

"It Can't Hurt!": Why Many Patients With Limited Life Expectancy Decide to Accept Lung Cancer Screening

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ABSTRACT

PURPOSE Lung cancer screening (LCS) has less benefit and greater potential for iatrogenic harm among people with multiple comorbidities and limited life expectancy. Yet, such individuals are more likely to undergo screening than healthier LCS-eligible people. We sought to understand how patients with marginal LCS benefit conceptualize their health and make decisions regarding LCS.

METHODS We interviewed 40 people with multimorbidity and limited life expectancy, as determined by high Care Assessment Need scores, which predict 1-year risk of hospitalization or death. Patients were recruited from 6 Veterans Health Administration facilities after discussing LCS with their clinician. We conducted a thematic analysis using constant comparison to explore factors that influence LCS decision making.

RESULTS Patients commonly held positive beliefs about screening and perceived LCS to be noninvasive. When posed with hypothetical scenarios of limited benefit, patients emphasized the nonlongevity benefits of LCS (eg, peace of mind, planning for the future) and generally did not consider their health status or life expectancy when making decisions regarding LCS. Most patients were unaware of possible additional evaluations or treatment of screen-detected findings, but when probed further, many expressed concerns about the potential need for multiple evaluations, referrals, or invasive procedures.

CONCLUSIONS Patients in this study with multimorbidity and limited life expectancy were unaware of their greater risk of potential harm when accepting LCS. Given patient trust in clinician recommendations, it is important that clinicians engage patients with marginal LCS benefit in shared decision making, ensuring that their values of desiring more information about their health are weighed against potential harms from further evaluations.

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INTRODUCTION

Achieving mortality reduction with lung cancer screening (LCS)^{1,2} while minimizing iatrogenic harm requires optimizing patient selection: screening people likely to benefit from early detection and not screening those unlikely to experience net benefit. Importantly, LCS can cause harm including overdiagnosis, distress from false-positive results, and complications of further testing.^{3,4} Accordingly, guidelines recommend against screening people with limited life expectancy and multiple comorbidities, who are more likely to suffer harm and less likely to experience benefit from screening.⁵⁻⁷ Patients with multiple comorbidities have a greater risk of complications from LCS including death as a result of lung biopsy or surgery.^{8,9}

Yet patients with multiple comorbidities and self-reported poor health are actually more likely to undergo screening than healthier patients.^{10,11} In general, patients often recall discussing benefits but not harms of LCS with clinicians.^{12,13} Little is known about the perspectives of patients with multiple comorbidities and limited life expectancy, or what considerations factor into their decision making regarding LCS. Exploring these perspectives is key to understanding the discrepancy between guideline recommendations and LCS uptake in this population with limited net benefit from screening.

The Veterans Health Administration (VA) provides an excellent opportunity to explore patient perspectives on LCS decision making. The VA is the largest nationally integrated health care system in the United States and has prioritized LCS with several initiatives.^{14,15} Veterans have greater rates of cigarette smoking and more



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comorbid conditions than non-Veteran populations.¹⁶ We sought to qualitatively analyze the experiences of patients with marginal anticipated net benefit from LCS, owing to multimorbidity and limited life expectancy, to explore factors that influence their decision making.

METHODS

This study was approved by the VA Bedford and VA Boston Healthcare Systems' Institutional Review Boards.

