Overcoming Barriers To Shared Decision Making

May 18, 2015
1:00 p.m. – 2:30 p.m. ET

Sponsored by:
Agency for Healthcare Research and Quality (AHRQ)

Presenters and moderator disclosures

The following presenters and moderator have no financial interest to disclose:

- Rebecca Burkholder, J.D. (National Consumers League)
- France Légaré, M.D. (Université Laval, Quebec)
- Mark Friedberg, M.D. (Brigham and Women’s Hospital and Harvard Medical School, RAND Corporation)
- Alaina Fournier, Ph.D. (Agency for Healthcare Research and Quality)

This continuing education activity is managed and accredited by Professional Education Services Group (PESG) in cooperation with AHRQ, AFYA, and AcademyHealth.

PESG, AHRQ, AFYA, and AcademyHealth staff have no financial interest to disclose.

Commercial support was not received for this activity.
Learning objectives

At the conclusion of this activity, the participant will be able to:

1. Identify key barriers to shared decision making from the patient’s and provider’s perspective.
2. Describe strategies for overcoming barriers to implementing shared decision making.
3. Describe AHRQ’s evidence-based initiative to promote shared decision making via the SHARE Approach, and how this program was developed to address common barriers to shared decision making.

Barriers To Shared Decision Making From the Patient’s Perspective

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Disclosures

Relevant Financial Relationships

None

Learning objectives

- Identify key barriers to shared decision making (SDM) from the patient’s perspective.
- Describe strategies for overcoming barriers to implementing shared decision making from the patient perspective.
Plan

- Shared decision making
- Barriers to shared decision making from the patient’s perspective
- Which barriers to shared decision making are common to patients and providers?
- Effective strategies for addressing barriers to shared decision making

Shared decision making (SDM)

- Interpersonal and interdependent process
- Recognizes that a decision is required
- Highlights best available evidence about risks and benefits of each option
- Takes into account the provider’s guidance and the patient’s values and preferences (patient specific)
Shared Decision Making is not happening!

<table>
<thead>
<tr>
<th>shared decision making component</th>
<th>% of studies reporting observation N=33</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledges a decision needs to be made</td>
<td>82</td>
</tr>
<tr>
<td>Acknowledges there is more than one way to deal with the problem</td>
<td>31</td>
</tr>
<tr>
<td>Explores the patient's expectations and ideas</td>
<td>63</td>
</tr>
<tr>
<td>Explores the patient's concerns</td>
<td>44</td>
</tr>
<tr>
<td>Verifies the patient understands information</td>
<td>50</td>
</tr>
<tr>
<td>Verifies the patient's desire to be involved</td>
<td>0</td>
</tr>
</tbody>
</table>

Mean OPTION score: $23 \pm 14\%$

Couët & al. 2013

What Are the Barriers To Shared Decision Making as Perceived by Patients?
Barriers from the patient’s perspective

Barriers from the provider’s perspective

Légaré et al. PEC 2008
Adapted from Cabana & al. Barriers to CPGs JAMA, 1999
Provider attitude influences intention of patients to share decisions

Patient Attitude
Patient Social Norm
Patient Moral Norm
Patient Self-efficacy

Patient Intention To Share Decisions

Physician Attitude

Légaré et al. Prenat Diagn. 2011

Barriers from BOTH the patient’s and provider’s perspective are similar!

Healthcare System Organizational Factors
Decision Making Interaction Factors

Individual capacity to participate in shared decision making

Power - permission - confidence - self-efficacy

Knowledge - condition - options - preferences & values
Power imbalance (patient-clinician)

Decision support
Characteristics of health care setting
Terminology used by clinicians

Time
Decision characteristics
Patient characteristics
Interpersonal characteristics of the clinician

Trust
Continuity

Work flow
Expectations of outcome of being involved in shared decision making
Perceived need for preparation to participate
Providing information about options

Joseph-Williams et al PEC 2014
Légaré et al PEC 2008
Some of These Barriers Are Myths!

It takes too much time!
We don’t’ know!

9 trials:
7: No difference
1: Longer
1: Shorter


Not everyone wants this!
At least some people do!

- About 26% to 95% of patients, with a median of 52%, would prefer a more active role.
- Time trend:
  - 50% of studies before 2000 compared to
  - 71% of the studies from 2000 and later
- Although client participation is linked to favorable client outcomes, the most vulnerable patients (low SES, elderly, immigrants) are less likely to ask for it, and providers are less likely to offer them to share decisions.

