


Strategies for discussing long-term prognosis when deciding on cancer screening for adults over age 75

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Abstract

Background: Consideration of older adults' 10-year prognosis is necessary for high-quality cancer screening decisions. However, few primary care providers (PCPs) discuss long-term (10-year) prognosis with older adults.

Methods: To learn PCPs' and older adults' perspectives on and to develop strategies for discussing long-term prognosis in the context of cancer screening decisions, we conducted qualitative individual interviews with adults 76–89 and focus groups or individual interviews with PCPs. We recruited participants from 4 community and 2 academic Boston-area practices and completed a thematic analysis of participant responses to open-ended questions on discussing long-term prognosis.

Results: Forty-five PCPs (21 community-based) participated in 7 focus groups or 7 individual interviews. Thirty patients participated; 19 (63%) were female, 13 (43%) were non-Hispanic Black, and 13 (43%) were non-Hispanic white. Patients and PCPs had varying views on the utility of discussing long-term prognosis. “For some patients and for some families having this information is really helpful,” (PCP participant). Some participants felt that prognostic information could be helpful for future planning, whereas others thought the information could be anxiety-provoking or of “no value” because death is unpredictable; still others were unsure about the value of these discussions. Patients often described thinking about their own prognosis. Yet, PCPs described feeling uncomfortable with these conversations. Patients recommended that discussion of long-term prognosis be anchored to clinical decisions, that information be provided on how this information may be useful, and that patient interest in prognosis be assessed before prognostic information is offered. PCPs recommended that scripts be brief. These recommendations were used to develop example scripts to guide these conversations.

Conclusions: We developed scripts and strategies for PCPs to introduce the topic of long-term prognosis with older adults and to provide numerical prognostic information to those interested. Future studies will need to test the effect of these strategies in practice.

KEYWORDS

discussing prognosis, older adults, primary care

INTRODUCTION

It takes 10-years before one in 1000 adults avoids death from breast or colorectal cancer (CRC) after screening.¹ Therefore, guidelines recommend not screening adults with <10 year life expectancy because the chance of harm (e.g., false positive tests, unnecessary work-up, and/or treatment of non-lethal tumors) is greater than the chance of benefit.^{2,3} Despite enthusiasm for screening, older adults are willing to discuss stopping screening with a trusted primary care clinician ("PCP") who individualizes the benefits and harms.⁴ However, patients do not understand why their PCP would discuss their life expectancy when discussing stopping screening.⁵ PCPs find estimates of patient life expectancy helpful when making screening recommendations but feel uncomfortable discussing patient life expectancy for fear of upsetting patients.⁶⁻⁹

We previously conducted a qualitative study of 45 PCPs and 30 adults >75 years to develop scripts and strategies for PCPs to use when discussing stopping cancer screening with older adults.¹⁰ These scripts did not include strategies for discussing patient life expectancy because PCPs and older adults see these as separate conversations.^{4,5} We subsequently pilot-tested the effect of providing 45 PCPs (14 of which were among the 45 who participated in the prior qualitative study) with 10-year prognosis for 1-5 of their patients (90 patients in total) and the scripts for discussing stopping screening before an encounter; 97% of PCPs found the prognostic information helpful and 78% used the information to discuss stopping screening.¹¹ Surprisingly, 46% also used the information to talk to their patients about their life expectancy; yet, only 22% of PCPs reported being comfortable discussing life expectancy. Meanwhile, 56% of patients were interested in their prognosis. This and other work highlights a growing need for strategies for PCPs to use to discuss long-term prognosis with older adults.¹² In our prior qualitative work,¹⁰ in addition to asking PCPs and older adults about strategies for discussing stopping cancer screening, we had also asked them to describe strategies for discussing long-term prognosis. In this article, we report our findings on PCPs' and adults' >75 perspectives on and strategies for discussing long-term prognosis.

METHODS

We aimed to learn PCPs and adults >75 years' perspectives on discussing long-term (10-year) prognosis and

Key points

- Many older adults think about their long-term prognosis. However, they have mixed views on the value of discussing long-term prognosis with primary care clinicians (PCPs).
- PCPs find information on patient long-term prognosis helpful for making recommendations about medical interventions for older adults but do not feel comfortable discussing long-term prognosis with older adults.
- Older adults and PCPs recommended that patients' interest in prognostic information be assessed, that PCPs explain how this information may be useful, and that prognostic information may be offered to those who are interested in the context of shared decision-making around medical interventions, such as cancer screening.