Participants

During the period November 2020 to November 2021, we recruited patients from 6 geographically diverse VA medical centers with established LCS programs. Using the VA's Corporate Data Warehouse, we identified patients who (1) met 2013 US Preventive Services Task Force age and smoking criteria for LCS eligibility but had not previously undergone VA LCS, (2) were offered VA LCS in the past 6 months based on clinician completion of an LCS clinical reminder in the electronic health record,¹⁷ and (3) had marginal anticipated LCS benefit based on a high Care Assessment Need (CAN) score (>70).¹⁸ The CAN score ranges from 0 to 99 and measures an individual's risk of hospitalization and death compared with other Veterans; greater scores correspond with frailty, more comorbidities, and decreased life expectancy, with a score >70 representing the 70th percentile and a 1-year risk of death or hospitalization >12%.^{18,19} The benefits of screening are decreased when life expectancy is <10 years,²⁰ and professional society guidelines recommend against screening those with limited life expectancy.²¹ Therefore, selecting patients with a greater probability of 1-year mortality is a conservative approach for identifying individuals for whom LCS might provide limited benefit. A total of 40 patients were purposively sampled, including both those who accepted and declined VA LCS, to broadly explore decision making about whether to undergo LCS among patients with diverse perspectives. Eligible patients were mailed study information with an invitation to participate; those who agreed provided consent before participation. We aimed to interview up to 8 patients from each of the 6 sites to obtain broad perspectives across various LCS programs. We conducted weekly team meetings to discuss interviews, concluding recruitment when we reached our target and found no new factors influencing patients' LCS decisions.

Data Collection

We created a semistructured qualitative interview guide based on relevant domains from our conceptual framework proposing that the decisions regarding whether to undergo LCS are influenced by the beliefs and knowledge of both patients and clinicians, as well as the local clinical context ([Supplemental Appendix](#)).²²⁻²⁴ Questions explored LCS decision making within the broader contexts of the patient's life and the patient-clinician relationship, while probing health

perceptions, screening beliefs, and perceived benefits and harms of LCS. Interviews were conducted by telephone and lasted 30-60 minutes; interviews were audio-recorded and professionally transcribed.

Analysis

We conducted a thematic analysis to identify factors that influence patients' decisions regarding LCS.²⁵ While data collection was still ongoing, 3 authors experienced in qualitative methods (E.R.N, J.H.B, R.E.B) from diverse disciplines began by reviewing 3 transcripts and made notes in the margins to capture patients' perceptions of their overall health, lung cancer risk, experiences discussing LCS (including benefits and harms) with their clinicians, and other factors influencing their decision to pursue LCS. Our codebook development focused on these areas, based on our research questions and conceptual model.²⁶ Via discussion of our margin notes, we developed an initial codebook comprising inductive codes that reflected patients' language and sentiments. We then applied this codebook to the same 3 transcripts and engaged in multiple discussions to iteratively refine our conceptual understanding of what each code represented and how it was applied to the transcripts. We then coded an additional 4 transcripts using a similar process, which led to further refinement via in-depth discussion among the team regarding the codes and interview content.²⁷ Once no new codes were identified, the remaining transcripts were independently coded by 5 team members (E.R.N, J.H.B, S.K.S, A.N.H, R.E.B). We continued to meet weekly to discuss passages that were conceptually complex to reach consensus and ensure consistent application of codes. We used NVivo 12 (QSR International) to organize and facilitate the coding process. After coding was complete, we extracted all interview content relevant to patients' decision making from NVivo and systematically reviewed this coded data by iteratively reading each passage and comparing it to other passages with the same code. This allowed us to further understand the range of experiences within a particular code and identify factors that influenced patients' decisions. We compared the factors we identified to our conceptual framework, allowing us to contextualize patients' narratives within the existing literature. Lastly, we compared coded data within themes between patients who agreed to or declined LCS.

RESULTS

Patient characteristics are listed in Table 1 (N = 40). A total of 26 agreed to VA LCS after discussing it with their clinician. Notably, whereas the remaining 14 patients were documented as initially declining VA LCS, some reported that they did undergo LCS either in or outside the VA. Those who declined LCS typically did so due to logistic or circumstantial barriers; their perspectives regarding LCS were largely similar to those who agreed to LCS, and we integrated their responses in the results. Each quote is followed by: [site

ID-patient ID, initial LCS decision as documented in the VA clinical reminder].

Patients shared several considerations, including their overall health and life goals, perceived benefits of LCS, trust in their clinician and the VA health care system, and avoiding anticipated regret over declining LCS, that influenced their LCS decision making, and we mapped these responses to domains in our conceptual framework (Table 2). Domains in our conceptual framework that patients considered less in LCS decision making included their perceived health and potential harms from LCS, of which they were often unaware. However, when probed, patients did think considerations regarding potential further testing, treatment, or referrals were relevant to LCS decision making.

