Shared Decision Making for Lung Cancer Screening

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Centers for Medicare and Medicaid Services

“The Centers for Medicare & Medicaid Services (CMS) has determined that the evidence is sufficient to add a lung cancer screening counseling and shared decision making visit, and for appropriate beneficiaries, annual screening for lung cancer with low dose computed tomography (LDCT), as an additional preventive service benefit under the Medicare program only if the following conditions are met…”

(February 5, 2015)


History and Stages of Coping with Lung Cancer Screening Policy

- Protracted frustration and near exhaustion (early trial data)
- Optimism and hope (NLST Data)
- Exuberance for implementation (USPSTF Policy Statement)
- Relief for coverage (CMS National Coverage Determination)

But then we read the details… (Apologies to Dr. Kubler-Ross)

1) Shock… what is this shared decision making business?
2) Denial… surely they don’t really mean that, do they?
3) Anger… they are just trying to reduce uptake?
4) Depression… we can’t possibly do this.
5) Bargaining… hmm, maybe we can do this a little bit
6) Acceptance… well, maybe this is the right thing to do.
Overview

What is Shared Decision Making?

Why Shared Decision Making?

Why Now, Shared Decision Making?

How can Decision Aids help?

What is Shared Decision Making?

Definition of Shared Decision Making

*Shared decision making* (SDM) is a collaborative process that allows patients and their providers to make health care decisions together.

It takes into account the best clinical evidence available, as well as the patient’s values and preferences.
**Shared Decision Making: A Meeting of Experts**

**PRACTITIONER**
- Invite patient to participate
- Present options
- Discuss risks, benefits, alternatives, uncertainties (using best available evidence)
- Elicit values and preferences
- Check understanding
- Discuss next steps

**PATIENT**
- Describes health, symptoms, and history
- Discusses values, implementation challenges, and preferred style of decision making

Patient is invited to and engages in decision making at the desired level.

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**Shared Decision Making (SDM)**

*Informed decision making* occurs when an individual...

- understands what the clinical service involves, including...
  - potential benefits, harms, limitations, alternatives, & uncertainties
- has considered personal preferences, as appropriate;
- has participated in decision making at the desired level
- makes a decision consistent with those preferences...

*Shared decision making* connotes a process in which providers and patients collaborate as partners in the decision-making process.


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**The SHARE Approach to SDM**

**SHARE** is a five step process that explores and compares benefits, risks, unknowns and harms with patients based on their individual wants.

S: Seek the patient’s participation
H: Help the patient explore and compare options
A: Assess the patient’s values and preferences
R: Reach a decision with the patient
E: Evaluate the patient’s decision

Why Shared Decision Making?  
How Did We Get Here?

- 1970s: medical ethicists began to focus on patient autonomy.
- Critique of paternalism/“just trust the doctor.”


- “Shared decision making is the appropriate ideal for patient–professional relationships…”
- “Shared decision making requires that a practitioner seek…to understand each patient’s needs…develop reasonable alternatives to meet those needs…present the alternatives in a way that enables patients to choose one they prefer.”

USPSTF Definition of Shared Decision Making

... a particular process of decision making by the patient and clinician in which the patient:
1. understands the risk or seriousness of the disease or condition to be prevented;
2. understands the preventive service, including the risks, benefits, alternatives, and uncertainties;
3. has weighed his or her values regarding the potential benefits and harms associated with the service; and
4. has engaged in decision making at a level at which he or she desires and feels comfortable.

(Sheridan et al., 2004, AJPM)
Optimal Patient Care

**Ingredients**
- Communication Skills
- Evidence-Based Medicine
- Shared Decision Making

(Hoffman et al., 2014, *JAMA*)

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**Shared Decision Making: Benefits for Patients**

- Improves knowledge
- Clarifies values for risks/benefits of options
- Reduces decisional conflict
- Reduces decision regret
- Improves realistic expectations about options


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**Shared Decision Making: Benefits for Clinicians**

- Improves informed consent procedures
- Might save time...
  - Expand counseling beyond constraints of busy office visits
  - Improve baseline knowledge prior to consultation
- Might reduce malpractice claims or the success of malpractice lawsuits
- May decrease practice variation and reduce cost

King & Moulton (2008); Barry, Daley, Bero, Ding, & Moulton (2008).
Why Now, Shared Decision Making (for lung cancer screening)?

1) Lung cancer screening is novel and awareness is low (virtually non-existent).
2) Lung cancer screening is complicated and has numerous concomitant potential benefits, harms, and unknowns.
3) There is a greater need for patient engagement because individuals eligible for lung cancer screening commonly experience stigma and bias and are less likely to be actively involved in their own healthcare.
4) It is suggested/recommended by every authoritative organization that has weighed in on lung cancer screening implementation.
5) We have to do it in order to be compensated for services.
6) It can facilitate optimal outcomes from lung cancer screening.

