

Older Adults and Forgoing Cancer Screening

“I Think It Would Be Strange”

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Importance: Although there is a growing recognition that older adults and those with extensive comorbid conditions undergo cancer screening too frequently, there is little information about patients' perceptions regarding cessation of cancer screening. Information on older adults' views of screening cessation would be helpful both for clinicians and for those designing interventions to reduce overscreening.

Objective: To obtain a deeper understanding of older adults' perspectives on screening cessation and their experiences communicating with clinicians about this topic.

Design: Semistructured interview study.

Setting: Senior health center affiliated with an urban hospital.

Participants: We interviewed 33 older adults presenting to a senior health center. Their median age was 76 years (range, 63-91 years). Of the 33 participants, 27 were women; 15 were African American, 16 were white, 1 was Asian, and 1 was American Indian.

Main Outcome Measures: We transcribed audio recordings of interviews and analyzed them using methods of grounded theory to identify themes and illustrative quotes.

Results: Undergoing screening tests was perceived by participants as morally obligatory. Although many saw continued screening as a habit or custom not involving any decision, cessation of screening would require a major decision. Many asserted that they had never discussed screening cessation with their physicians or considered stopping on their own; some reported being upset when their physician recommended stopping. Although some would accept a physician's strong recommendation to stop, others thought that such a physician's recommendation would threaten trust or lead them to get another opinion. Participants were skeptical about the role of statistics and the recommendations of government panels in screening decisions but were more favorable toward stopping because of the balance of risks and benefits, complications, or test burdens.

Conclusions and Relevance: For many older adults, stopping screening is a major decision, but continuing screening is not. A physician's recommendation to stop may threaten patient trust. Effective strategies to reduce nonbeneficial screening may include discussion of the balance of risks and benefits, complications, or burdens.

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SCREENING FOR CANCER IS PART of standard medical care, and educational and advocacy efforts for clinicians and the public aim at increasing cancer screening rates.¹ However, the risks and benefits of screening are altered by comorbid illness, poor functional status, or advanced age.²⁻⁵ Positive results from screening tests lead to a cascade of diagnostic and treatment interventions that carry risk.² The risks may be amplified by conditions such as dementia, which make compliance with testing and treatment regimens more difficult.⁶ Recent studies suggest that cancer screening is conducted in many patients who are un-

likely to benefit from such testing because of either advanced age or serious illness.⁷⁻¹⁰

See Invited Commentary at end of article and see also page 542

Drawing on these studies, some experts have called for efforts to reduce cancer screening in populations where it is either nonbeneficial or potentially harmful. For example, the US Preventive Services Task Force³ has begun to issue recommendations for age-based stopping points for some disease screening, such as stopping routine screening for colon can-

cer at age 75 years or cervical cancer at age 65 years.¹¹ Organizations such as the American Geriatrics Society¹² have recommended an individualized approach to screening decisions for older adults.

Despite the growing consensus that we need to curb overscreening, changing patient and physician behavior will be difficult in light of older adults' highly favorable views of screening. One study¹³ found that most residents of a retirement community planned to continue screening throughout their lives, and 43% would continue screening even against a physician's recommendation. A national telephone survey of adults aged 50 years or older found that only 9.8% had plans to stop screening. These plans were unrelated to self-reported health status or age, with individuals aged 70 years or older no more likely to stop than those aged 50 to 69 years.¹⁴

These attitudes are similar to those seen in Americans more generally; most Americans surveyed see screening as an undisputed good and fail to recognize how screening tests can be harmful or nonbeneficial.^{15,16} Positive attitudes may help motivate individuals to undergo screening when their health status or age makes screening tests beneficial, but when they are older or ill, these same attitudes and limitations in understanding may make it hard for them to accept recommendations to stop screening.

Despite the data on older adults' highly positive views of screening, there is little information about how they respond to recommendations to stop screening or what considerations factor into their decisions. We conducted this study to examine older adults' beliefs and opinions about cancer screening and their experiences discussing screening cessation with their physicians. Our goal is to provide information for clinicians having such discussions and to guide the design and implementation of interventions aimed at reducing overscreening. We conducted semistructured interviews about cancer screening decisions with older adults seeking care at a senior health clinic. We chose this open-ended approach because little is known about how older adults will react to recommendations to stop screening or what variables may be most important to their decisions.

