medications have some side effects. Being active is unlikely to make your sciatica harder to treat in the future.</td>
<td>Fewer than 1 in 100 people have complications, which could potentially include bleeding, headache, and infection.</td>
<td>The main risks associated with this surgery are infection (2 in 100), blood clots (1 in 100) and damage to the nerves (less than 1 in 100).</td>
</tr>
</tbody>
</table>
Current Risk
Select Risk Calculator
ACC/AHA ASCVD  Framingham  Reynolds

The marked fields either require input or are out of range.

These figures are used to calculate my risk of having a heart attack in the next 10 years:

- **Age**: 40 - 75
- **Gender**: M  F
- **Population Group**:  
- **Smoker**: No
- **Diabetes**: No
- **Treated SBP**: No

Select Current Intervention

- **Statins**: No  Std Dose  High Dose

Systolic Blood Pressure: 90 - 250 mmHg
HDL Cholesterol: 10 - 120 mg/dL
Total Cholesterol: 100 - 350 mg/dL

Benefits vs Downsides according to my personal health status.
If a fistula forms, this creates a path from the intestines to the bladder that shouldn't be there.
Meta-analysis of 132 RCTs of DAs
Compared DAs to usual care and/or alternative interventions
Impact of Decision Aids

✓ Improve decision quality

✓ 3% higher knowledge
✓ 88% more realistic expectations
✓ 55% more informed values-based choices
✓ Reduce decisional conflict

✓ 34% fewer left undecided
✓ 37% less passive in decisions
✓ Improve patient-provider communication
✓ Increase active participation in patient/provider interaction
✓ Change decisions
  • 16% less surgery
  • 11% drop in PSA testing

The Cochrane Library 2015
Likely effects

✓ Improved health outcomes
✓ Less regret
✓ Improved patient satisfaction
✓ Reduced litigation
✓ Improved adherence
✓ Reduced cost of care
DO DECISION AIDS HELP?

“Patients get it more. They understand the stakes and are more comfortable being involved in decisions since they have a better grasp of the issues.

People are also more comfortable asking me questions.”

Corey Siegel, MD
Director of IBD Center
Dartmouth-Hitchcock Medical Center
WHAT DO PATIENTS THINK?

A RECENT SURVEY OF 1400 PEOPLE
I understand there is more than one way to treat my condition.

Survey of back pain, knee and hip osteoarthritis Emma viewers from May 2010 to May 2014
I UNDERSTAND THE PROS & CONS OF EACH OPTION

Survey of back pain, knee and hip osteoarthritis Emmi viewers from May 2010 to May 2014

92%
I have a better idea which treatment makes the most sense for me.
ARE YOU LEANING TOWARD A DIFFERENT TREATMENT OPTION?

Survey of back pain, knee & hip OA
EmmiDecide viewers

47% NO
30% YES, AWAY FROM AGGRESSIVE OPTIONS
15% DON’T KNOW
7% YES, TOWARD AGGRESSIVE OPTIONS
BREAST CANCER
Early-Stage Invasive Breast Cancer
How much information?
So no need to rush into a decision overnight. Give yourself some time to think about what's really important to you.
Doctors believe mastectomy and lumpectomy with radiation have the SAME ability to extend your life.

They know that, even though they have different risks, lumpectomy and mastectomy are both equally good at treating breast cancer.
EMOTIONAL DISCLOSURE & HONEST RESPONDING
Which of these do you agree with?

- Having some kind of breast is important to me
- Keeping my original breast is important to me
- I'm OK with the idea of having one breast gone
- I'm comfortable with the idea of wearing a prosthesis
- Sensation (feeling) in my breasts is important to me
- I'm still not sure how I feel
This rhythm is controlled by your heart's electrical system.
CONSIDER CROHN’S DISEASE

**Activity in a theoretical patient with Crohn’s disease**

- **Disease onset**
- **Diagnosis**
- **Early disease**
- **Pre-clinical**
- **Clinical**

- **Stricture**
- **Fistula/abscess**
- **Surgery**
- **Inflammatory activity** (CDX, ADA, CRP)
Even when people can’t feel fistulas, they can be causing problems.
HSTCL
HEPATOSPLENIC
T-CELL LYMPHOMA
We don’t think risk, we feel it.
Click to edit title

Number/Risk/Frequency
32 out of 100 people exhibit this property

Color
#0000FF
Change the color by clicking the square above or specifying a value

show this legend

Click on any square/icon in the array to set the number of risk events, or just set the number in the highlighted box.

www.iconarray.com
Your risk of heart disease and stroke

Your risk of having heart disease or stroke in the next 10 years has been calculated based on your answers and is shown in the graph below.

If there were 100 people exactly like you, 25 of them would have heart disease or stroke in the next 10 years.

Risk
Optimism &
Randomness

People who get heart disease or stroke in the next 10 years
How many get relief from their problems and can stop taking steroids (prednisone)?

Immunomodulators

30
HELP PEOPLE CONSIDER TREATMENT THEY FEAR
What are your concerns about taking medication daily?

- Cost
- Side effects (like muscle aches)
- I already take too many medications
- Getting my prescriptions and refills
- Having more follow-up appointments with my doctor
- I'm not concerned

continue
ULCERATIVE COLITIS: WHEN PATIENTS DON’T WANT TO KNOW
At what point do you believe surgery is a reasonable treatment option for ulcerative colitis?

- 4% when you first learn that you have ulcerative colitis
- 17% after trying medications that were not effective
- 78% only as a last resort
- 2% never
La la la la la la la la... I can't hear you!
Why consider surgery?

- Gets rid of UC digestive problems
- Colon cancer risk very low or zero
- No regular colonoscopies
- Can eat and drink almost anything
- Stop or avoid steroids and prescription medications
RISKS OF COLECTOMY WITH ILEOSTOMY

The main risks are the chance of a bulge (hernia) around the ostomy, or if the ostomy becomes longer (prolapse). Or the skin in the area can become irritated.

Would you like to hear more about these risks now?

more info  skip
Intestines poke out

It's less common, but other times the ostomy becomes longer and a little section of the intestines can sort of bulge or poke out through the stoma (prolapse).
Preferences Sliders

0 - Not at all important  

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Extremely important - 1

Dying from prostate cancer over the next 10 years?

5 %

Having no control over your bladder (incontinence) or frequent leaks?

73 %

Erectile Dysfunction (ED) (not being able to have an erection sufficient for intercourse)?

1 %

Having wetness in the rectal area?

12 %
Based on your preferences the best treatment options are:

1. Surveillance
2. Radiation Therapy
3. Surgery

Return to Preference Sliders
When my son was 4 we thought he had a milk allergy.

When we heard it was Crohn’s, my world flipped upside down.
THANK YOU

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October Health Literacy Month Blog Series

www.emmisolutions.com/blog

New articles every weekday in Oct!