Shared Decision Making for Chronic Conditions and Long-Term Care Planning

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Shared Decision Making for Chronic Conditions and Long-Term Care Planning

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- SHARE@ahrq.hhs.gov
Learning Objectives

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

1. Describe the rationale and research behind shared decision making and its potential for improved outcomes in chronic disease.
2. Explain the differences and complementary qualities of motivational interviewing and skills of shared decision making.
3. Outline the clinical applications of shared decision-making principles to chronic disease.
4. Distinguish between how shared decision making is used in medical treatment choices and for other preference-sensitive choices frequently faced by aging veterans (e.g., choice of long-term services and supports).
5. Explain the short- and long-term outcomes of successful shared decision making for aging veterans.
Shared Decision Making (SDM) and Chronic Disease

Cathleen E. Morrow, M.D.
Department of Community and Family Medicine
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Definitions of SDM

- A communication skill, focused on patient’s values and preferences as they apply to facilitate high-quality patient care in the context of medical decision making.
- An attitude and philosophy; an approach to thinking about effective patient care.
- Acknowledges the collaborative nature of good medical care and the dual expertise involved in all decision making—that of patient and doctor.
Interpersonal and interdependent process.

Recognizes that a decision is required and that providing information is helpful but not sufficient.

Highlights best available evidence about risks and benefits of each option married to the patients values and preferences.

Dynamic interplay between the provider’s guidance and the patient’s values and preferences.
**SDM – The Conversation**

- Is an instrument of care, appropriate to the uncertainties of illness and treatment.
- In chronic disease care, is especially important: changes over time; individual patient response varies; patient values and preferences are critical to management and must be frequently re-visited.
- Especially called for when best option is not clear: these are common in chronic disease!
Categories of Care

- Effective care – evidence-based
- Preference-sensitive care
- Supply-sensitive care
- "Geographic variation" work in the 1970s by Wennberg observed that physician preference dominated the type of care and choices offered to patients.
- In the 1990’s Wennberg identified that SDM was central to countering geographic variation and tendency for care to be physician preferred.
Which Category of Care?

- Supply sensitive care
- Preference sensitive care
- Effective care

- Antibiotics for strep throat
- Cardiac catheterization for chest pain
- Immunization for Hep B
- Breastfeeding
- Hip replacement surgery
Evidence-based information about the options

Values clarification

http://decisionaid.ohri.ca/decguide.html
Cochrane Reviews of Decision Aids

- Improve: • knowledge
- Improve: • realistic expectations
- Lower: • decisional conflict
- Improve: • patient – practitioner communication

Motivational Interviewing (MI)

- A second important communication skill designed to enhance uptake of medical advice and improve outcomes.
- Utilized most effectively in evidence-based decision making when evidence is abundant and ‘choice’ is less relevant.
- Tobacco cessation provides classic MI content.
MI: Where are you on a scale of 0 to 10 in your interest in quitting? What would it take to get to next higher number?

SDM: Given that there are a number of options, can you help me understand what is important to you in this matter? What are your values and preferences?
Confirm that there is a decision to be made and clarify that the patient has a role.

Verify understanding of the options, risks, and benefits.

Frame decision in light of what is personally important (values and life circumstances).

Plan next steps.

Decision Support in the Clinical Encounter.

http://decisionaid.ohri.ca/decguide.html
AHRQ SHARE Approach

- **Step 1:** Seek your patient's participation.
- **Step 2:** Help your patient explore and compare treatment options.
- **Step 3:** Assess your patient's values and preferences.
- **Step 4:** Reach a decision with your patient.
- **Step 5:** Evaluate your patient's decision.
Challenges in Chronic Disease Management: Patient View

- Many chronic diseases do not have overt symptoms that impact patients’ daily lives.
- Many patients deny or minimize the impact of chronic diseases on their lives.
- Patients want to be “well,” and they often feel that way.
- No one likes to take medicine.
- The diagnosis of a “disease” has important and often negative impact on patients’ psychological and emotional health and well-being.
Challenges in Chronic Disease Management: Provider View

- We have limited time with patients.
- Educating patients about chronic disease is a complex and lengthy process.
- Providers vary in their skills and interest to educate, explain, and understand where a given patient is along the trajectory of their acknowledgment and understanding about a diagnosis.
- Many providers are fatigued by the effort and feel “it’s not worth it.”
- This leads to self-fulfilling prophecy.
Principles in Chronic Disease Management

- You can’t get it all done in one visit!
- Relationship over time is essential: ongoing conversation.
- Message: We can manage this problem effectively together; we are partners in successful outcomes; we will work at this to make you healthier.
- Flexibility for management: e-visits, telemedicine, phone management.
- Current payment modalities often not helpful!
- ACOs and capitated payments will improve this challenge over time.
Evidence Base

- Systemic review of 50 studies (2015).
- Increased overall patient satisfaction.
- Reduced costs: Elective surgery, BPH surgery, PSA screening, end-of-life care.
- Studies that looked at behavioral measures (reaching a decision; adherence) showed positive results in 37 percent of the cases.
- Studies of self-reported symptoms (e.g., QOL, mental function, etc.) were 42 percent positive.
- No negative results were found.