Why does this paper matter?

Older adults often think about their long-term prognosis but rarely discuss long-term prognosis with their PCPs even though this information could help patients be more realistic about their likelihood of benefitting from different medical interventions and make higher quality decisions. We developed strategies for PCPs to use to discuss long-term prognosis with older adults when engaging older adults in shared decision-making.

potential language for these conversations. To help patients understand why this may be important, we explained it can take 10 years before an older adult may benefit from cancer screening; therefore, clinicians are being encouraged to estimate patient 10-year life expectancy. Beth Israel Deaconess Medical Center's (BIDMC's) IRB approved written consent for this study.

Study sample

Our study sample has been described previously.¹⁰ Briefly, participants were recruited from six primary care

practices (an academic geriatric and internal medicine practice and four community practices) affiliated with Boston's BIDMC. Attending-level PCPs that cared for adults >75 were eligible. Patients 76–89 years were eligible if they were English-speaking, cognitively-intact, not in hospice, and had the capacity to participate. Patients 76–79 also had to have at least one condition included in the Charlson Comorbidity index, as we aimed to recruit patients with approximately 10-year life expectancy^{13,14}; the average life expectancy of adults aged 75 is 12 years.¹⁴ As the study's first aim focused on discussing stopping cancer screening, patients also had to have a colonoscopy within 10 years or a screening mammogram within 3 years (women only). They could not have a history of breast (women) or colorectal cancer, a recent abnormal screening test, documentation of having stopped screening, or low screening intentions (measured using a validated scale).¹⁵ Because the U.S. Preventive Services Task Force uses age 75 as a threshold for considering stopping cancer screening, participants had to be >75.^{16,17} Adults ≥90 were excluded because few are screened.^{18,19}

PCP recruitment

We emailed PCPs at each site asking them to participate in one-hour focus groups because we were interested in the exchange of ideas that may occur during a focus group.²⁰ However, we completed individual interviews with PCPs who could not attend a focus group but wanted to participate. Participants were provided a meal and \$50 incentive. We aimed to include approximately 50% of PCPs from community practices.

Patient recruitment

We conducted individual interviews with patients because of the sensitivity of the topic. To ensure patient participants' were diverse by age (75–79, 80+), sex, race, and site (community vs. academic), we used purposeful sampling.²¹ We received randomized lists of all potentially eligible patients from BIDMC's data repository stratified by these criteria and sequentially attempted to reach patients from each list. After confirming eligibility based on patients' medical records and obtaining PCP approval, a research assistant (RA) mailed patients a study informational letter. An RA called patients who did not opt-out to re-confirm eligibility and schedule in-person individual interviews at the patient's home or medical center.

Interviews lasted approximately 45 minutes and patients received a \$25 incentive.

Data collection

PCP and patient interviews were audio-recorded and occurred concurrently between August 2017 and April 2018. One investigator (MAS), an internist at the academic practice, conducted all PCP interviews and an RA (ARJ) trained in qualitative methods conducted all patient interviews. A second RA (MK) observed all interviews to take field notes. The patient semi-structured interview guide (Text S1) asked patients to describe their views on discussing their 10-year life expectancy with their PCP. The PCP semi-structured interview guide (Text S2) asked PCPs to describe their thoughts about discussing patient long-term prognosis, barriers and facilitators to these conversations, and any language used. Then they were shown the Lee-Schonberg prognostic index on ePrognosis and a Cho et al. table that estimates life expectancy based on age, race, and comorbidity to learn their thoughts on the usefulness of these tools.^{22–24} At the end of the interview, all participants were shown example scripts investigators drafted for these conversations (initial drafts are in Text S1 and Text S2) and asked to provide feedback.