METHODS

SETTING AND PARTICIPANTS

This study was conducted in a senior health center affiliated with an urban public hospital and was approved by the Indiana University Institutional Review Board. Potential participants were adults aged 60 years or older attending regularly scheduled primary care or specialty memory practice clinic visits. Participants could have normal cognition or mild cognitive impairment, as documented after comprehensive evaluation in a memory clinic. These persons were included if their Mini-Mental State Examination (MMSE)¹⁷ score was 20 or higher. We included some persons with cognitive impairment because mild cognitive impairment and dementia affect the risk-benefit ratio of screening.^{6,18} All persons were judged by their treating physician to have the capacity to give informed consent for study participation and had been making decisions for their own health care, including cancer screening. Partici-

Table 1. Characteristics of the 33 Study Participants

Characteristic	Data
Age, mean (SD), y	75.7 (7.3)
Age, median (range), y	76 (63-91)
Female sex, No. (%)	27 (82)
Race, No. (%)	
African American	15 (45)
White	16 (48)
American Indian	1 (3)
Asian	1 (3)
Educational level, mean (SD), y	11.7 (3.2)
Mild cognitive impairment, No. (%)	14 (42)
Self-assessed socioeconomic status, No. (%)	
Comfortable	5 (15)
Enough to make ends meet	15 (45)
Not enough	13 (39)
Chronic medical conditions, mean (SD), No.	2.5 (1.4)
Personal history of cancer, No. (%)	2 (6)
Screening or vaccination completed, No. (%)	
Colon cancer within past 5 y	19 (58)
Breast cancer within past 2 y (in women)	21/27 (78)
Cervical cancer within past 3 y (in women)	6/27 (22)
Prostate cancer within past 2 y (in men)	2/6 (33)
Influenza vaccination within past 1 y	23 (70)
Pneumococcal vaccine polyvalent ever	22 (67)

pants were ineligible if they had an MMSE score below 20 or did not speak English.

During the recruitment period, research assistants attended clinic sessions and considered all patients attending the session for enrollment. Medical records were reviewed to determine eligibility and we requested permission to enroll from each participant's physician.

MEASUREMENTS

Data collection included demographic variables, information on chronic health conditions, and recent experiences with cancer screenings and vaccinations (**Table 1**). Semistructured face-to-face interviews were conducted in private clinic rooms by 1 of 2 trained research assistants (see eAppendix; <http://www.jamainternalmed.com>). The first section included open-ended questions about patient perceptions and recent experiences with screening decisions. The second section probed a list of potential decision-making factors, such as physician recommendations, statistical data about the test, and hypothetical conditions such as living in a nursing home. Each person was asked to respond to the potential impact of the factor on his or her decision-making process. Audio recordings of the interviews were transcribed for analysis. Transcribed interviews and codes were entered into NVivo software (version 8; QSR International) to allow for sorting of the coded segments of text.

STATISTICAL ANALYSIS

We conducted a thematic analysis, informed by methods of grounded theory.¹⁹ This approach relies on careful reading of the text to identify major themes in the data. The first 5 interviews were coded by all investigators using open and axial coding.^{19,20} During the initial reading, phrases, sentences, or longer segments of text were identified by the investigator and labeled (open coding). Codes were based on the important concepts that emerged from the interviews rather than on the interview questions or other predefined categories. Team meetings were used to discuss the emerging codes. After the open

coding process, the codes were organized into larger categories to reflect the major themes (axial coding). Subsequent interviews were read by all investigators but coded in detail by 1 of 3 investigators (A.M.T., P.H.S., or G.A.S.). At each team meeting, we discussed emerging themes and selected representative quotes. Subsequent interviews led to revision and refinement of the themes. Minutes from these meetings were used by one of us (A.M.T.) to write descriptive memos for each theme.

We used several strategies to establish trustworthiness of the data. Interviews were read by all investigators; disagreements about the meaning of themes or codes were discussed at team meetings and resolved by consensus. We included investigators with varied backgrounds, including a physician with a doctorate in philosophy (P.H.S.), a geriatrician (G.A.S.), and a general internist (A.M.T.) and nonphysician research staff with backgrounds in education (K.M.) and health care compliance (L.R.H.). Conducting interviews until theme saturation was reached also improved the trustworthiness of the data by ensuring that key themes had been successfully identified.