Kiesler DJ, Auerbach SM, 2006
Hibbard JH, Greene J. 2013

Not everyone can do this!
SDM translates into specific behaviors that are modifiable in patients and providers

**Essential behaviors**

- Define/explain problem
- Present options
- Discuss pros/cons (benefits/risks/costs)
- Discuss patient values/preferences
- Discuss patient ability/self-efficacy
- Present doctor knowledge/recommendations
- Check/clarify understanding
- Make or explicitly defer decision
- Arrange followup

Makoul & Clayman, 2006

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**What Can Be Done To Address Barriers To Shared Decision Making as Perceived by Patients?**
Effective interventions for addressing barriers to shared decision making exist (n=39 trials)

- Any implementation intervention is better than no implementation intervention at all (i.e., passive dissemination is not effective).
- An implementation intervention targeting BOTH patients and providers is superior to implementation of interventions targeting solely one or the other.

Patient decision aids are needed!

- Improve decision quality with...
  - 13% higher knowledge
  - 82% more accurate risk perception
  - 51% better match between values & choices

- 6% reduced decisional conflict
- Helps undecided to decide (41%)
- Patients 34% less passive in decisions
- Improved patient-practitioner communication (7/7 trials)
- Potential to reduce over-use
  - -20% surgery
  - -14% PSA – prostate screening
  - -27% Hormone replacement tx

Stacey, et al., 2014
Patient decision aids may not be enough!
(Collins ED et al. 2009 in J Clinical Oncology)

[Bar chart showing the effectiveness of decision aids]

Public campaign to raise awareness is effective

Training of providers is needed!

https://innovations.ahrq.gov/profiles/

Combined with patient decision aids

Légaré et al. CMAJ 2012
1. I made the decision alone.
2. I made the decision, but considered the opinion of my doctor.
3. My doctor and I decided equally.
4. My doctor made the decision, but considered my opinion.
5. My doctor made the decision alone.

Key messages

- To fully reach patient-centered care, patients need support to participate in decision making.
- Shared decision making is a process whereby patients are supported to make decisions.
- Facilitators to shared decision making:
  - Patient decision aids
  - Decision coaching
  - Public awareness campaigns
  - Training of health professionals
  - Targeting patients and providers is needed

Légaré et al. CMAJ 2012
Citations


Citations, cont.


Thank you
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Overcoming Barriers to Shared Decision Making
Primary Care Provider Perspectives
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Disclosures

Relevant Financial Relationships

None

Learning objectives

- Identify key barriers to shared decision making (SDM) from the provider’s perspective.
- Describe strategies for overcoming barriers to implementing shared decision making from the provider’s perspective.
We evaluated a demonstration of SDM

- 8 sites containing 34 primary care clinics
  - Selected for prior quality improvement experience
  - Some without prior decision aid experience
- July 2009 to June 2012
- Sponsored by the Informed Medical Decisions Foundation
  - Free decision aids
  - Technical assistance
  - Learning collaborative
- Qualitative evaluation at 18 months


Objectives of evaluation

- Identify barriers and facilitators to implementing shared decision making in primary care settings.
- Develop options for evaluation and measurement of shared decision making performance.
Semi-structured interviews

- 23 leaders and clinicians from all demonstration sites
- 10 patients from one site who had each received a decision aid during the demonstration
- Protocol investigated facilitators and barriers to:
  - Engaging clinicians
  - Integrating decision aids into key operational tasks
- We analyzed interview responses inductively for recurrent themes

Key steps of shared decision making based on decision aids

<table>
<thead>
<tr>
<th>Decision opportunity identification</th>
<th>Decision aid use</th>
<th>Post-DA conversation</th>
<th>Health care delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opportunity recognized</td>
<td>DA distributed</td>
<td>Clarify medical information</td>
<td></td>
</tr>
<tr>
<td>DA matched to opportunity</td>
<td>Patient uses DA</td>
<td>Elicit values and preferences</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Make shared decision</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Care consistent with final shared decision</td>
<td></td>
</tr>
</tbody>
</table>
Barriers to shared decision making

- Overworked physicians do not recognize decision opportunities and distribute decision aids reliably.
  - Site leaders who relied on physicians to trigger the distribution of decision aids estimated that only 10 to 30 percent of patients facing decision opportunities received the corresponding decision aids.