Analysis

Interview audio recordings were professionally prescribed verbatim. We used NVivo 11 qualitative software and Braun and Clarke's methods for thematic analysis.²⁵ At least two investigators (MAS and ARJ or MK) listened to each interview as they were completed to become familiar with the data and to revise and improve the scripts and interview guides as needed. After the initial three patient interviews and first two focus groups, three investigators (SJ, MAS, MBH) independently reviewed interview transcripts to develop a codebook that included both a priori (identified via literature review and denoted in the codebook [Text S3]) and emergent codes. Disagreement about the meaning of themes or codes were discussed and resolved by consensus. Once a codebook was established, it was used by at least two investigators on the entire dataset. As new themes emerged, new codes were developed and previously coded interviews were recoded. Thematic saturation was achieved when no new themes were described and were reached at the 28th patient interview and 6th PCP focus group; however, we completed 2 additional patient interviews and 1 additional

TABLE 1 Participant characteristics (n = 30 patients
≥75 years, n = 45 primary care providers)

Patient characteristics	n = 30
Age, mean (SD), years	81 (3)
Age ^a	
76–79 years, No. (%)	13 (43)
80–84 years, No. (%)	13 (43)
85–89 years, No. (%)	4 (13)
Sex	
Male, No. (%)	11 (37)
Female, No. (%)	19 (63)
Race ^a	
Non-Hispanic White, No. (%)	13 (43)
Non-Hispanic Black, No. (%)	13 (43)
Hispanic, No. (%)	2 (7)
Asian, No. (%)	1 (3)
American Indian or Alaskan Native, No. (%)	1 (3)
Education ^a	
<High-school, No. (%)	4 (13)
High-school, No. (%)	7 (23)
Some college, No. (%)	7 (23)
College degree or beyond, No. (%)	12 (40)
Income ^a	
\$35 K or less, No. (%)	11 (37)
>\$35 K to \$65 K, No. (%)	5 (17)
>\$65 K or higher, No. (%)	12 (40)
Declined to answer, No. (%)	2 (7)
Marital status	
Married or living as married, No. (%)	10 (33)
Single/divorced/separated/widowed, No. (%)	20 (67)
Schonberg mortality index score ^b , mean (SD)	10 (4)
Somewhat to not at all confident in filling out medical forms by yourself, No. (%)	7 (23)
The site where the individual interview was conducted	
In patient's home, No. (%)	14 (47)
At the academic medical center, No. (%)	16 (53)
Primary care provider (PCP) characteristics	n = 45
Recruitment site	
BIDMC academic (2 practices), No. (%)	24 (53)
BIDMC community (4 practices), No. (%)	21 (47)
Race	
Non-Hispanic White, No. (%)	36 (80)
Non-Hispanic Black, No. (%)	0
Hispanic, No. (%)	4 (9)
Other, No. (%)	5 (11)

(Continues)

TABLE 1 (Continued)

Patient characteristics	n = 30
Age range	
<40 years, No. (%)	9 (20)
40–59 years, No. (%)	26 (58)
60+ years, No. (%)	10 (22)
Years in profession ^a	
<10 years, No. (%)	11 (24)
11–19 years, No. (%)	11 (24)
20+ years, No. (%)	23 (51)
Proportion of patient panel ≥75 years	
<5%, No. (%)	1 (2)
5%–9%, No. (%)	7 (16)
10%–20%, No. (%)	11 (24)
21–30%, No. (%)	10 (22)
>30%, No. (%)	13 (29)
Missing, No. (%)	3 (7)
Female, No. (%)	32 (71)
Role	
Internal Medicine, No. (%)	37 (82)
Internal Medicine/Geriatrics, No. (%)	3 (7)
Family Medicine, No. (%)	1 (2)
Nurse Practitioner, No. (%)	4 (9)

^aProportions do not add to 100 due to rounding.^bSchonberg mortality index: Scores ≥10 are associated with >50% chance of 10 year mortality. Thus, adults who score ≥10 are estimated to have <10- year life expectancy.²⁴

focus group that were already scheduled.²⁶ During interpretive analysis, we explored whether: PCPs themes differed from patient themes²⁵; whether patient themes differed based on age (75–79 vs. 80+), sex, race (white vs. other), or education (college vs. less); or whether PCP themes varied by their practice site (community vs. academic) or years in practice (≥20 vs. less); to do so we stratified codes by these characteristics. We also asked three PCPs and two patient participants to review the identified themes to confirm their validity. Direct quotes and participants' study identification numbers were used to illustrate themes.

RESULTS

Participant flow has been described previously.¹⁷ Briefly, seven practices were approached; one refused participation. Of 90 PCPs at the 6 participating sites,

45 participated (38 in a focus group and 7 in an individual interview). No PCP declined participation and thematic saturation was achieved before needing to approach additional PCPs. Of the 45 PCPs, 21 (47%) were community-based and 23 (51%) had been in practice ≥ 20 years, Table 1. All PCPs spoke at least once during a focus group (on average PCPs spoke 28 times [± 23]).

