

The Conundrum and Challenge of Lung Cancer Screening Shared Decision-making Implementation

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In this issue of JGIM, Dr. Wiener and colleagues present findings regarding the implementation of shared decision-making (SDM) for lung cancer screening among health care systems that were early adopters.¹ The study methods were elegantly designed to provide parallel perspectives from the clinician and patient regarding key aspects of the SDM construct: information sharing, deliberation, and use of decision aids. The parallel process of data collection and analysis provides an opportunity to compare and contrast perspectives.

Lung cancer screening (LCS) presents significant challenges with regard to shared decision-making. It is unique among cancer screening tests in having eligibility criteria that include behavioral risk factors (smoking), having low levels of awareness in the general population, and subjecting those screened to range of harms that include false positives, incidental findings, overdiagnosis, and health risks from cumulative radiation exposure. These unique factors present communication challenges for the clinician and patient when having a discussion about LCS. Further, LCS is being implemented in a policy era of the Affordable Care Act (ACA). The ACA mandates that coverage be provided for preventive services that receive a Grade A or Grade B recommendation from the United States Preventive Services Task Force (USPSTF).² In the case of LCS, the USPSTF recommendation statement includes a shared decision-making process prior to initiating LCS. Subsequently, the Centers for Medicare & Medicaid Services has mandated counseling and a SDM visit to receive coverage for LCS.³ This study provides insights into the challenge of LCS SDM and how clinicians and patients are responding to some of the tensions and perhaps contradictions between clinical practice, evidence-based screening guidelines, and coverage mandates.

The authors explore three core aspects of the shared decision-making framework in this qualitative study: information sharing, deliberation, and use of decision aids. Although the construct of SDM is salient to a broad range of medical

decisions, a formal process of SDM that incorporates a structured decision aid (DA) is most applicable to decisions of equipoise where the balance of risks and benefits are close and the decision is sensitive to patient values and preferences. One finding from the clinician interviews in this study was the tendency to emphasize benefits over harms. When harms were discussed, the concrete and quantifiable outcomes of nodules or false positive tests were more often raised than the conceptually complex and less quantifiable outcomes of overdiagnosis or health risks due to radiation exposure. The magnitude of risk due to overdiagnosis or radiation exposure cannot be directly quantified from the National Lung Screening Trial (NLST)⁴ and estimates are subject to greater uncertainty than those directly observed in clinical trials.⁵ Overdiagnosis, detecting cancer that would not have become clinically evident in one's lifetime, is a difficult concept and challenges commonly held beliefs pertaining to cancer progression and outcomes.⁶ Developing methods to convey these outcomes remain a challenge for the field of risk communication and shared decision-making.⁷ However, lacking a consensus of risk estimates or visual aids to present harms were not the only barrier to communicating harms that clinicians noted in this study. One reason cited for clinicians not presenting harms was a strong personal belief that the benefit of LCS, for a patient population at high risk for lung cancer, was reason enough to make a recommendation to proceed with LCS. In contrast to provider ambivalence, patients consistently sought clear explanations of the purpose, process, and the primary benefits and harms of LCS. Some patients expressed frustration with a lack of information.

The communication of outcomes has benefits over and above the ethical mandate to inform patients. Anticipation of adverse outcomes may decrease the anxiety experienced if a false positive, for example, is detected. In addition, a LCS strategy requires a commitment to follow-up and repeated screening to achieve the benefits observed in clinical trials. Adherence may increase if the patient is knowledgeable and aware of the complete screening process.

This study also revealed challenges of a second aspect of the SDM process, that of deliberation. In the context of SDM, deliberation incorporates a value assessment process and a discussion between the patient and clinician regarding how values impact the decision. In this study, clinicians expressed concern regarding the emotional stress incurred by patients

when thinking about future adverse events, including the risk of cancer or detection of cancer. Although some patients experienced a positive deliberation process, others noted it lead to anxiety and fear. This finding is highly relevant to the veteran population, a significant proportion of participants in this study, due to high rates of mental illness including post-traumatic stress syndrome.⁸ The impact of prospection, or anticipating future emotions and events, on decision-making and patient outcomes requires further research in the context of SDM.⁹ What can be done to ease the emotional stress of this process? Answers are complex but training providers to address these emotions and, when necessary, involving mental health providers may be helpful.

