The Need for Brevity During Shared Decision Making (SDM) for Cancer Screening: Veterans’ Perspectives on an “Everyday SDM” Compromise

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Abstract

Introduction. Detailed or “full” shared decision making (SDM) about cancer screening is difficult in the primary care setting. Time spent discussing cancer screening is time not spent on other important issues. Given time constraints, brief SDM that is incomplete but addresses key elements may be feasible and acceptable. However, little is known about how patients feel about abbreviated SDM. This study assessed patient perspectives on a compromise solution (“everyday SDM”): 1) primary care provided makes a tailored recommendation, 2) briefly presents qualitative information on key tradeoffs, and 3) conveys full support for decisional autonomy and desires for more information.

Methods. We recruited a stratified random sample of Veterans from an academic Veterans Affairs medical center who were eligible for lung cancer screening, oversampling women and minority patients, to attend a 6-hour deliberative focus group. Experts informed participants about cancer screening, factors that influence screening benefits, and the role of patient preferences. Then, facilitator-led small groups elicited patient questions and informed opinions about the everyday SDM proposal, its acceptability, and their recommendations for improvement.

Results. Thirty-six Veterans with a heavy smoking history participated (50% male, 83% white). There was a strong consensus that everyday SDM was acceptable if patients were the final deciders and could get more information on request. Participants broadly recommended that clinicians only mention downsides directly related to screening and avoid discussion of potential downstream harms (such as biopsies).

Discussion. Although further testing in more diverse populations and different conditions is needed, these patients found the everyday SDM approach to be acceptable for routine lung cancer screening discussions, despite its use of an explicit recommendation and presentation of only qualitative information.

Keywords
cancer screening, democratic deliberation, patient-centered care, shared decision making

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Introduction

An underappreciated reality about primary care is that most medical interventions can be highly preference sensitive (i.e., the appropriateness of the intervention hinges on patient preferences). For instance, even though recommendations about colon cancer screening and statin prescribing are often clear-cut, these interventions can be preference sensitive for many patients. In fact, multiple preference-sensitive decisions are likely to arise within a single primary care visit. Preference-sensitive decisions...
decisions is shared decision making (SDM). In broad terms, SDM involves collaborative communication where patients and providers engage in an informed conversation, discuss current evidence and the patient’s preferences, and come to a decision together.7,8

Unfortunately, current approaches to SDM involve detailed initial presentations of information that are difficult to routinely carry out in the primary care context.1,9–11 Detailed or “full” SDM, as promoted in many current guidelines and policies, is clearly appropriate for many major medical decisions but requires at least 5 to 10 minutes for a single decision, far longer than can be accommodated in a typical 15-minute primary care provider (PCP) visit.1,5 Competing demands, limited face-time, and the inability to routinely complete SDM outside of face-to-face primary care visits result in often having only 1 to 2 minutes for SDM for any single decision,1,12 or needing to forego SDM completely. Time spent discussing one decision is time not spent on other important issues, like reviewing the medication list or addressing a patient’s urgent concerns. This gap between time to complete full SDM and primary care realities may be at the root of repeated failures to implement SDM into routine practice for preference-sensitive decisions.

To address these challenges, we have proposed a very brief, compromise approach to SDM (“everyday SDM”) that is incomplete but still includes key elements to advance the goals of patient-centered communication.1 Everyday SDM is designed to take 1 to 2 minutes to fully complete. In an everyday SDM encounter, the PCP focuses on three key elements: 1) make a highly tailored recommendation (ideally based on individualized estimates of marginal risks and benefits; i.e., estimate absolute risk reductions/increases)3,4,13–15; 2) briefly present qualitative information on the key tradeoffs for an individual; and 3) carry out a brief conversation where decision making can be more fully personalized to individual preference. During this brief conversation, the clinician can modify the initial recommendation based on the views and preferences expressed by the individual. More important, during this conversation, it is critical that the clinician conveys full support of the patient’s desire for more information and power to decline the initial recommendation (see Figure 1).