Patients Documented as Declining VA LCS Were Interested in Screening

Some patients who were documented as having declined LCS did not recall that conversation with their clinician but expressed receptivity to LCS:

Nobody approached me with [LCS] or told me about anything like that. I'd be fine with being screened. [6-08, decline]

Others cited circumstantial or logistical reasons for declining LCS, including adverse social determinants of health such as housing instability or transportation barriers, despite concerns about lung cancer:

Lung cancer screening is off the radar because I [don't know] where I'll be living next month... It doesn't change the fact that I am concerned about lung cancer. [5-08, decline]

Factors That Influenced Willingness to Accept LCS Personal Health and Life Goals

Many patients expressed that a strong motivation to undergo LCS was taking care of their health, which in turn would

extend their life, allowing them to fulfill important goals such as spending time with family, living with their pets, and maintaining active hobbies:

If there is something wrong and [clinicians] find it, there is a possibility that they can cure it and I can live longer...and it's by them prolonging my life that I can see more of my grandkids' baseball games. [2-36, agree]

I smoked for long, I decided that it would not be a bad idea to have a lung test at least once a year...I raise a garden and do this and that around the house. I enjoy working. I want to stay active and must have my health checked to do the best I can do. [6-38, agree]

Perceptions of LCS: "It's Better to Know"

Many patients emphasized the benefits of LCS, viewing screening as an opportunity to catch cancer early, get their lungs checked, and obtain information:

I thought, it can't hurt! It would be a lot better to know about [cancer] than to not know about it. I've been wondering why I feel like shit all the time, what if it's from [cancer]? [1-21, agree]

The desire for more information persisted even when life expectancy was limited. When interviewers probed about whether patients would want to be screened if they only had 1-2 years life expectancy due to a health condition other than lung cancer, several replied:

Probably. For peace of mind. [1-66, decline]

If there is a bucket list and I need to do something, I want to be able to do it...I don't understand why anybody wouldn't want to know. It gives you a chance to plan for the inevitable. [6-54, agree]

A few patients reflected that there might be a point at which they would decline screening:

If I'm on my way out and I'm told, "You got 6 months to live," no, it [LCS] wouldn't make any difference. [1-26, agree]

Trust in Clinician Recommendation and the VA System

Another common factor in Veterans' decisions to undergo LCS was clinician recommendation. Patients detailed several reasons as to why they agree with clinician recommendations including established rapport and the clinician's perceived expertise. One patient spoke about how, if the clinician has earned his trust, he would be unlikely to go against their advice:

I ask the specific reasons why I'm having [a test], but I don't contest it. If they say it's needed, I trust them. [2-24, agree]

Another patient initially declined LCS but changed her mind:

It's simply because my pulmonologist has requested it and just feels as though it's important that I get [screened]. And I'm not going to argue with him, so I have decided I would go through with it. [1-46, decline]

Table 1. Patient Characteristics

Characteristic	Patients (N = 40)
Age, median (SD; range)	70 (6.0; 57-79)
Male, no. (%)	38 (95.0)
White, no. (%)	40 (100)
Current smoker, no. (%)	18 (45.0)
Chronic obstructive pulmonary disease, no. (%)	18 (45.0)
CAN score, median (SD; range) ^a	85 (5.0; 70-96)
Agreed to screen, no. (%)	26 (65.0)
Screened at VA, no. (%)	21 (52.5)

CAN = Care Assessment Need; VA = Veterans Health Administration.

Note: No characteristic had missing data.