RESULTS

Of 42 potential participants, 33 patients enrolled, 2 were not approached because the physician did not approve participation, 3 did not demonstrate understanding of the study during the consent process, and 4 refused to participate. The participants' median age was 76 years (range, 63-91 years). Twenty-seven of 33 were women; 15 were African American, 16 were white, 1 was Asian, and 1 was American Indian (Table 1). The mean length of the interviews was 25 minutes (range, 13-40 minutes). We found that patients considered screening a moral obligation and did not consider continuing screening as a decision. Few had discussed screening cessation with a physician.

OBLIGATION TO UNDERGO SCREENING

Patients' highly favorable views of screening were reflected in the many reasons to screen that they spontaneously expressed (**Table 2**), but overriding these specific reasons was a sense that screening was a moral obligation. For instance, an 84-year-old woman described the choice between stopping and continuing screening:

I think I should, because [stopping] would be the same as me taking my life. And that's a sin.

Screening was also equated directly with health and life:

I know that I need that done because I love my life, you know. I want to live.

SCREENING NOT A DECISION

The continuation of screening typically was characterized not as a decision but as something done automatically. A 91-year-old woman discussing her prior screening experiences stated,

Whenever we were told we were supposed to do something, I just, you know, did it.

For some patients, continued screening occurred as a matter of routine or habit, sometimes in response to a physician prompt, a form letter, or other brief re-

Table 2. Factors Spontaneously Raised by Participants That Would Lead to Screening

Factor	Quotation From Participant
Desire to live longer	I want to stay on this earth as long as possible, and the best way to do it is to take these tests.
Desire to prepare for end of life	Because if I've got cancer. . . I want to know so that I can get ready with the Lord to go.
Desire to gain knowledge	I want to know. And if I didn't keep getting them, I wouldn't know.
Desire to obtain treatment	Try to get it taken care of, or let Dr S know about it.
Early detection of cancer	I would want them to do it as soon as I could for fear that if I did have it, they would be able to catch it before it spread too far.
Habit or custom	Because I was getting [mammograms] every year. Well, I've been having them done periodically.
Fear of cancer	I feel like cancer's about the worst thing you could have, and I think it would go over all the rest of [my other medical conditions].
Reassurance	It would give me peace of mind.
Racial differences in risk	I feel like all black women should have it because different things happen to us.
Family history	I just feel like it's something I need to do. . . because I have a family history of cancer.

minder. Some expressed an expectation for an annual test. One 75-year-old woman said that she decided to have a mammogram "because I was getting them every year."

Others simply went along with the plan for screening with little discussion or understanding of the purpose of the test:

Interviewer: And what went into the decision to have the mammogram done?

Participant: I'm not sure, other than it was a good thing to have on record.

When physicians recommended continuing screening, patients generally accepted the recommendation without further questioning or discussion:

Doc said I needed it, and I . . . told them to go ahead and do it.

LIMITED COMMUNICATION ABOUT SCREENING

Many participants stated that they had never discussed stopping with a physician or considered stopping on their own. Patients described discussions about both continuing and stopping screening as being very brief and containing little information. Many did not express any discomfort with this, suggesting that they did not have an expectation of receiving more information:

Interviewer: Can you tell me about what the doctor said to you the last time you made a decision about cancer screening?

Participant: Just recommended a mammogram.

Interviewer: [D]id you discuss the benefits or the harms of the test?

Participant: No.

Interviewer: Was there anything that the doctor said or did that you found especially helpful during that conversation?

Participant: No, not really. . . . Just seemed unconcerned and just a . . . typical test.

Table 3. Reasons to Forgo Screening Spontaneously Raised by Participants

Factor	Quotation From Participants
Poor health or advanced age	If I'm 90 and I'm crippled up with arthritis, forget it. If I'm 85 and I'm crippled up with arthritis and I have memory problems and I can't talk to people, forget it.
Screening no longer appropriate Intergenerational equity	They didn't do a Pap smear because there wasn't nothing to check. That's why I don't have it anymore. There's no real point to it, and I do think there is getting to be a burden on senior citizens who can't really do very much to help, and they are costing more time and money to be spent on their problems, when small kids aren't getting as much help as they need.
Burden on family and others	I don't like to be a burden or an interference with my son's life because he has to learn how to live as an adult without his wife.
Lack of family history	I don't have no history of cancer at all, of any kind, in my family. That's what influences my decision.