The everyday SDM approach differs from current models of more detailed “full” SDM (see Table S.1). For instance, detailed SDM approaches typically guide clinicians to make initial presentations of the pros and cons of the decision in a neutral fashion and to avoid making an initial recommendation.16–18 In contrast, everyday SDM begins with a highly tailored recommendation to frame the brief conversation that follows. Ideally, the PCP’s recommendation is informed by, though not dictated by, guideline-level analysis of how preference-sensitive the screening decision is; that is, based on a
patient’s risk factors and general health and the resulting (individualized) estimates of marginal absolute risk reductions and increases with screening, how sensitive is the estimated net benefit to different assumptions about the range of preferences in the population? Using validated prediction models to account for a patient’s full combination of risk factors can much more accurately inform how to tailor recommendations,1 but everyday SDM does not require the use of prediction models. The key concept is that the strength of the recommendation varies along a continuum based on the evidence for and magnitude of net benefit: high-net-benefit care is encouraged, low-net-benefit care is discouraged, or, if benefits are in close balance with harms, the patient is informed about how the decision is preference-sensitive and what key factors generally affect the decision (Figure 2).

Second, full SDM often emphasizes communicating quantitative information about pros and cons, whereas everyday SDM emphasizes communicating qualitative information about key tradeoffs, omitting numbers unless the patient desires more information. Everyday SDM then guides clinicians to convey strong support for the patient’s authority to make the final decision, go against the initial recommendation if desired, and request additional information. In this way, everyday SDM shares the same goal of supporting patient autonomy as all approaches to SDM.19

Abridging SDM definitely requires some compromises. Whether such compromises are acceptable to patients is unknown, however. Therefore, we used deliberative methods to obtain patient perspectives on the acceptability of everyday SDM in the specific context of low-dose computed tomography (CT) lung cancer screening (LCS). LCS provided a good basis for discussing preference-sensitive decision making because it is widely accepted to be preference sensitive for many patients,20 and national guidelines recommend and Medicare requires detailed SDM for initial LCS decisions in primary care.21,22 Although there is, as of yet, little evidence on the clinical impact of these SDM policies, some have voiced concern that requirements for detailed SDM are one reason for poor LCS uptake in the United States.23

Methods
The study used deliberative methods designed to educate and then assess the public’s informed views on controversial and complex topics.24–26 Deliberative methods facilitate participants working together to develop reason-based, independent judgements about sometimes controversial issues, giving them an opportunity to explore a topic in-depth, question experts, and engage peers in collaborative discussion. Our deliberative focus group design emphasized the following: 1) obtaining a stratified random sample of participants from the target population (oversampling to enhance diversity), 2) in-depth background education, 3) group deliberation and discussion, and 4) consensus building. All methods were approved by the institutional review board.

Recruitment
Our goal was to recruit a diverse sample of patients with different backgrounds and opinions who might have an SDM conversation about LCS with their PCP in the near future. Using the Veteran’s Affairs (VA) Corporate Data Warehouse, we created a stratified random sample of patients enrolled at a single academic VA Medical Center with the following inclusion criteria: 40 to 80 years old; ≥20 pack-year smoking history; and individuals who currently smoke or who quit smoking within the last 15 years. Because we desired the opinions of those with a range of lower and higher lung cancer risk, we included younger patients and those with lower pack-year history than would be eligible in national LCS guidelines at the time. We used proportionate random sampling for age, and disproportionate random oversampling for women and racial/ethnic minorities to enhance the diversity of backgrounds and opinions. Patients were excluded if they had a documented condition that would potentially impact their ability to participate (see Supplemental Methods).

Deliberative Focus Group Design
We conducted two deliberative focus groups, each lasting approximately 6 hours. Participants in both
deliberative focus groups heard presentations from experts and engaged in small group activities with a trained facilitator. A central element across all presentations and activities was conveying the idea of tailored LCS recommendations that take into account multiple clinical factors (race, family history, comorbidity, life expectancy), including all potential combinations of these factors that can occur across patients in a screening population. Although we did not discuss specific methods for how to best establish tailored recommendations (e.g., informed by prediction models v. clinical gestalt), we emphasized how considering different combinations of risk factors across individuals can better inform SDM and will inherently result in a continuum of net benefit within screening populations, and almost always a discourage zone (due to low cancer risk or limited life expectancy), an encourage zone (due to higher lung cancer risk and reasonable life expectancy), and a gray preference-sensitive zone in between. While this “continuum” framing differs from that of most current LCS guidance, the principles for when to discourage and encourage screening are aligned with established principles in current LCS guidelines (see Supplemental Methods). We also informed participants that, by explicitly including a preference-sensitive zone, tailored recommendations are conceptually different from dichotomous eligible/not eligible cutoffs in many current guidelines.