Sources:
Evidence Base for SDM

- In MD-led decision making, one-third of patients do not feel well-informed.

- With SDM, patients:
  - Have more accurate understanding of risks and benefits
  - Have less decisional conflict
  - Increased congruence with their own values.

- SDM is a CMS quality metric and requirement for patient-centered medical home recognition.

Sources:
Adherence matters! Estimates are that one-third of hospital admissions can be attributed to non-adherence with medication, leading to $100 billion in costs annually.

Non-adherence is multi-factorial, but engaged patients who have shared in the decision process and feel their values and preferences are understood and part of the consideration for decisions are more likely to remain adherent.

Targeted Conditions for Medication Adherence Programs

Which conditions are the most receptive to programs to improve medication adherence?

- Hypertension: 61.0%
- Diabetes: 57.6%
- Heart failure: 55.9%
- COPD: 52.5%
- CAD: 50.8%
- Cholesterol: 39.0%
- Asthma: 37.3%
- HIV: 25.4%
- Stroke: 18.6%
- Mental illness: 16.9%
- Depression: 16.9%
- Other: 15.3%
- Osteoporosis: 11.9%

Source: HIN Improving Medication Adherence
January 2013
Need for SDM: Adherence

- Multiple studies show:
  - Post-MI medication adherence to be 40 to 50 percent 1 to 2 years post event.
  - Hypertension medication adherence to be 40 to 60 percent.

- Statin users have higher BMIs, and they consume more calories than non-users. Over a 10-year period, statin users’ BMIs and caloric intake increased compared to matched controls.

Sources:
Choudhry NK, Winkelmayer WC. 2008;23(2):216-218..
Adherence: Diabetes Mellitus (DM)

- 62 to 64 percent of patients with Type 2 DM on insulin adhered.
- One-third of young patients on insulin filled their prescriptions.
- 36 to 93 percent of Type 2 DM patients took prescribed oral agents for 6 to 24 months.

SDM Approach to Chronic Disease

- Goals: Nurture an activated patient who “owns” his or her disease and is enthusiastic about controlling it.

- Respect that patients have their own timeframe, personal and family needs, and need attention to their individual circumstances.

- SDM:
  - Acknowledges and embraces patient autonomy.
  - Appreciates that no decision is a choice.
  - Is NEVER about patient abandonment.
You have Diabetes: Tell me how you understand that? What does it mean to you?

What do you think you need to manage this problem well?

Tell me what is important to you about this diagnosis?

Who else is involved in helping you manage it?

There will be a lot of decisions to make over time to manage your condition. If I understand something about your preferences, I will be better able to help you.
Talking to Patients: Hypertension

- You have high blood pressure. Tell me what that means to you?
- What is important to you when you think about this medical problem?
- Do you have any specific preferences for how we might go about treating this condition?
- Who else is going to be involved in helping you get this problem under control?
Talking to Patients: Hyperlipidemia

- You have high cholesterol? What do you know about that?
- Can you tell me what is important to you about this problem and how to treat it? Preferences? Values?
- Who else is part of helping you manage it?
- What else should I know that might help me to best understand how to help you?
Statin/Aspirin Choice
Decision Aid

Current Risk

Risk for 100 people like you who do not medicate for heart problems

Cost

Daily Routine

Standard dose statins
One pill once a day

Other Benefits

Standard dose statins
The use of statins reduces your stroke risk by about one fifth.

Side Effects

Standard dose statins
Common side effects
nausea, diarrhea, constipation
(most patients can tolerate);
Muscle aching/stiffness
5 in 100 patients
(some need to stop statins because of this);
Liver blood test goes up
(no pain, no permanent liver damage):
2 in 100 patients
(some need to stop statins because of this);
Muscle and kidney damage
1 in 20,000 patients
(requires patients to stop statins).

Future Risk

Risk for 100 people like you who do take standard dose statins

Over 10 years
7 people will have a heart attack
91 people will have no heart attack
2 people will be saved from a heart attack by taking medicine

http://statindecisionaid.mayoclinic.org
Lessons Learned

- SDM is never about patient abandonment; sometimes patients will ask you to make a decision for them: “Tell me what to do, Doc.”

- If you know what is important to your patient, and something about their values and preferences, you will create more realistic plans that patients can live with.