An 83-year-old woman described accepting her physician's recommendation to stop screening mammography after being given very little information:

She just looked at my paper and said she didn't think I needed them anymore.

Only 1 patient whose physician recommended against screening because of the patient's age was upset by the recommendation.

POTENTIAL FACTORS IN DECISION MAKING

Some patients spontaneously mentioned factors that would influence a decision to forgo screening, such as poor health or the burden on others (**Table 3**). During the interview, we also asked participants to consider some factors that may influence their screening decisions; we describe several that elicited especially strong reactions (see **Table 4** for all factors).

Active Discouragement of Screening by Physician

When asked how they would respond if their physician recommended against a cancer screening test, many participants said they would question the physician's recommendation or seek a second opinion:

I think it'd be strange for a doctor to advise not having that done, but I would take his word for it too, and ask why.

Some participants expressed disbelief that a physician would ever recommend stopping cancer screening:

You've been told something, this cancer can be prevented if you have these tests and then all of a sudden he tells me that I wouldn't benefit from that anymore. I couldn't see why.

In contrast, a few participants voiced unquestioning acceptance of the physician's recommendation either to screen or to forgo screening.

Government Panels

There were many negative responses to recommendations from experts or government panels. Common themes included the fact that guidelines for cancer screening and other healthful behaviors had changed in the past:

I have heard so much of the government changing their minds on this . . . just like for example, coffee's not good for you, then coffee's right for you, you know . . . I don't have too much faith in some of them.

Others raised concerns about financial incentives for the government to recommend against screening.

Statistics

Several participants expressed the opinion that statistical information is not relevant to individual decision making:

I would not consider myself part of the statistics, and I think each individual person is different.

Others expressed optimism that even if the chance of benefit was low, they might be the one to benefit from the test.

Burdens and Benefits

Many participants expressed that they would be convinced to stop screening owing to the burdens of the test or if the burdens outweighed the benefits. Several brought up their experiences with colonoscopy as an example of a highly burdensome procedure:

I don't want to, mainly because I don't like that stuff you have to drink and then the fact that you have to spend so many hours on the toilet.

COMMENT

Our study of older adults attending an urban senior health center demonstrated that these adults felt a strong moral obligation to continue cancer screening. Although participants viewed undergoing screening as not a decision—because it is automatic, recommended, or morally obligatory—many did see cessation of screening as requiring a major decision. These findings emphasize how public health campaigns are working well to communicate the health benefits of screening, so much so that patients do not even consider undergoing screening as something to decide. Patients expect clinicians, like the rest of the health care establishment, to encourage and endorse screening. Given the steady drumbeat of physicians and public health campaigns in favor of screening, patients may find a recommendation to stop, once they reach a certain age, to be jarring. Our finding of a positive attitude toward screening is consistent with previous research finding widespread support for screening, among US adults,¹⁵ older adults in the United States,^{13,14} and physicians.²¹

Public health education and physician endorsement may have created a high degree of "momentum" for continuing screening, even in situations in which the benefits may no

Table 4. Factors to Consider in Forgoing Screening

Factor	Quotations From Participants	
	Factor Would Lead to Forgoing Screening	Factor Would Not Lead to Forgoing Screening
Limited life expectancy	Oh yeah. That would dictate whether the test would be important to take or not.	No, doctors don't know how long you're gonna live.
Other medical conditions	With all that's wrong with you, I think I would get tired of going and getting something, because by that time. . .I'd have to have somebody to take me. . .I think I would just give up.	None
Severe memory problems	If your memory's gone, and everything else, I'm thinking, there's no point in having all those tests done.	None
Living in a nursing home	If I'm in a nursing home and the screening tests are coming up, no, I wouldn't bother with it because my life is going to end. . .I'm going to die anyways.	I don't think none of that would influence me. . .They always want you to go to nursing homes.
Burdens of the test or burdens outweighing benefits	I used to work at a hospital where we did colonoscopies and I don't know what they do now for cleaning out the colon, but it wasn't pleasant when I worked down there. . .drinking all that Colyte or whatever.	None
Risks	If they told me I was going to come in to some danger and I'm already not that well. . .I just say no, I don't want to have it.	They do tell you [about the risks]. And I think they should tell patients. . .it could happen. . .but usually don't. I wouldn't want to hear any risk.
Lack of benefit or life expectancy not long enough to benefit	Why should I submit myself if I will not benefit from it?	None
Recommendation by independent experts or government panels	None	I have heard so much of the government changing their minds on this. . .just like for example, coffee's not good for you, then coffee's right for you, you know. . .I don't have too much faith in some of them.
Statistics that help explain what happened to others who underwent the test	None	I would not consider myself part of the statistics, and I think each individual person is different. What happens to someone else may not happen to me. . .I might be the one that would be helped.
Physician actively discouraging patient from undergoing the test	If my doctor said that he didn't think I'd benefit, I'd take his word.	I think I might seek another doctor, get a second opinion.
Lack of insurance coverage	That might entail a lot more than I can afford.	It's important to me, yes it is very important to me. But if my health was really at stake, I'd take a chance on maybe if they'd pay for it a little at a time, even, I would want to have it.