We used the first focus group to pilot the educational materials and streamline presentations and activities based on feedback. Such revisions included clarifying the presentation content based on participant questions, better defining activity instructions, and reallocating the time allotment for each focus group component (see Table S.2 for detailed changes). Importantly, participants in the first pilot focus group did not receive detailed information about or deliberate on the “everyday SDM” approach. The second focus group used the refined presentations and activities to deliberate each element of the “everyday SDM” approach. Two weeks prior to each of the focus groups, participants received an educational brochure providing background information on LCS and explaining the session’s goals.

To optimize the diversity of each small group, participants were placed into predetermined small groups proportionately stratified by age and gender (age ≤ 60 v. >60; see Table S.3 for detailed demographics that resulted for each small group). All small groups were guided by a trained facilitator. Participants completed a pre- and post-focus-group survey that asked about demographics, smoking history, current health status, health literacy, and any previous LCS decisions. To assess whether we had recruited a sample with diverse health-seeking preferences, the validated Medical Maximizing-Minimizing Scale to assess general preferences for more versus less health care was also included in the pre-survey. Participants then engaged in expert-led plenary sessions and small group activities. The small group activities were designed to reinforce concepts and key points from the plenary and facilitate an informed and open conversation between participants. The experts were instructed to make presentations that fairly represented all sides of key issues. The first plenary was led by an expert in decision making and risk communication (BJZ) and focused on the pros and cons for including a preference-sensitive zone in screening guidelines. The second plenary, led by an expert in cancer screening and decision science (RAH), walked participants through background information on LCS, the factors that determine individualized cancer risk (including tobacco use and the importance of smoking cessation) and life expectancy, screening harms, and the role that personal preferences and scientific uncertainty play in determining when screening is more versus less preference-sensitive (see expert presentation slides in Supplemental Material). Importantly, both expert presentations and all information conveyed during small groups focused on reinforcing general concepts but did not address specific circumstances for an individual patient or mention specific decision tools that might be used to support SDM. For example, while we discussed the existence of a “discourage zone” and relevant concepts like limited life-expectancy and low cancer risk that are germane to this zone, we did not discuss specific life expectancy or risk thresholds that might place a person in such a zone. This included strict avoidance of making any comments about the net benefit of LCS for individual participants. The third and final plenary and small group activity focused explicitly on “everyday SDM,” the proposed compromise approach to SDM. The two experts discussed the advantages, compromises, and pitfalls of the everyday SDM approach.

The day concluded with a question-and-answer session and a final small group activity where participants deliberated on the acceptability of the everyday SDM approach and, if generally acceptable, changes they would want. A summary of the participants’ questions and the experts’ responses throughout the session can be found in Table S.4. Participants had the opportunity to listen to and critique audio recordings of a PCP giving guidance using the everyday SDM approach (see transcripts in Suplemental Methods). Participants
individually rated the acceptability of the everyday SDM approach twice (on a scale of 1–6, 1 = Completely Unacceptable, 6 = Totally Acceptable)—once before small group deliberation on the pros and cons of the approach, and then again afterward. This allowed us to assess for differences in individual acceptability ratings and group consensus ratings. Facilitators displayed the range of initial individual responses to the group and discussed the rationale for the ratings. After the second round of individual ratings, facilitators asked for a final group-level consensus rating. The facilitators defined group consensus to the participants as having “overwhelming agreement but not necessarily unanimity” and also mentioned to the groups that consensus should be a “product of a good-faith effort by all of us to address the needs and concerns of each person at the table and make a decision we can all live with.”

Analysis

Small group sessions were audiotaped, transcribed verbatim, and de-identified. The principal investigator (TJC) and two study team members (SS, CH) used a rapid analysis approach to build agreement on findings. This is an intensive, team-based approach to qualitative analysis that involves triangulation and an iterative analytic process to develop a preliminary understanding of qualitative data. After a full analytic team review of one transcript, we inductively developed an initial set of domains and definitions, which were revisited and refined with the review of a subsequent transcript. Once we reached agreement and consensus on the domains and definitions and determined analysis could be done with a high level of consistency, all remaining transcripts were independently reviewed and summarized (SS, CH) using a Matrix Analysis approach (Table S.5). Matrices were reviewed during weekly team meetings with the principal investigator and questions and discrepancies were addressed. Through this analytic process, we were able to monitor for the emergence of new codes and themes and thereby identify if we were approaching sufficient inductive thematic saturation with our qualitative data.