“As long as you have the physicians in the middle of [distributing decision aids], they have too many other things on their plate to reliably ensure this would happen every time ... in a 10- to 15-minute appointment.”

“We hear physicians say: ‘I seem to be the problem here, how do I get myself out of the loop so we can get [the decision aids] to people that need to get them?’”

“In the real world ... I’m not sure we can expect the physicians to identify patients.”
Barriers to shared decision making

- Overworked physicians do not recognize decision opportunities and distribute decision aids reliably.

- **Insufficient provider training**
  - Recognizing decision opportunities and having post-decision aid conversations are skills providers must learn.

  "We found that physicians felt that they were already doing shared decision making before we introduced the decision aids. To me, it’s not really shared decision making when there is only a 15-minute appointment, and patients can’t really engage in a conversation when they don’t know much about the topic."

Barriers to shared decision making

- Overworked physicians do not recognize decision opportunities and distribute decision aids reliably.

- **Insufficient provider training**
  - Recognizing decision opportunities and having post-decision aid conversations are skills providers must learn.

  "You really have to pay attention to the clinicians in this equation. You can’t just ask them to do something and assume that they’ll know what you mean. ... We under-attended the training of our clinicians."
Barriers to shared decision making

- Overworked physicians do not recognize decision opportunities and distribute decision aids reliably.
- Insufficient provider training
- Inadequate clinical information systems
  - Not able to track the full sequence of steps involved in shared decision making
    - Unable to flag patients as candidates for decision aids or indicate which patients received them
    - Lacked mechanisms for communicating patient-reported values and preferences to providers
    - No longitudinal functions to track patients through the shared decision-making process, including determining whether patients had timely post-decision aid conversations with providers

Barriers to shared decision making

- Overworked physicians do not recognize decision opportunities and distribute decision aids reliably.
- Insufficient provider training
- Inadequate clinical information systems
  - Not able to track the full sequence of steps involved in shared decision making
  - Not able to integrate with decision aids

“All of the information from the decision aid questionnaires is off the chart. There is documentation that a decision aid was given... but anything from the surveys is kept completely separate.”
Solutions sites employed

- Automatic triggers for decision aid distribution
  - Trigger on patient age and gender (for screening)
    Site leader: “The more automatic you can make it, the more successful decision aids can be in primary care, whether that’s having the health tech[nician] prescribe it or having it be an automatic mailing based on visit type. Anything you can do to streamline process and not rely on clinicians’ memory to include [the decision aid] as part of visit routine will be a successful strategy.”

- Trigger on specialist referrals (for surgical procedures)
  - Relative greater focus of specialist visits may facilitate more reliable performance of post-decision aid conversation.
  Site leader: “In the specialty clinic, the [decision aids] are much more frequently discussed. It is a bigger challenge for the primary care practice because there may be several things a patient wants to discuss, but when you see a specialist, you see the doctor for a particular purpose.”
Solutions sites employed

- Automatic triggers for decision aid distribution
  - Trigger on patient age and gender (for screening)
  - Trigger on specialist referrals (for surgical procedures)
    - Relative greater focus of specialist visits may facilitate more reliable performance of post-decision aid conversation.

- Engage team members other than physicians.
  - Example: “Decision coach” to introduce the decision aid
    Patient: “When you’re with the doctor, you don’t get a chance to ask a lot of questions. ... A nurse I had never met [before] came in and introduced me to [the decision aid]. She had a CD and a book about the surgery. ... Of course I was interested in that.”

Measuring the successfulness of implementing shared decision making

- Process measures should capture all steps of shared decision making.
  - “All-or-none” measures may be appropriate.

- Remember, even if a decision aid is prescribed and used, poor performance of the post-DA conversation can completely undermine shared decision making.
Vulnerability in later steps of SDM

Rate-limiting steps = targets for measurement

Measuring the successfulness of Implementing shared decision making

- Process measures should capture all steps of shared decision making.
  - “All-or-none” measures may be appropriate.

- Measures of decision quality
  - In the end, was care consistent with the patient’s values and preferences?
Measuring the successfulness of implementing shared decision making

- Process measures should capture all steps of shared decision making.
  - “All-or-none” measures may be appropriate.
- Measures of decision quality
  - In the end, was care consistent with the patient’s values and preferences?
- Indirect measures of shared decision making performance
  - In theory, shared decision making should produce variability that is driven entirely by patients, not providers.
  - If each provider in an organization has a PSA screening rate of 100% or 0%, the organization is unlikely to have implemented shared decision making successfully.