Of 84 eligible patients reached by phone, 30 (36%) participated. Patients who declined were similar in age, race, and practice site as participants but were more often male. On average patient participants were 81 years (± 3), 19 (63%) were female, 13 (43%) were non-Hispanic Black, 13 (43%) were non-Hispanic white, and 18 (55%) had not completed college.

TABLE 2 PCP themes regarding discussing long-term prognosis with adults^a ≥ 75 years^b

PCP themes	Example quotes
Varying views on the value of discussing long-term prognosis	
<i>Helpful</i>	<i>For some patients and for some families having this information is really helpful. It may not be for everybody but I think knowing that you can access this information and use it, for some patients and families in certain circumstances can be really, really helpful. (FG1, PCP8)</i>
For short life expectancy	<i>It might be more appropriate for somebody with a cancer diagnosis or a terminal diagnosis. (FG3, PCP4)</i>
Prognosis is helpful	<i>I would be excited to have tools like this. (IntPCP1)</i>
For high literacy patients	<i>The ones who are very educated, they want percentages. (FG5, PCP5)</i>
<i>Unhelpful</i>	<i>For most of my patients, I would say it is not helpful. (IntPCP5)</i>
Harmful	<i>Whatever number they hear, they grab onto that and they think that's it and if that's all I've got, then you leave without an understanding of what that number means and in this setting, I think it would be more alarming and upsetting to this lady than anything else and not to know what to make of it. So I would not use it with a patient. I personally do not think I would use it. (FG1, PCP6)</i>
Unpredictable	<i>I've had people bring in stuff about life expectancy, and I tend to dismiss it. You know, because I say, "That number is a calculation based on you know the chance of large number of other people who have been through it, and it does not really help with an individual person." (IntPCP4)</i>
Prognosis not helpful	<i>I would not use risk calculators because then it makes it seem like we are being robots. (IntPCP6)</i>
<i>Uncertain if helpful</i>	<i>I am not sure how useful these are. I still do not know if telling someone their life expectancy is fourteen years, you know when their 65-years-old, it's going to be helpful. (FG2, PCP1)</i>
Prognosis helpful to PCP but not patient	<i>I think it would be helpful to have an estimate. I would not give the number to the patient. (FG1, PCP5)</i>
Uncomfortable discussing long-term prognosis	
	<i>It is not an easy conversation because nobody wants to think about death. (FG7, PCP2)</i> <i>I do not think the exact number or exact final date would come up, that I would hear myself saying that to people. It's just been something kind of taboo. It's kind of one of those things that you do not want to do. (FG3, PCP3)</i>
Facilitators of these conversations	
If patient brings it up	<i>It's on their minds but I want them to bring it up. (FG4, PCP3)</i>
Doctor-patient relationship	<i>There are some patients you just get a sense that it's okay for you to ask these questions. There are certain questions — certain patients you just know you should not be saying things like that. (FG3, PCP6)</i>
Patient informational needs	<i>It depends on how much information a patient wants. (IntPCP6)</i>
Prognosis is long	<i>Using it where there is a positive feels easier. (IntPCP2)</i>
Barriers to these conversations	
Unrealistic perceptions	<i>Many times healthy people in their 70's even 80's do not really see themselves as near the end of life. (FG4, PCP1)</i>
Lack of training	<i>That would be helpful to address with patients, but I do not know how to do that. (FG7, PCP3)</i>
Focus on what matters most to patient	<i>It hopefully would change the framework for how we are approaching that person's care from less about these numbers and more about what's most important to that person. (IntPCP6)</i>

^aCodes were grouped into major themes which are highlighted in bold.

^bFG, Focus Group; PCP, Primary care provider, Int, Individual Interview.