Results

A total of 320 eligible patients received a recruitment letter and phone call: 137 were not reached, 120 declined to participate, and 63 verbally agreed to participate in one of the two session dates. Of those that agreed, 36 (57%) attended the focus groups: 18 attended the initial pilot, and 18 attended the final “everyday SDM” deliberation (Figure S.1).

The 18 who attended the SDM deliberation had an average age of 63, smoked 45 pack-years on average, with 78% being individuals who currently smoke. Women comprised 44% of the participants, 94% were Caucasian, and 89% had at least some college education. A majority (61%) were medical maximizers (those predisposed to want to take medical actions like screening tests), while 11% were minimizers (those predisposed to avoid unnecessary medical actions). Approximately a quarter (22%) of participants already had received at least one CT screening exam. Full participant demographics and pre-post survey responses can be found in Tables 1, S.6, S.7, and S.8.

| Table 1 Demographic Information of Participants in Shared Decision Making Deliberation |
|---------------------------------------------------------------|
| Gender, n (%) |  |
| Male | 10 (55.6) |
| Female | 8 (44.4) |
| Race, n (%) |  |
| Caucasian | 17 (94.4) |
| Black or African American | 0 (0) |
| American Indian/Alaskan Native | 1 (5.6) |
| Age, mean (SD) | 63.4 (7.8) |
| <55 | 1 (5.6) |
| 55–59 | 6 (33.3) |
| 60–64 | 4 (22.2) |
| 65–69 | 3 (16.7) |
| 70 + | 4 (22.2) |
| Smoking status, n (%) |  |
| Current smoker | 14 (77.8) |
| Quit | 4 (22.2) |
| Pack-year history, mean (SD) | 45.3 (15.9) |
| 20–29 | 1 (5.6) |
| 30–39 | 4 (22.2) |
| 40–49 | 8 (44.4) |
| 50–59 | 2 (11.1) |
| 60–69 | 1 (5.6) |
| 70 + | 2 (11.1) |
| Min/max (2.6–3.36 cutoff) |  |
| Minimizer | 2 (11.1) |
| Maximizer | 11 (61.1) |
| Neutral | 5 (27.8) |
| Lung cancer screening decisions |  |
| Already received a screen | 4 (22.2) |
| Screen is scheduled | 0 (0) |
| Never had one, but discussed it | 1 (5.6) |
| Never had one, have not discussed it | 8 (44.4) |
| Unsure | 3 (16.7) |
| Other: “I want screening!” | 1 (5.6) |
| Missing | 1 (5.6) |
The Acceptability of a Very Brief “Everyday SDM” Approach

Prior to the small group discussion, one out of the five small groups rated the “everyday SDM” approach highly acceptable (6/6 group-level acceptability rating), two rated it acceptable (5/6 rating), and two rated it slightly acceptable (4/6 rating). At the end of the Forum, all five small groups reached a consensus that the “everyday SDM” approach was acceptable: two small groups rated it highly acceptable and three small groups rated it acceptable. Participants understood that LCS is only one of many topics to discuss during a PCP visit and, therefore, it should not dominate the appointment. As one participant stated, “Just like everybody else though, [I’ve] got other issues that I have to talk to them about every time, I don’t want to take away from that” (Caucasian male, ID3059).

Individual ratings before and after deliberating strongly supported the group-level ratings (Table S.9), with almost all participants rating everyday SDM as acceptable or highly acceptable. One participant’s initial “slightly unacceptable” individual rating did not change after small group discussion. To achieve consensus on acceptability in this group, the initial qualitative presentation of pros and cons needed to explicitly omit presentation of downstream potential screening harms like biopsies and invasive procedures, due to concerns that this presentation would be overly off-putting to some patients naïve to LCS (a consistent theme across other groups, described further below). Other participants in this group found this to be an acceptable amendment. Multiple participants proposed making the conversation even more concise than what was proposed initially by the experts. Beyond allowing adequate time for competing demands, participants felt that concise presentation of the initial recommendation (and rationale) is likely to be easier to understand and would allow for earlier patient input during the conversation. Participant views on tradeoffs of the everyday SDM approach are detailed below and summarized in Table 2.