Implications

- Achieving shared decision making will require “new operating systems” for primary care practices.
  - Major investments will be needed to develop and improve educational, operational, and informatics systems.
  - Payment reform may be necessary.
Implications

- Achieving shared decision making will require “new operating systems” for primary care practices.
- There are no data yet on the successfulness of shared decision making in medical home implementations.
  - “Quadruple axel” of primary care: Ability to do this well implies that many other capabilities are present and functioning.
  - Given the degree of difficulty, expect some disappointments as practices figure out how to do this.
  - Watch the measures in this space: Distributing decision aids is not sufficient to guarantee that shared decision making has occurred.

Implications

- Achieving shared decision making will require “new operating systems” for primary care practices.
- There is no data yet on successfulness of shared decision making in medical home implementations.
- Key issue for policy makers: How high to set the bar for deciding what counts as “engagement” in shared decision making
  - Lower bar: Count or rate of decision aid distribution
  - Higher bar: All-or-none process measures including all steps of shared decision making
Thank you
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Development of the SHARE Approach
Addressing Barriers to Shared Decision Making Identified by Formative Research During the Development Phase

Alaina Fournier, Ph.D.
Office of Communications and Knowledge Transfer
Agency for Healthcare Research and Quality (AHRQ)
Presentation objective

- Describe AHRQ’s evidence-based initiative to promote:
  - Shared decision making via the SHARE Approach
  - How the program was developed to address common barriers to shared decision making

Disclosures

Relevant Financial Relationships

None
The Agency for Healthcare Research and Quality

- AHRQ is a Federal agency that is part of the U.S. Department of Health & Human Services.
- AHRQ works to produce and disseminate evidence to make healthcare safer, of higher quality, more accessible, equitable, and affordable.

Patient-centered outcomes research (PCOR)

The Affordable Care Act directs AHRQ to disseminate and implement patient-centered outcomes research (PCOR).

**PCOR is a type of research that:**
- Assesses the effectiveness of preventive, diagnostic, therapeutic, palliative, or health delivery system interventions
- Compares the benefits and harms of available interventions
- Aims to find out how well interventions work in everyday practice settings, not just in clinical trial settings
- Focuses on outcomes that matter to people
AHRQ’s Effective Health Care Program

- Synthesizes PCOR through systematic reviews and comparative effectiveness reviews
- Translates PCOR findings into plain-language resources for patients and health care professionals to support decision making
- Disseminates PCOR-based decision aids to those who need them (www.effectivehealthcare.ahrq.gov)

Goal: Improve health care quality and patient health outcomes through informed decision making by patients, providers, and policymakers.

AHRQ’s Educating the Educator Project

- Project launched in 2013
- Aimed to facilitate the dissemination and use of PCOR decision support resources in shared decision making between health professionals and patients
AHRQ’s SHARE Approach Workshop

Accredited training program on shared decision making

- Create a **train-the-trainer workshop curriculum** and **collateral tools** to help clinicians learn how to use Effective Health Care and PCOR resources in shared decision making.
- Conduct **10 workshops** per year across the country.
- Provide support to trainees with **Webinars, technical assistance, and a learning network**.

Formative research approach

- **Literature Review**
- **Health Educators Needs Assessment**
  - Online Survey: Over 2,300 respondents
  - 7 Focus Groups: Treating and non-treating clinicians
  - 6 Key informant interviews

**What are:**
- Operational models of shared decision making
- Key competencies for shared decision making
- Health professionals roles
- Barriers to shared decision making
- Training approaches

**Purpose:** To inform the development of a training program that would meet the needs of health care professionals

* OMB No. 0935-0179
Identified barriers for providers

- Common themes identified *(Survey, focus groups, interviews, literature review)*
  - Time constraints
  - Belief that “we already do shared decision making”
  - Belief that it is generally not applicable
    - Patients don’t want it.
    - It’s not applicable in most clinical situations.
  - Lack of organizational support
  - Lack of access to trusted sources/decision aids

Identified barriers for patients

- Common themes identified *(literature review)*
  - Not knowing that they can and should be involved
  - Health literacy/numeracy barriers
  - Cultural issues
  - Geographic/demographic variables
    - Rural populations
    - Older adults
The SHARE Approach