LDCT Participants Pilot Project
Mixed Methods Approach

- Conducted interviews and surveys with 27 individuals who had participated in LDCT for lung cancer screening within the last year at private practice radiology clinics in Kentucky or South Florida.
- Results showed that screening participants:
  1. were very satisfied with their experience
  2. were almost completely unaware of any of the potential harms associated with LDCT for lung cancer screening
  3. were motivated to participate to reduce lung cancer mortality and the simplicity of the screening (painless, quick)
  4. reported that they did not talk with health care providers (or family members) about their decision to have LDCT.

(Lillie, Studts, & Byrne, Under Review).

Perceived Barriers to Lung Cancer Screening Focus Groups with Screened & Unscreened

Stigma
- Feeling stigmatized from younger healthcare providers, describing them as "people that don't know the culture we grew up in"
- Worried about being blamed or made to feel like a social outcast, "making me feel like an idiot or stupid for smoking"

Distrust
- Uncertainty about the value of screening, comparing "new machines to screen" to a "scam...a money-making scam...like a bait and switch"

(Carter-Harris, et al. (2015), Health Expectations)
USPSTF Final Guideline for Lung Cancer Screening

Shared Decision Making

- "The decision to begin screening should be the result of a thorough discussion of the possible benefits, limitations, and known and uncertain harms."

[Humphrey et al., 2013, Annals of Internal Medicine, Online]
[Moyer et al., 2013, Annals of Internal Medicine, Online]


Centers for Medicare and Medicaid Services

For the initial LDCT lung cancer screening service: a beneficiary must receive a written order for LDCT during a lung cancer screening counseling and shared decision making visit:

1. Determination of beneficiary eligibility
2. Shared decision making, including the use of one or more decision aids, to include benefits and harms of screening, follow-up diagnostic testing, over-diagnosis, false positive rate, and total radiation exposure;
3. Counseling on the importance of adherence to annual lung cancer LDCT screening;
4. Counseling on the importance of maintaining cigarette smoking abstinence or tobacco treatment


LCS targets a unique population that likely requires substantial engagement efforts to achieve optimal outcomes.
How can Patient Decision Aids (PtDA) or Decision Support Tools (DST) help?

- Evidence-based tools to prepare people to participate in their health decisions in ways they prefer (decision role)

- Patient DAs aim to accomplish three things to prepare a person for decision making...
  1. Provide facts about condition, options, and features
  2. Clarify values (about features) that matter to patient
  3. Help people share their values with health care providers and others

Patient Decision Aids for LCS

- Patient Decision aids (PtDA) must be used in SDM process
- PtDAs vary greatly in content but mostly include:
  - Clear statement of the decision being considered
  - Information about health condition, treatment options, benefits, harms, probabilities, appropriate statistical values, and scientific data
  - Description of the options that allows patients to imagine how their personal preferences, beliefs, and values would be impacted by making a decision to have screening.

- CMS acknowledges that many decision aids exist and does not require the use on any single one of them; they only require that a decision aid is used.


Outcomes of Patient Decision Aids (PtDAs)

- Patients and practitioners who use DAs make better decisions.
  1. Patients participate more
  2. Patients know more
  3. Patients have more realistic expectations
  4. Patients are more likely to receive an option with features they most value
International Patient Decision Aid Standards Collaboration (IPDAS) Quality Criteria

I. Content
   • Facts, values, guidance in decision making

II. Development Process
   • Attention to a systematic development approach

III. Effectiveness
   • Designed with attention to key outcomes

http://ipdas.ohri.ca/

To promote informed decisions, many LCS Decision Aids are needed.

Implementation Algorithm

Takeaway

While implementing SDM may not be the norm within cancer screening programs, SDM can be reasonably justified as a viable platform to facilitate implementation of high quality lung cancer screening.

There are numerous resources available with an emerging database to support the utility of decision support tools for lung cancer screening.

- AHRQ Suite of Lung Cancer Screening Tools

- Lung Cancer Alliance Resources
  - http://www.lungcanceralliance.org/am-i-at-risk/screening-center-resources/

- The Ottawa Hospital Research Institute Decision Aid Inventory
  - https://decisionaid.ohri.ca/AZinvent.php
Overview

- Shared Decision Making is a collaborative approach to facilitating complex healthcare choices.
- There are numerous patient, clinician, and system benefits to implementing SDM.
- SDM has become a supported (and in some cases mandatory) component of the lung cancer screening process.
- Decision aids can provide structure and support SDM and several tools are available specifically for lung cancer screening.

Primary Challenges

- Identifying and selecting from the available patient decision aids to support the various decision support needs for your program.
- Monitoring accuracy and updating of these tools as new data is available and shifts occur in lung cancer implementation and policy.
Steps/Structure of a SDM Consultation

1. Invite the patient to participate
2. Present the decision/option(s)
3. Provide information
   - potential benefits, harms, uncertainties
   - check for understanding
4. Assist patient in evaluating decision based on goals and concerns
5. Facilitate deliberation/decision making
6. Assist with behavioral implementation

(Adapted from Informed Medical Decisions Foundation, 2012)