The Importance of Emphasizing Tailored Initial Recommendations and Information

Participants highly valued tailored recommendations and receipt of tailored information whenever possible. They wanted to feel listened to, respected, and treated as a unique person rather than “a number.” Furthermore, they emphasized how individuals are different and that guidance should fit each person’s unique set of characteristics. While they understood that individuals who are heavier smokers are at the highest risk for developing lung cancer, they expressed a desire to have as many individual factors considered as possible when evaluating lung cancer risk, including environmental and personal factors, such as work or military exposures, secondhand smoking, and family history: “It doesn’t matter what age, [it] depends on the person. You know people in your family, if it runs in your family or whatever” (Caucasian male, ID1047).

Participants tended to focus on cancer risk and conceptualized the continuum of tailored screening guidance in terms of four categories: 1) low risk, 2) gray area, 3) high risk, and 4) beyond risk (Table 3). While there was sometimes confusion about exactly how patients are placed into these categories, it was clear that participants were able to move away from conceptualizing risk and benefit as dichotomous (at risk/not at risk; net benefit/no net benefit), and grapple with the idea of risk and benefit on a continuum—and that different patients should get different guidance tailored to their particular set of risk factors and health status. Ultimately, participants came to a consensus that dichotomous guidelines with only

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**Table 2** Summary of Key Deliberation Findings

| Theme                                      | Description                                                                                                                                                                                                 |
|--------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Brevity is beneficial during shared decision making | Brevity aids understanding and gives room for other important topics. There should be a path to opt-in to a longer conversation if desired. Rather than just one or two risk factors at a time, consider all risk factors together to fully characterize a person’s overall risk/benefit profile (age, gender, family history, personal behaviors and health history, environmental exposures, etc.) Participants endorsed four different categories of guidance when it comes to lung cancer screening (see Table 3). |
| Guidance needs to be tailored              |                                                                                                                                                                                                             |
| Clinicians need to support patient autonomy | Strong desire for the patients to be the final deciders                                                                                                                                                       |
two categories of guidance (screen/don’t screen), based on simple cutoffs like age and pack-years, are too simplistic: “What they are using for guidelines are very antiquated and they’re very simple” (Caucasian female, ID2012).

The Importance of Supporting Patient Autonomy

Participants strongly endorsed the importance of patients being the final deciders. There was an understanding that patients have the right to agree or disagree with the recommendation, “It’s up to you, this is still up to you, this is [the PCP’s] recommendation, but you’re making the ultimate decision” (Caucasian male, 3059). However, participants recognized difficult tradeoffs around supporting autonomy in situations where discouraging screening was clinically appropriate. Some voiced concern about the ability of a patient to disagree with their provider when the recommendation was discouraging screening: “It’s almost like the doctor’s representing the hospital and they’re not going to do this because he doesn’t think you should have it. It doesn’t matter what your decision is” (Caucasian male, ID1037). On the other hand, several participants suggested it would be best if PCPs did not have a conversation when discouraging screening was clinically appropriate, “If I’m being discouraged, I’m not getting recommended, it’s probably because I don’t qualify, so why are you even bringing it up?” (Caucasian female, ID2036).

Tradeoffs of the “Everyday SDM” Approach

Participants recognized tradeoffs are inherent in any initial approach to SDM because people differ in their desire for information. As one participant mentioned, “I see where [clinicians are] kind of in a rock and a hard place because everybody’s different, like he said, [some patients] know [they] don’t want to know nothing, [some] want to know everything” (American Indian male, ID3126). However, the brief initial presentation of information and the proposed “opt-in” solution was ultimately supported by participants: If a lengthier conversation about lung cancer risk and screening options was desired, the patient should have the option to review a decision aid or make additional appointments with their PCP to engage in a more in-depth conversation (opting-into full SDM if desired), “Instead of trying to worry about [the] 15 [minutes] or, you know, half-hour window of squeezing everything in, set up a specific [appointment]” (Caucasian male, ID1064).