*Training design principles to address provider barriers*

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Training Design Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time constraints</td>
<td>• Created a simple five-step process easily implemented with examples</td>
</tr>
<tr>
<td></td>
<td>• Interdisciplinary – leveraging entire health professional team</td>
</tr>
<tr>
<td></td>
<td>• Training that emphasizes time is not as big a barrier when you look at the evidence.</td>
</tr>
<tr>
<td>“We already do it”</td>
<td>• Demonstration via video – What does it really look like.</td>
</tr>
<tr>
<td></td>
<td>• Checklist of key activities</td>
</tr>
<tr>
<td>Not applicable</td>
<td>• Training on what the literature actually shows</td>
</tr>
<tr>
<td></td>
<td>• Explicit invitation to be involved</td>
</tr>
<tr>
<td>Lack of organizational support</td>
<td>• Module on implementing shared decision making in the practice setting, including gaining leadership support</td>
</tr>
<tr>
<td></td>
<td>• Administrator/senior leader brief to gain buy-in</td>
</tr>
<tr>
<td>Lack of access to PCOR and DA</td>
<td>• Module on PCOR: What it is, and where and how to find trust resources/decision aids</td>
</tr>
<tr>
<td>Lack of know-how</td>
<td>• Training program</td>
</tr>
<tr>
<td></td>
<td>• Ongoing Webinar series</td>
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<td></td>
<td>• Learning network</td>
</tr>
</tbody>
</table>

SHARE Approach

*Training design facilitators for patient barriers*

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Design Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not knowing that they have a role to play</td>
<td>• A key component of the SHARE Approach framework if the INVITATION to participate in decision making</td>
</tr>
<tr>
<td>Health literacy and language barriers</td>
<td>Inclusion of a communication module that addresses:</td>
</tr>
<tr>
<td></td>
<td>• Role of health literacy, including tools and resources – use of universal precautions</td>
</tr>
<tr>
<td></td>
<td>• Working with medical interpreters</td>
</tr>
<tr>
<td></td>
<td>• Cultural competency strategies</td>
</tr>
<tr>
<td></td>
<td>• Health numeracy</td>
</tr>
<tr>
<td></td>
<td>• Teach-back with shared decision making</td>
</tr>
<tr>
<td>Cultural issues</td>
<td></td>
</tr>
<tr>
<td>Demographic variables</td>
<td>Implementation module with multiple examples of how shared decision making can be implemented in the practice setting, including:</td>
</tr>
<tr>
<td></td>
<td>• Examples of a variety of ways to deliver decision aids</td>
</tr>
</tbody>
</table>
Training resources

- Shared decision-making toolkit on the AHRQ Web site
  - Train-the-Trainer workshop curriculum modules
  - 9 informational tools (with links to other evidence-based resources)
  - Video, screensaver, poster
  - Links to other AHRQ resources that support or are related to shared decision making

The SHARE Approach
Essential Steps of Shared Decision Making

1. Seek your patient's participation
   - Communicate that a choice exists and invite your patient to be involved in decisions.

2. Help your patient explore and compare treatment options
   - Discuss the benefits and harms of each option.

3. Assess your patient's values and preferences
   - Take into account what matters most to your patient.

4. Reach a decision with your patient
   - Decide together on the best option and arrange for a follow-up appointment.

5. Evaluate your patient's decision
   - Plan to revisit decision and monitor its implementation.

www.ahrq.gov/shareddecisionmaking
April 2014   AHRQ Pub. No. 14-0026-3 EF
The SHARE Approach
Train-the-Trainer Workshop

- Consists of four modules and a training module (~6.25 hours of training)

- **Module 1**: Shared Decision Making
- **Module 2**: Accessing and using PCOR Resources
- **Module 3**: Communication
- **Module 4**: Putting Shared Decision Making Into Practice

**Training Module**

Ongoing support from AHRQ

- **AHRQ provides ongoing support activities for participants of the workshop.**
  - SHARE Approach Web conferences
  - Technical assistance to workshop trainees
  - SHARE Approach Learning Network (coming soon!)
The SHARE Approach

- All Effective Health Care materials described here may be found on AHRQ’s Effective Health Care Web site:
  
  http://effectivehealthcare.ahrq.gov/

- Shared decision-making tools and resources are available on AHRQ’s shared decision-making Toolkit Web site:
  
  http://www.ahrq.gov/shareddecisionmaking/

The SHARE Approach Web site also contains information about upcoming SHARE Approach workshops around the country.

Citations


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Agency for Healthcare Research and Quality

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- Questions will be read aloud by the moderator.
- SHARE@ahrq.hhs.gov