TABLE 3 Patient themes regarding discussing long-term prognosis with PCPs^a

Patient themes	Example quotes
Varying Views on the utility of discussing long-term prognosis	
Helpful	<i>It's a good thing that they should tell you. (Patient11)</i> <i>It would help make decisions about my health. (Patient7)</i>
If life expectancy short	<i>It would be more useful if the period were shorter. (Patient1)</i> <i>Unless I am sick, I do not think I want to go in and hear it. (Patient22)</i>
If life expectancy is long	<i>I cannot imagine, unless the conversation is do not worry I expect to see you in twenty or thirty years. (Patient14)</i> <i>I think that the doctor should talk about that if it's going to make you have a longer effect on your life. (Patient 28)</i>
For planning	<i>Let me know. I may make different plans. (Patient 1)</i> <i>It would help me in planning for life priorities. Practical concerns around housing. (Patient 20)</i>
With a strong doctor-patient relationship	<i>I put my trust in him and I would expect for him to tell me things like this. (Patient 30)</i> <i>We are very comfortable, as a matter of fact my doctor should be training other doctors how to approach people. (Patient 15)</i>
Prognosis helpful	<i>I would love to see the calculator. (Patient 8)</i> <i>It's a good idea, you could learn something. (Patient 27)</i>
Unhelpful	<i>I do not know how those conversations will be of any value. (Patient 3)</i> <i>I do not want to know really — you know the thing is they are not God. (Patient 29)</i>
Unpredictable	<i>I would probably say, "What are you talking about? Even I do not know how many years more I have." (Patient 6)</i> <i>Do not do this. What for? Who knows? It's useless. (Patient 16)</i>
Uncontrollable	<i>I do not have no control over it. What's going to be is going to be. (Patient 25)</i> <i>The only one who can take you out of here is the good Lord above. (Patient 30)</i>
Prefers to live in the moment	<i>I'm not worried about dying in 10 years, I'm worried about the quality of life in the next 10 years. (Patient 20)</i> <i>I do not want to worry about ten years. I just want to have a good time now. (Patient 22)</i>
Anxiety Provoking	<i>I think it would cause anxiety in a number of people. (Patient 24)</i> <i>I believe it would bother me. I would hope I would not let it bother me too long, but I would worry about it for a little while, because it would be on your mind. (Patient 22)</i>
Not something doctors do	<i>I'd never had a doctor talk to me about that. (Patient 28)</i> <i>I think that the whole idea of talking to somebody about um you have got another 5 years to live or you got a 50/50 chance of living another 10 years, goes beyond what a doctor does. (Patient 3)</i>
Prognosis not helpful	<i>I do not want a calculator available to tell me how long I'm going to live. I do not like that. (Patient 19)</i> <i>I would not trust anybody to give me an exact number. (Patient 20)</i>
Uncertain if helpful	<i>I do not know. I am not thinking about it. (Patient 23)</i> <i>I do not think it would have much effect whatsoever. (Patient 21)</i>
Thinks about it on their own	<i>I'm always thinking about it. I do not know if I'm going to see tomorrow anyway. (Patient 29)</i> <i>Well, I always wonder how long I will live. I always wonder about that. (Patient 5)</i>
Discusses with family	<i>I try to prepare the generation going to be left here, but they do not want to listen. (Patient 27)</i> <i>I have gotten my daughter to the point where she will listen to me and my oldest son. The other two, they are not ready for it yet, but they will be. (Patient 9)</i>

^aCodes were grouped into major themes which are highlighted in bold.

PCP themes

PCPs described two main themes including: (1) disparate views on the utility of discussing long-term prognosis with older adults and (2) discomfort with these discussions, Table 2. PCP themes did not vary by PCP site or years in practice.

Disparate views

Some PCPs found discussing long-term prognosis helpful, "I always do the life expectancy. They like it." (focus group #5, PCP #5 [FG5, PCP5]). However, others felt that these discussions would be unhelpful. "I don't feel like introducing a specific conversation that focuses on how

much time someone has left offers any health benefit,” (individual interview, PCP #2 [IntPCP2]). Still others were uncertain about the utility of these conversations. “I don’t know if this would scare people or help them.” (FG3, PCP6).

PCPs who felt that these discussions would be unhelpful felt that mortality was unpredictable “anyone can die tomorrow” (FG5, PCP3), and that patients were not interested in this information. Although several PCPs felt that prognostic information could help inform their clinical recommendations, some felt that prognostic tools were “too long”, (FG4, PCP1) but could be useful if “incorporated in a way that was easy to use and recalculated at a regular interval,” (FG4, PCP3).