While participants highly valued receiving an initial recommendation, they also recognized the possibility that the PCP’s initial presentation of information could potentially bias a patient’s decision. In discussing this issue, they were more concerned about the biasing effects with more detailed initial presentations of information and quantitative information. They felt that concise initial presentations focusing on qualitative information and emphasizing only the most important factors affecting the decision would lead to earlier patient involvement and less bias.
Along this line, several participants felt strongly that PCPs should only mention the risks and benefits that are directly related to the CT scan (i.e., false-positives, potential need for follow-up testing, low-dose radiation exposure) and avoid initially mentioning details about potentially “scary” consequences (i.e., biopsies, surgeries) that occur downstream. “Personally, you tell me all that crap upfront, I’m not going to even get it, I won’t get it, I don’t want to know that” (Caucasian male, ID3059). Others pushed back on this, noting that it could be considered irresponsible not to provide patients with all relevant information about potential downstream consequences and next steps. For example, one participant said, “You can’t give somebody a piece of information and not explain the whole thing because for some people, they might want it that way but for other people, it’s just leaving you kind of [in the dark]” (Caucasian female, ID2044). In debating this issue, the group sought to accommodate those wanting more focused initial information presentations, endorsing the idea of a staged approach where false-positives are discussed before the CT screen, but downstream harms resulting from false-positives are only discussed if a screen is positive, “A biopsy would be another step in that at some point, but there’s no reason even mentioning it until you’re at that point” (Caucasian female, ID2003). An important aspect emphasized again here was that patients should retain the choice to “opt-into” a more in-depth conversation, “Say there are pros and cons, or there’s ups and downs and let the patient decide whether he wants to know what those pros and cons are as opposed to just automatically unloading all this information” (Caucasian male, ID3014).

Discussion

Everyday SDM is designed to fulfill essential aspects of patient-centered communication while being feasible to implement during a single primary care clinic visit with many competing demands. Though brief, the “everyday SDM” approach is consistent with current ethical norms and best practices guiding SDM, informed consent, and patient-centered communication. Nonetheless, this approach is a substantial departure from more time-intensive SDM approaches currently promoted by many policymakers and researchers. In the context of LCS, these informed participants not only felt that a very brief 1- to 2-minute SDM conversation was acceptable but also that conciseness in the initial presentation of information could enhance the quality of the overall SDM conversation. Furthermore, they felt it would be wasteful to spend a substantial portion of a clinic visit discussing solely LCS, as they had other health concerns and did not want to sacrifice too much time to any single discussion, unless they requested additional information.

We found strong patient support for several aspects of everyday SDM. Participants had a strong desire for not only receiving recommendations from a clinician but routinely receiving recommendations that are more tailored than those in most current guidelines. In practice, tailoring recommendations based on multiple patient variables may require informatics support to reliably collect this information and automate multivariable risk calculations. All five small groups endorsed the “opt-in” compromise as an acceptable solution to dealing with variation, across a patient population, in preferences for information and decisional control: After an initial recommendation and brief discussion, individuals desiring more information or desiring to be more engaged in decision making need an opportunity to “opt-into” full SDM. In coming to endorse this “opt-in” solution, participants discussed how some patients would prefer not to be made aware of all issues that would be raised in a more detailed SDM discussion, while others would want to be made fully aware of all details and highly engaged. Participants ultimately decided that, to deal with a diversity of decision-making preferences, they would be comfortable relying on an initial PCP recommendation and brief initial conversation if the PCP also 1) conveyed qualitative information about the benefits and the more immediate downsides of screening (e.g., false-positives), 2) fully supported patient requests for more information, and 3) supported patient autonomy in making the final decision. Ideally, a tailored recommendation delivered in this way would enhance patient autonomy rather than undermine it. Future studies should investigate how satisfied patients are with this approach when implemented in routine practice, in diverse patient populations (including non-Veteran populations), and for different medical decisions. In particular, it will be important to study whether patients feel supported and comfortable rejecting the clinician’s tailored recommendation or asking for more information, and whether decisions differ substantially after everyday SDM versus detailed SDM. Studies could also examine the impact of the patient-clinician relationship on patient satisfaction with this approach, as well as the feasibility of modifications to the everyday SDM approach, like providing detailed materials prior to a clinical encounter.

In the context of LCS, current SDM approaches often emphasize neutral, quantitative presentations of
information rather than the tailored recommendations endorsed in the everyday SDM approach. For example, the LCS decision aid developed by the Agency for Healthcare Research and Quality to support SDM presents four pages of neutral information (text boxes, graphs, and an icon array). Even the one-page “option grid” still takes >5 minutes for just the initial presentation of information. In everyday SDM, this type of high-quality, detailed quantitative risk-benefit information would be individualized to each patient, but would only be presented to the patient if they request more information (opt-into full SDM approach).