^a CAN scores range from 0 to 99, measuring a Veteran's risk of hospitalization and death compared to other Veterans; a score >75 represents the greatest-risk quartile, having a predicted probability of death or hospitalization in the next year > 15%.^{18,19}

Table 2. Key Factors in Patient Decision Making Regarding LCS, With Representative Quotes

Key Factors ^a	Representative Quotes
Factors that influenced patients' LCS decision making	
Overall health and life goals	"My main reason [for screening] is I want to stay alive for my boy, I don't want him going back to the Humane Society." [3-82, agree] "As long as I can make it to the place, I have no problem getting screened....If they do see something they'll catch it early." [3-94, agree]
Perceptions of LCS benefits: "it's better to know"	"I would like to know [if I had lung cancer]. I figure that way I could get a lot of things in order. Paperwork, who to leave what to, stuff like that." [3-83, agree] "It would probably be useful because it might find something to answer questions about what some of the things I have wrong." [4-94, decline]
Trust in clinician recommendation and the VA	"I just do what they tell me. And I don't even know why sometimes. It doesn't matter to me why. Because the doctor said I needed to have it done, talk about a blind follower." [2-15, agree] "If you're a patient of the VA...if you listen to the doctors and you do what they tell you to do, I think it will do nothing but improve your health. And I have all the faith in the world for all the doctors and nurses at the VA." [2-36, agree]
Anticipated regret about declining LCS	"No, I don't understand why somebody wouldn't want to pursue [LCS] unless they have a death wish." [4-87, agree] "I would probably pursue [LCS] because I think it's [lung cancer] more or less a ghost rider and it would sneak up and bite you in the butt any time." [4-74, agree]
Circumstantial and logistical considerations	"I have a traveling problem. I don't have a vehicle and I've got to arrange transportation and that affects my decision. I live way out in the boondocks. So, I'll try to get to it when I can." [6-08, decline]
Factors patients considered less in LCS decision making	
Perceived health and symptoms	"My health issues, I'm not overly concerned about any of them. I just do what they ask me to do and go in and take the lab tests and stuff that they run to check." [5-20, agree] "I've had 9 stents put in, 6 heart attacks and quadruple bypass. And my arteries in my lower extremity are plugged up. I get tired pretty easy....Other than that, most of my health problems have just been accidents. I've never really, say, been sick." [6-45, agree]
Perceptions of LCS harms: lack of knowledge about further evaluations and management	Many patients were unaware of LCS harms: "I had nothing to lose by it [LCS] for sure, and I wanted to take advantage of it." [5-45, agree] When potential for downstream evaluations were raised by the interviewer, patients had concerns: "If it's [LCS] like an x-ray, I don't care. But if it ain't and it's like a needle poke then I don't like it...just the needles, no more of those." [5-11, decline] "That is a concern that, if they find something and then they say oh, we need more tests, more tests and then it turns out to be nothing and you're wasting a lot of time and in the meantime you're all stressed out because there might be something." [6-10, decline]

LCS = lung cancer screening; VA = Veterans Health Administration.

Note: Each quote is followed by: [site ID-patient ID, initial LCS decision as documented in the VA clinical reminder].

^a All key themes mapped to a priori domains in conceptual framework of factors posited to influence patient LCS decision making (Supplemental Figure), except for circumstantial and logistical considerations, which emerged as a key influence on patient decision making in analysis. Of note, whereas our conceptual framework asserted that perceived health and symptoms and perceptions of LCS harms would influence LCS decision making, our analysis revealed these domains to play a lesser role in patient decision making.

Anticipated Regret Over Declining LCS

Some patients opted to undergo screening to avoid anticipated regret about missing the chance to detect lung cancer early:

I didn't want to kick myself in the fanny for not doing it [LCS]. [1-45, agree]

Several patients had witnessed family or friends' experiences with cancer, which influenced their LCS decision making:

I've had some friends die of lung cancer and so it's always a concern and something I sure don't want to have happen, and so that's why I went ahead with the screening. [5-48, agree]

Factors That Did Not Play a Key Role in LCS Decision Making

Perceived Health Status and Symptoms

Patients' overall health status, symptoms, or life expectancy did not appear to strongly affect their decisions to accept or decline LCS. One patient answered in response to a prompt to consider LCS in a hypothetical scenario of having limited life expectancy:

I'll be 74 this month. I'm not in that great a shape. I don't exercise, I don't do nothing but sit down and watch TV....I'd say that I'd want it [LCS] and I'm not concerned about my age as far as dying. [2-24, agree]

Patients discussed comorbidities and how symptoms affect their daily life, but frequently did not see themselves as unhealthy and remained optimistic about health outcomes:

I have COPD, arterial disease from smoking for so many years, a stent in the right leg, stent in my heart,...I still get winded just like I'm getting winded now [talking]....I'm not too worried about my health because I've had such good care. [5-08, decline; of note this patient explicitly described declining LCS due to housing instability]

Others did perceive their health as poor, but this did not deter them from accepting LCS because they thought it would be better to know if they had cancer:

I'm running out of steam as far as [my health] goes. I have problems with my legs, and I've had surgery recently on the arteries in my neck, and I take blood pressure medicine, breathing medications, and just about all of it really. It just about ruins me....I'd rather I be screened to find out where I have or where I haven't got it [lung cancer]. [3-28, agree]

Perceptions of LCS Harms: Lack of Knowledge About Further Evaluations and Management

Many patients did not recall their clinician discussing possible LCS harms or additional testing (eg, annual screening, additional imaging tests, biopsy) after initiating LCS. One patient declined LCS because he did not have enough information:

What does it entail? Why was I selected? Is that like an annual screening, do they do 2 scans once a year or what? I have no clue. [6-10, decline]

Given the thoughts of limited information from clinicians, many patients perceived LCS to consist only of an initial scan, unaware that LCS is a longitudinal process requiring yearly screens over the course of several years, with potential for additional procedures:

I wouldn't have any problem with a CT scan. It's not invasive at all. If they wanted to go in and do a biopsy of something along that line, I might have to think about that because that is invasive. [3-98, agree]

Some patients reflected that they preferred to make health and LCS decisions 1 step at a time:

I try to take things as they go along instead of worrying about something that may not even happen. I deal with it when I find out what's wrong with it. [2-30, agree]

However, when interviewers described potential additional evaluations or treatment of screen-detected findings, many patients indicated that they would not necessarily pursue further tests or cancer treatment, particularly if they were intensive or invasive:

It would depend on how intense the issue was...I probably wouldn't do chemotherapy, mostly because of my age. [5-20, agree]

When asked if potential additional procedures would change his mind about initiating LCS, one patient, seemingly unaware that the goal of LCS is early cancer detection to allow curative surgery, responded:

Not unless it's something really, really involved into it. I don't want to be cut into. [3-28, agree]

A few patients expressed concerns about getting into a "hamster wheel," in which LCS findings trigger downstream evaluations and referrals:

I hate to get in that wheel. You go see 1 [clinician] and then they start passing you around. It's like a hamster in a wheel, it just keeps going... every time you go to a specialist, they send you to another one for another opinion and pick on something else and you go 3, 4 times and then you wind up back where you were to start. [3-74, decline]

DISCUSSION

High-quality LCS relies on screening individuals likely to benefit while avoiding screening those who are less likely to benefit and more likely to experience harm, owing to

comorbidities, frailty, or limited life expectancy. Overscreening occurs commonly in the context of LCS and other cancer screenings, highlighting how challenging it is for clinicians and patients to balance benefits and harms when deciding whether to pursue screening.²⁸⁻³⁰ The present study fills a critical gap by identifying key motivations explaining why patients with marginal anticipated LCS benefit are receptive to LCS.

Similar to other studies, we found that Veterans commonly trusted and deferred to clinician recommendations.^{13,31,32} Patients' reliance on clinician recommendations has important implications, especially given that clinicians often lack knowledge regarding further evaluations in the LCS continuum, seldom incorporate shared decision-making tools, and are unsure how to incorporate life expectancy into screening decisions.^{30,33-36} Given insufficient time and competing demands during clinical visits, clinicians might offer little information to patients on LCS harms and the longitudinal LCS process.^{33,35} Reflecting this, many participants in the present study were unaware of potential harms of LCS and further evaluation and treatment. It is likely that inadequate knowledge of the LCS process, discomfort with prognostication, insufficient time during clinic visits, and hesitation to discuss sensitive topics might all be contributing factors to the lack of nuanced shared decision-making conversations.^{18,33}