Discomfort with these conversations

Many PCPs described feeling uncomfortable discussing long-term prognosis and noted a lack of training. “I’m not quite sure how to incorporate it because I don’t have communication training in this area,” (FG1, PCP1). PCPs expressed more comfort discussing prognosis near the end-of-life or when prognosis was long. “I think that presenting mortality figures would be fraught with difficulty unless you were giving good news,” (FG1, PCP2). PCPs also felt more comfortable having these conversations with patients with whom they had a long-term relationship or when patients initiated the conversation. They also noted that “it depends on how much information a patient wants about their prognosis,” (IntPCP6). Several PCPs felt that these conversations would be more useful “for the really highly intellectualized” (IntPCP5) and that these conversations would be more difficult with patients who were unrealistic about their health. “Yes, they are a baby boomer, but that doesn’t mean they are invincible” (FG4, PCP3).

Some PCPs offered suggestions for these conversations. “I would take a page from the palliative care book, in terms of asking people if that’s information they want,” (IntPCP1). They would approach the topic by asking something like: “For some people it helps to have an estimate of how much time they may have left so they can better prepare. Is that something you would like to talk about?” (IntPCP1). Some suggested asking patients how much longer they think they will live to get “a sense of where they think they are at,” (FG3, PCP1). If information about prognosis is offered, PCPs recommended stressing the inherent uncertainty with language such as “Everybody’s different, we can’t predict the future for sure. We’ve been surprised many times,” (IntPCP4). Several PCPs also felt strongly about not sharing a specific number, “that should be a last resort,” (IntPCP6). PCPs

“The chances of benefitting from cancer screening tests are much lower as we get older. This is because in general you have to live for more than 10 years to benefit from these tests. Would it be helpful to talk about how much longer you are likely to live to help us decide together about cancer screening tests? This discussion may also be helpful for making decisions about other medical tests or treatments and may allow us to focus on what matters most to you in your life.”

For patients interested in learning their 10-year life expectancy/prognosis:

***Life expectancy:** “Since information on how long you may have to live would be helpful to you in planning for your future, based on information from others your age and in similar health (and based on available risk calculators), I would estimate that your life expectancy is around 5-10 years. Of course, everyone is different and it is impossible to know the future.”*

***Prognosis:** “Since information on how long you may have to live would be helpful to you in planning for your future, based on risk calculators, out of 100 adults your age with similar health problems, around 50 would be alive in 10 years while 50 would not (OR you have a 50% chance of living 10 years). Regardless, I will do everything I can to help you live comfortably for as long as possible.”*

FIGURE 1 Scripts for discussing long-term prognosis and/or life expectancy with older adults

also described how these discussions could be helpful if they were made part of a larger discussion regarding what matters most to patients. “I see this as part of a bigger discussion about values,” (FG1, PCP1).

Patient themes

Patients also had disparate views on the utility of discussing long-term prognosis with PCPs; yet, many described thinking about their long-term prognosis on their own, Table 3. Patient themes did not vary by their age, race, sex, or educational attainment.

Disparate views

Some patients did not want to discuss their long-term prognosis, “I know I got to go but I don’t want to hear it,” (Patient5). Some questioned the utility of these conversations because death is unpredictable and not something they control. They also felt these conversations could be anxiety-provoking. “It’s frightening to talk about,” (Patient17). Some described preferring to live in the moment. “Let me live my life, I don’t want to worry about whether I am going to wake up tomorrow,” (Patient3) and being more concerned about quality rather than quantity of life.

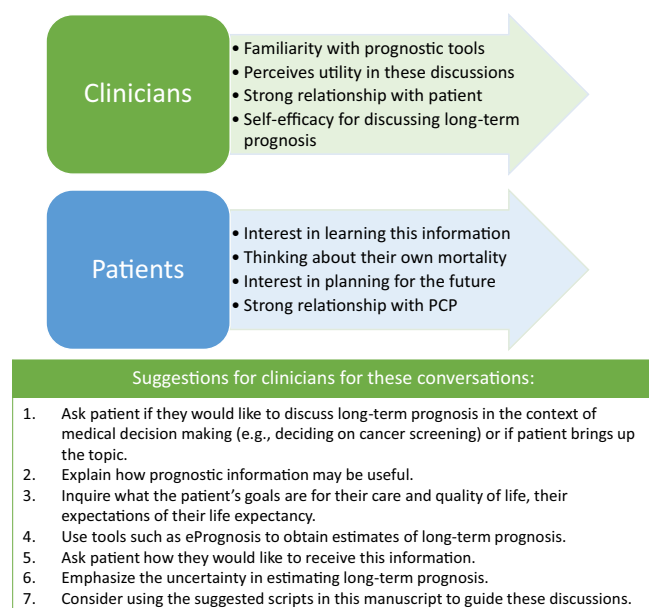


FIGURE 2 Factors increasing likelihood of productive discussions about long-term prognosis