longer outweigh the risks or burdens. In this case, an active force may be needed to slow down or stop the behavior. Adults considering cancer screening tests report that clinicians are their most important source of information.²² Some of our findings may guide the crafting of messages that are acceptable to patients and effective in reducing unnecessary screening. For example, framing the conversation in terms of increasing burdens in relation to benefits seems most acceptable to patients and may maintain or promote trust. This is likely to be more effective than citing statistics about the patient's likelihood of benefiting from the test or national guidelines about when to stop screening. In our study, when asked how they would respond to a physician's recommendation to stop screening, many participants said that they would question the recommendation or seek a second opinion, and some expressed the belief that a physician would never make such a recommendation. Although some participants stated that a hypothetical recommendation to stop would threaten their trust, such recommendations might be more effective in the context of an established trusting relationship with a primary care provider.

We found that patients were skeptical and suspicious about the recommendations of experts and gov-

ernment panels to stop screening, expressing the concern, for example, that such recommendations were formulated to save money. Patients also expressed limited trust in statistics. A panel's recommendation against screening may be based on complex statistics on estimated remaining life expectancy, risks, and rates of adverse effects, but our findings demonstrate the danger of assuming that patients will consider these statistical data helpful. Although some experts recommend that physicians incorporate information about individual patients' prognoses into their screening recommendations,²³ the same distrust and lack of understanding of statistics may keep such approaches from being persuasive. Patients may well believe that the statistics simply do not apply to them, as one of our participants said.

In contrast, our participants seemed to respond well to the idea that screening does not make sense if the burdens—including pain, time requirements, or stress—are expected to outweigh the benefits. This way of explaining why the physician is no longer recommending screening seemed to hold some promise for both patient understanding and acceptance. Of note, the burdens of colonoscopy were repeatedly cited as reasons not

to continue with this screening test as the patient aged. Some participants also reported that they would not wish to keep undergoing screening if they lived in a nursing home, perhaps because such residence was seen by many of them as a proxy for imminent death and a low quality of life. In this setting, the benefits of life extension might seem limited, justifying cessation of screening.

The emphasis on decreasing benefits and increasing risks of screening may help patients to understand that at certain ages, or with certain comorbid conditions, other goals of care may have a higher payoff for improving quality of life and even extending life. Just as the public health and medical message to patients is that screening is a wise and admirable choice when they are middle aged and otherwise healthy, so must messages explain why not screening, and focusing on other aspects of care, may be wise and admirable when patients are older or ill.

This study has several limitations. It was conducted in a single public hospital setting and cannot be generalized to other settings. A high proportion of participants were female. Most participants were considering the cessation of screening tests as a hypothetical rather than real choice. Patient response may have been different if in fact each patient's personal physician had proposed stopping screening tests. We deliberately included some participants with known mild cognitive impairment who may have had diminished understanding of these issues. However, such individuals were still judged to have decision-making capacity by their physicians and would probably be making such decisions in routine clinical practice.

In conclusion, messages about the benefits of cancer screening have been so effective that patients continue screening out of a moral obligation or even a custom. When crafting messages to promote reconsideration of cancer screening, clinicians should be aware that discussions about advanced age, statistics, and the recommendations of government panels may at best be unconvincing to older adults and at worst diminish trust. Messages about increasing risks and burdens of screening are likely to be more effective, but because of deeply held beliefs about the benefits of screening, messages delivered in a physician-patient encounter may not be enough to change patient practice. Cultural and policy changes are also needed to modify the widely accepted beliefs that favor screening at all times.

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Online-Only Material: The eAppendix is available at <http://www.jamainternalmed.com>.

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