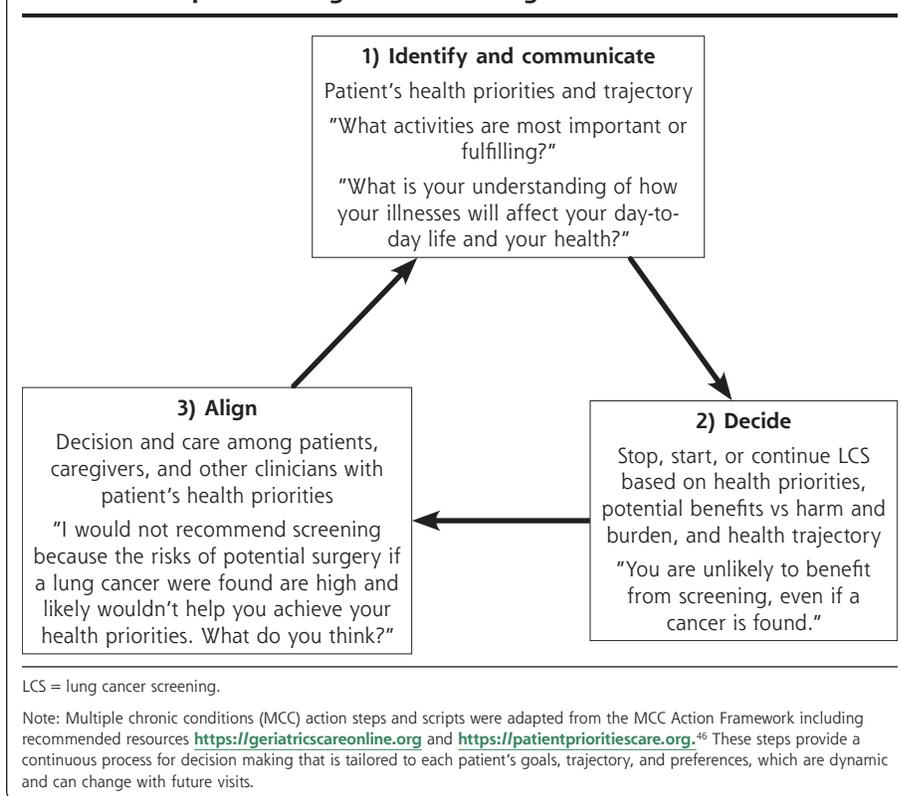
We found that despite having limited life expectancy, serious comorbidities, and/or frailty (based on CAN score), there were multiple reasons patients were still motivated to undergo LCS. Whereas patients interviewed were not made aware of their estimated life expectancy, they often did acknowledge that their health was poor or that they were functionally limited. Nonetheless, many expressed pro-screening attitudes and viewed LCS as an opportunity to take better care of their health, noting the benefit of early cancer detection while perceiving LCS as noninvasive and having few harms.^{12,13,31,37} In addition, patients were motivated to get screened because they anticipated having regret if they declined LCS and then later developed lung cancer.^{38,39} Even when posed with hypothetical scenarios of limited life expectancy, they felt it was better to know, explaining that the nonlongevity benefits of LCS, such as peace of mind and helping them plan for their future, were key motivations for screening.⁴⁰ Consequently, when a trusted clinician initiates LCS discussions, patients—including those who might not benefit from LCS—agree to LCS because it aligns with their health care beliefs and the central role health care plays in their daily lives. This can lead to low-value care that consumes health care resources and potentially creates iatrogenic harm.⁴¹