We were surprised by many participants’ opinion that clinicians should not routinely discuss the downstream consequences of a false-positive (i.e., invasive procedures and their complications) during the initial screening conversation. During the deliberation, the groups acquiesced to the preferences of those patients who felt strongly that they would not want to hear about biopsies and other follow-up testing during the initial screening discussion. Thus, the groups ultimately supported deferring discussion of these downstream consequences to subsequent conversations about positive findings, unless more information was requested by the patient during the initial screening conversation. Although each small group came to similar conclusions, we also had a large proportion of maximizers among the participants. In addition, we did not explicitly ask participants about prior experiences with biopsies and other medical procedures, and it is unclear how including people with such prior experiences might affect group decision making. Future studies should examine how widespread this opinion might be among an informed public.

While participants accepted the idea that screening is clinically inappropriate for some patients and should be discouraged, due to low lung cancer risk or poor overall health, they also identified tensions with supporting the patient’s role as final decider in this context. Such tensions are not specific to everyday SDM, however, nor did this issue impact participant’s overall views on the acceptability of the everyday SDM approach. Rather, these tensions arise because wanting care against advice (i.e., when that care is discouraged) is inherently different than refusing recommended care. It is generally accepted that there are very few instances in which a patient declining an intervention should not be respected (e.g., enforcing treatment for active tuberculosis)—while clinicians generally have much greater leeway when they are the ones discouraging care they feel is harmful.

Regarding SDM in the discourage zone, we did not explore in this study circumstances in which not raising the topic at all would be preferable versus circumstances where raising the topic and then giving the rationale for discouraging the intervention would be preferable. Also, while we discussed the general concept of explicitly including a discourage zone, we did not have patients deliberate on how to best identify those whose risk and life-expectancy are such that screening should be discouraged. Neither did we assess how patients felt about the need for physicians to disclose when their personalized recommendations differ substantively from typical screening recommendations and provide a rationale for this difference. These would all be interesting topics to pursue in future studies. The idea of using prediction to give guidance about when to discourage screening may be potentially controversial. In prior work, we found that conventional guideline eligibility criteria (at the time: age 55–80; ≥30 pack-years; quit <15 years ago) did a reasonable job of identifying a group of patients for whom screening is preference-sensitive or high-benefit and avoiding selection of patients for whom screening may be net harmful (based on low lung cancer risk and limited life-expectancy). Furthermore, it may be confusing and controversial for personalized SDM tools to give guidance about discouraging screening based on criteria that differ from current eligibility criteria in national guidelines. Thus, when studying implementation of tools to personalize SDM for LCS, we have relied on conventional guideline criteria to identify those ineligible for screening (i.e., all those in the discourage zone) and only used a prediction-based approach to examine how preference-sensitive screening is for those eligible, in order to better inform everyday SDM for individuals in this heterogeneous group. This approach of augmenting conventional eligibility criteria with prediction, to facilitate more personalized SDM and better identify high-benefit patients, was recently endorsed in the updated CHEST LCS guideline.

Limitations

The quality of the feedback stems from the quality of our deliberative process and the ability to inform participants about the relevant issues and tradeoffs. Including a diversity of opinions and backgrounds is a key factor in designing high-quality deliberations. Because of the intensive nature of deliberation sessions, they are often conducted with small groups. A limitation of smaller samples is that individuals’ viewpoints within these small samples may not be representative of the relevant community. However, the more important consideration for our deliberation is the diversity of opinion rather than
representativeness. The study team strategically worked to recruit an ethnically diverse group, but the final attendees ended up being majority Caucasian. However, we were able to randomly sample and include patients across a range of age groups and urban/rural locations, successfully oversample Veteran women, and recruit individuals who self-report as both medical maximizers and medical minimizers. Nonetheless, the patients attending our 6-hour deliberation may be more interested in LCS and generally more “activated” than the broader population of patients eligible for LCS. Additional work is needed to examine the generalizability of these findings across additional, more diverse samples of patients and for other conditions.

Conclusion

Brief “everyday SDM” is designed to be a more feasible method for dealing with preference-sensitive decisions in primary care. Our deliberation sessions found that informed participants judged the three-step process to be an acceptable compromise in the context of LCS. Future research should assess the generalizability of these findings to other populations and other preference-sensitive decisions in primary care. If the everyday SDM process is found to be both feasible and broadly acceptable, its widespread adoption could allow for much needed progress toward the goals of patient-centered care in busy outpatient settings.

Authors’ Note

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Supplemental Material

Supplemental material for this article is available on the Medical Decision Making Policy & Practice website at https://journals.sagepub.com/home/mpp.

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