- Doing nothing is a choice. Sometimes it helps to identify that.
Other Lessons Learned

- Agency and self-efficacy are essential to controlling chronic diseases.
- “Management” of a chronic disease includes supporting patients’ sense of self-efficacy. Creating a sense of partnership leads to increased satisfaction for both provider and patient.
- In the long-run, SDM saves time during visits and curtails frustration.
- Decisions in chronic disease are not ‘done’ – circumstances change over time and require re-visiting the issues frequently.
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Shared Decision Making for Aging Veterans:
Long-Term Care Planning

Sheri Reder, Ph.D., M.S.P.H
VA Puget Sound Health Care System
What is SDM?

We define SDM as a collaborative, patient-directed decision making process that assists veterans in assessing their health-related needs, setting priorities, and making choices that achieve their goals.

SDM aligns with several VA initiatives, and it’s supported by VA leadership.
Why Aging Veterans?

- Though the rate of growth is slowing, older veterans are the fastest growing cohort we serve.
- By 2017, nearly 10 million of our 21.7 million veterans (46%) will be over 65.
- About 70 out of 100 people need long-term services and supports (LTSS) during their lifetime.
Conventional Use of SDM – Treatment

Traditional decision aids are used to provide health information, help prepare for a conversation with a health care provider, and/or make a decision about a specific treatment or whether to have a screening test.

<table>
<thead>
<tr>
<th></th>
<th>Dialysis</th>
<th>Kidney transplant</th>
<th>Conservative care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Summary</strong></td>
<td>Your kidney failure is treated using special equipment to remove waste</td>
<td>You receive a kidney from another person. They may be a living or deceased donor</td>
<td>Your kidney failure is managed through diet and medication. You will get specialised support when needed for end of life care</td>
</tr>
<tr>
<td></td>
<td>products from your blood</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How the treatment is done</strong></td>
<td>Treatment can be done either at home or in a dialysis centre using a machine or special dialysis fluid</td>
<td>You will have an operation where you receive a kidney</td>
<td>You will continue seeing your kidney specialist, who will help manage your symptoms, diet and medication</td>
</tr>
<tr>
<td><strong>My suitability for this treatment</strong></td>
<td>Most people with kidney failure are suitable, unless you have serious illness affecting other body systems</td>
<td>A transplant is currently suited to younger patients without serious health issues besides kidney disease</td>
<td>This is suitable for all patients, however is usually chosen if you have a poor quality of life or life expectancy, often due to illness affecting other body systems</td>
</tr>
<tr>
<td><strong>My life and work</strong></td>
<td>There are different types of dialysis. Home treatments are more flexible than others</td>
<td>Most people are able to resume normal activities and work within 3–6 months after transplant</td>
<td>Your health will deteriorate, so your life expectancy will decrease</td>
</tr>
</tbody>
</table>

SDM: Other Preference Sensitive Choices

SDM works best for preference sensitive choices. These decisions do NOT need to be treatment choices. For aging veterans, SDM is a best practice for choices that support aging-in-place.

- Provide decision aids (Worksheets) and comprehensive information for veteran and family – [www.va.gov/Geriatrics](http://www.va.gov/Geriatrics)
- Facilitate collaborative, asynchronous discussions among the patient, family, social worker, and medical care team.
- Support patient-directed decisions, with the goal of decisions accepted by all.
Research studies (including Reder, 2009) indicate veterans and their family caregivers need:

- **More information** about long-term care options, in general.
- More information about **home and community-based services**, so they can remain at home/be independent.
- To be **asked about their life goals** and how LTSS can help support them.
- **Decision aids (i.e., worksheets)** to facilitate making choices about LTSS.
Shifting Veteran’s Role

Our goal is to shift the veteran’s role—and the care team process—from a medical model, focusing on provider expertise, toward a process of patient-directed decisions.
Outcome Measures

Proximal measures – goal of increased:
- Access/referrals to home and community-based services.
- Veteran-directed choices based on goals and priorities.
- Veteran and family caregiver satisfaction with decision process.
- Completion rate of advance directives.
- Veteran aging-in-place.
- Care team acceptance of veteran choice(s).

Distal measures – goal of decreased:
- Emergency department and urgent care visits.
- Number and length of inpatient hospital stays.
Staff Roles – It’s a Team Effort

- The shared goal is veteran-directed decisions facilitated by care team input and quality information.
- With SDM, roles filled by team members are interdependent.
- This is achieved through collaborative, often asynchronous, discussions with veterans; and supported by team members communicating with each other and respecting veteran’s choice(s).
Social work/care management should take the lead to adopt SDM process and framework to help veterans make LTSS choices.”

— Michael Kilmer
GEC Web Site – Key SDM Info and Tools

- SDM overview and Decision Aids – Worksheets for veterans and family/caregivers
- Key source of comprehensive range of LTSS and detailed descriptions
- Information about geriatric programs and resources for older veterans on well-being, advance care planning, and paying for long-term care

www.va.gov/Geriatrics
Home and Community-Based Care (HCBC)

These services help chronically ill or disabled Veterans of any age remain in their homes. You can receive more than one service at the same time.