We found several factors that patients considered less in LCS decision making, awareness of which might help improve patient-centered shared decision-making conversations about LCS. Importantly, hypothetical scenarios regarding limited life expectancy or their perceived health did not appear to play a key role in patient decision making about screening. This suggests that explicitly referencing a patient's poor

health or limited life expectancy during shared decision-making conversations might not change an individual's preferences for screening. Indeed, in a national survey, most older adults indicated that they do not want clinicians to explicitly discuss life expectancy.⁴² Many patients interviewed perceived few or no downsides to undergoing an initial LCS scan and preferred to make medical decisions 1 step at a time. This resulted in patients agreeing to LCS even when they would not necessarily want to undergo additional invasive testing or treatment for lung cancer that would be necessary to reap the mortality benefits of LCS. In addition, a few patients expressed concerns about starting on the "hamster wheel." Discovering lung nodules or incidental findings that result in several referrals and tests but ultimately do not turn out to be cancer is an important consideration given that 96% of LCS findings in the National Lung Screening Trial were eventually deemed to be not cancerous.² Furthermore, the "hamster wheel" represents additional health care burden, an underappreciated source of health care nonadherence and an important consideration given that patients with multiple comorbidities spend an average of 2 hours a day on health care-related activities.^{43,44}

Some patients in the present study who were documented as having initially declined VA LCS stated that in fact, they would like to undergo screening, suggesting a need for more in-depth conversations discussing the tradeoffs of LCS, anticipated outcomes, and how patients weigh them. To curb low-value LCS, clinicians might need point-of-care decision support to identify individuals unlikely to benefit from LCS (eg, patients with life expectancy of a few years or less). Such tools could empower clinicians to discourage LCS, using sample phrases that resonate with patients (eg, "Your other health issues should take priority," "Screening is not recommended for you by medical guidelines," "You are unlikely to benefit from screening, even if a cancer is found").^{21,45} In more nuanced cases in which there might be some benefit to LCS (eg, life expectancy 5-10 years)²⁰ but also increased risk of harm due to comorbidities, the American Geriatrics Society's framework for approaching care decisions for older adults with multiple chronic conditions could help guide conversations and lead to more informed and values-based decisions (Figure 1).⁴⁶ Acknowledging the LCS continuum (ie, longitudinal follow-up, further referrals, evaluations) during the initial shared decision making, in alignment with patients' goals, is essential for facilitating informed choices consistent with patients' values.

Figure 1. American Geriatrics Society's multiple chronic conditions action framework adapted for lung cancer screening.



The present study has limitations. Although we attempted to recruit a diverse sample, this study primarily comprises White, male Veterans with limited life expectancy and lacks perspectives from patients with diverse racial and gender backgrounds. We theorize that this was due to a combination of factors including the predominantly male Veteran population, site selection, the absence of oversampling, and distrust in research.^{47,48} Nevertheless, this study echoed results of both VA and non-VA studies with more diverse patient demographics in finding pro-screening attitudes and a lack of understanding of the LCS continuum and potential harms.^{33,49,50} We relied on data generated from electronic health record clinical reminders to identify Veterans who agreed vs declined LCS; yet, it is probable that clinicians completed some clinical reminders incorrectly such that they did not accurately reflect actual patient decisions. Based on clinical reminder data, our sample consisted of nearly twice as many patients who agreed to vs declined LCS. Whereas there were many similarities between the perspectives of patients who agreed vs declined LCS, it is possible that including more patients who declined LCS would yield different findings.

Implications

Improving the quality and patient-centeredness of LCS requires that patients are informed regarding the entire LCS continuum, including additional procedures and referrals, and

engaged in shared decision-making conversations to align the decision of whether to undergo screening with patient values. This is particularly important for individuals with multiple comorbidities and limited life expectancy, who are less likely to benefit from LCS and at greater risk of downstream harm, but who studies suggest are actually more likely to undergo LCS.¹⁰ Our work highlights the importance of providing clear guidance and point-of-care tools to help clinicians identify and engage in shared decision making with individuals who have marginal anticipated benefit from screening.



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Key words: lung cancer; lung cancer screening; qualitative methods; key informant/depth interviewing; cancer: screening; chronic care: comorbidity/multimorbidity; primary care issues: patient-centered care

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[Supplemental materials](#)

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