Perspectives of the clinician and patient regarding use of DAs in this study revealed variation in the patients' desire for detailed quantitative information; for some it was helpful and for others it was a barrier to discussion. Clinicians recognized this variation among their patients. As noted by the authors, the findings suggest promising pathways for improving the efficacy of SDM. Strategies could include the assessment of individual decision-making style and skill and comfort in processing numeric information.

Are clinicians justified in leaning toward a strong recommendation for LCS rather than engaging in a comprehensive SDM process? The USPSTF has issued a Grade B recommendation for LCS among eligible patients (based upon age, smoking history, and a level of comorbidity that does not limit life expectancy or the ability or willingness to have curative lung surgery).² Grade B evidence is defined as a recommendation for the service on the basis that "a net benefit of the intervention is moderate or moderate certainty that the net benefit is moderate to substantial." The USPSTF statement goes on to recommend SDM, specifying that the initiation of LCS should be the result of a thorough discussion of the possible benefits, limitations, and known and uncertain harms including anxiety, false positives, incidental findings, overdiagnosis, and radiation exposure. Is there an inherent contradiction in issuing a Grade B recommendation *and* specifying a need for a SDM approach? Clinicians may question the value of engaging patients in a complex, conceptually challenging, and emotionally laden conversation if they plan to give a strong recommendation to have LCS. A comparison to the breast cancer screening guidelines is illustrative. The USPSTF recommendation statement provides a Grade C recommendation for breast cancer screening for women aged 40–49 years of age, noting that "Women who place a higher value on the potential benefit than the potential harms may choose to begin biennial screening between the ages of 40–49 years."¹⁰ A Grade C recommendation indicates a decision of equipoise and more naturally lends itself to the SDM construct. Clarity

regarding these distinctions and what they mean at the population and individual level can inform the relationship between evidence-based cancer screening guidelines and their application in medical decision-making.

Despite these challenges, it is an ethical imperative to inform patients about the process, benefits, and harms of LCS before initiating the screening pathway. Not all outcomes of LCS can be easily quantified but the concepts can be shared. The degree to which individuals choose to engage in value-based deliberation or to default to a recommendation may then be individualized. Provider and patient education about SDM, training to increase communication skills among providers, and infrastructure support for a LCS program are all needed to support a feasible and effective approach to SDM for LCS.

Conflict of Interest: The authors declare that they do not have a conflict of interest.

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REFERENCES

1. **Wiener RS, Koppelman E, Bolton R, Lasser KE, Borrelli B, Au DH, Slatore CG, Clark JA, Kathuria H.** Patient and Clinician Perspectives on Shared Decision Making in Early-Adopting Lung Cancer Screening Programs: A Qualitative Study. *J Gen Intern Med*. 2018. DOI: <https://doi.org/10.1007/s11606-018-4350-9>.
2. **Moyer VA, Force USPST.** Screening for lung cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2014;160:330-8.
3. Centers for Medicare & Medicaid Services. National Coverage Determination (NCD) for LUNG CANCER SCREENING with Low Dose Computed Tomography (LDCT) (210.14). <https://www.cms.gov/medicare-coverage-database/details/ncd-details>. Accessed March 3, 2018.
4. **National Lung Screening Trial Research T, Aberle DR, Adams AM, et al.** Reduced lung-cancer mortality with low-dose computed tomographic screening. *N Engl J Med* 2011;365:395-409.
5. **Ripping TM, Ten Haaf K, Verbeek ALM, van Ravesteyn NT, Broeders MJM.** Quantifying Overdiagnosis in Cancer Screening: A Systematic Review to Evaluate the Methodology. *J Natl Cancer Inst* 2017;109.
6. **Marcus PM, Prorok PC, Miller AB, DeVoto EJ, Kramer BS.** Conceptualizing overdiagnosis in cancer screening. *J Natl Cancer Inst* 2015;107.
7. **McCaffery KJ, Jansen J, Scherer LD, et al.** Walking the tightrope: communicating overdiagnosis in modern healthcare. *BMJ* 2016;352:i348.
8. **Trivedi RB, Post EP, Sun H, et al.** Prevalence, Comorbidity, and Prognosis of Mental Health Among US Veterans. *Am J Public Health* 2015;105:2564-9.
9. **Lempert KM, Phleps EA.** The Malleability of Intertemporal Choice. *Trends Cogn Sci* 20 (1):64-74, 2016
10. **Siu AL, Force USPST.** Screening for Breast Cancer: U.S. Preventive Services Task Force Recommendation Statement. *Ann Intern Med* 2016;164:279-9