- Adult Day Health Care
- Home Based Primary Care
- Homemaker and Home Health Aide Care
- Hospice Care
- Palliative Care
- Respite Care
- Skilled Home Health Care
- Telehealth Care
- Veteran-Directed Care
Palliative Care uses comfort care with a focus on relieving suffering and controlling symptoms so that you can carry out day-to-day activities, and continue to do what is most important to you. Palliative care aims to improve your quality of life – in your mind, body and spirit.

Palliative Care can be combined with treatment that is aimed at curing or controlling your illness. It can be started at the time of your diagnosis, and may be provided throughout the course of the illness.

Video about Palliative Care

Palliative care helps Veterans and their families manage illness with plans of care. Watch this video to listen to Veterans and doctors talk about how VA palliative care helps patients live their lives.

Watch video
Decision Aid Worksheets

Veteran

- Guides veteran through SDM process.
- Used to identify goals, priorities, and plans, make decisions, or just start a discussion.
- Can be completed or just reviewed; not a professional assessment tool.

Caregiver

- Helps family caregivers assess their roles and responsibilities.
- Can prompt readiness for participation in shared decisions.
Other SDM Hardcopy Materials

1. Overview of Long Term Services and Supports
2. Shared Decision Making with Workshops
3. Advance Care Planning
4. Well-Being for Older Adults
5. Shared Decision Making for Veterans and Family Members
Use SDM for Advance Care Planning (ACP)

SDM is a natural fit for Advance Care Planning.

- **Any veteran** who is considering LTSS also should have an ACP discussion.
- The SDM process can help in **ACP discussions**, such as who would make treatment choices for the veteran if they could no longer do it.
- **Planning ahead** allows veterans to make important end-of-life choices when they can focus on them without pressure.
www.va.gov/Geriatrics includes an ACP section.

It provides links to the VA Advance Directive form, and a Values Worksheet.

And, it includes resources that support discussions about end-of-life choices, such as handouts, podcasts, and links to interactive Web sites.
The SDM approach is flexible—based on the situation, collaborative discussions about long-term services, and supports that can lead to discussions about advance care planning.
SDM Implementation Components

SDM requires change in behaviors. Because good information is rarely sufficient to change behavior, this multi-faceted implementation program includes:

- **Orientation and Training** for all levels of staff from leadership to clinic/service line management and staff to those most closely involved with collaborative SDM discussions.

- **Policy and Program Changes** to address gaps in availability and access to services, including funding (e.g., use of electronic wait lists; involvement of Veteran Community Partnership Organizations).

- **Tools and Information** in hard copy and online that facilitate veteran-directed decisions (e.g., decision aids).
SDM Site Implementation Steps

1. **Leadership Orientation** – Provides brief sessions for national and VAMC leadership prior to training to ensure support for SDM.

2. **Training 1** – For all staff and management of any clinic/service line that plans to implement SDM:
   - Overview of SDM
   - Implementation
   - Team roles
   - Care team process

3. **Training 2** – Skills practice for social workers and other staff who most frequently discuss LTSS with veterans; uses case scenario teaching model.
4. **Implement SDM for aging veterans** – Determine your clinic screening criteria, use the GEC Web site and SDM hardcopy materials, and start having SDM discussions.

5. **Interviews** – Staff, veterans, and family caregivers will be invited to participate in a quality improvement assessment interview.


**Note:** We are also conducting analyses from databases on outcome measures, such as number of LTSS referrals to home and community-based services and number of advance care directives completed.
Implementation Sites

Funding for development, implementation, and assessment of Shared Decision Making for Aging Veterans has been provided from multiple sources, including national offices of:

- Geriatrics and Extended Care
- Rural Health
- Patient-Centered Care and Cultural Transformation
- Care Management and Social Work Services (key collaborator in this work)
Key SDM Concepts – Review

The SDM approach supports:

- Veteran self-identification of goals and priorities, based on their values, preferences, and needs.
- Involvement of care teams in collaborative, often asynchronous, discussions with the veteran.
- Veteran understanding of medical conditions, the likely effects on health and function, and options for obtaining services and support.
- Provision of comprehensive information and use of decision aids to support veteran-directed choices.
- Access to home and community-based services to support aging-in-place.
SDM: Collaboration – Veteran at Center

- Social Worker
- Nurse Care Manager
- Family
- Veteran
- Caregiver
- Other Care Team Members
- Physician
- Veteran

Care Team Members
Contact information

We look forward to collaborating with you on implementation of SDM for Aging Veterans.

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SHARE Approach Resources

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