Yet others were interested in these discussions. “It would be very helpful, at least I’d know how long I might be here,” (Patient28). These patients felt the information could be helpful in planning for their future, their housing, and for financial planning. Some felt “the more information you have the better off you are,” (Patient11). Others described wanting the information but being afraid to ask, “I didn’t ask him how long I have to live because he’d think I’m crazy,” (Patient28). Like PCPs, patients said they would feel more comfortable having these discussions with PCPs they knew well. “If you have a good relationship with your doctor, they have to know how to approach this,” (Patient15). Patients also recommended that PCPs first assess patient interest in this information. Some patients questioned feasibility; “you can’t have very much conversation because they don’t spend that much time with you,” (Patient13).

Prognosis is on patients’ minds

Patients described thinking about their prognosis on their own “I always wonder how long I will live,” (Patient5) and talking about it with friends. “You’re at an age where people discuss it” (Patient13). Further, patients discussed trying to prepare their families but often found family did not want to have these discussions. “They don’t want to hear anything about me leaving this world, but still we got to talk about those type of things,” (Patient27).

Scripts

Patients found the initial scripts for introducing the topic of the long-term prognosis (Text S1 and Text S2) as too “negative” (Patient3) and “uncomfortable” (Patient 10). They did not like terms like ‘how much time you have left’ or ‘calculated’ (Patient 6). Patients recommended the topic be introduced in the context of clinical decision-making because if it was brought up “out of the blue” (Patient 7) they would think something was wrong. Patients also recommended that PCPs explain why the information may be useful. PCPs found the original scripts patronizing, uncomfortable, and too verbose. Based on participant feedback, we drafted a short script to introduce the topic of long-term prognosis within the context of cancer screening decisions; however, a different clinical context could be used. The script asks patients if it would be helpful to them to discuss their life expectancy and provides rationale for this information. For patients interested we also drafted scripts for PCPs to share numerical information. Participants tended to feel more comfortable with PCPs communicating prognosis rather than life expectancy. “I would be more apt to go with the percentage versus the five to ten,” (IntPCP7). Patients appreciated that percentages implied some uncertainty, “I would go with the 50/50, because no one can tell you exactly how long you going to live,” (Patient 22). Participants in the last focus group and individual interviews did not offer new suggestions for revising the scripts (Figure 1).

DISCUSSION

Similar to prior studies, PCPs and older adults had varying views as to whether discussing older adults’ long-term prognosis is helpful.^{4–6,25–29} Despite this, participants offered suggestions for these conversations. Participants felt that discussion of long-term prognosis should be anchored to clinical decisions, that the discussion include information on why long-term prognosis may be useful, that patient interest in their prognosis be assessed before numerical information is shared, and that the scripts for these discussions be brief. PCPs were also interested in trainings for these discussions. Although our scripts may be used to facilitate such trainings, we anticipate that PCPs will modify the language to what works for them as they become more experienced.

Because prior qualitative studies have also found that PCPs have mixed views about the utility of discussing long-term prognosis and fear that these discussions could be anxiety-provoking for patients,^{4–6,26–30} few have developed strategies for these discussions. Moré et al.

interviewed 15 clinician experts in prognosis communication and found that experts felt that discussing long-term prognosis could help patients establish realistic expectations, plan for their future, and enhance shared decision-making.⁹ They recommended that these conversations be adapted to individual preferences and occur over time. Based on their findings, the authors created a timeline of issues for clinicians to address based on patient life expectancy (e.g., financial and retirement planning for patients with 10–20 year life expectancy). Our study supports that it is important to assess patient's interest in prognostic information and to tailor the discussion to individual priorities and adds to the literature by providing language PCPs may use for these discussions.

Our study is one of the first to highlight that older adults often think about their own prognosis. PCPs could acknowledge this and ask patients if they are interested in discussing their long-term prognosis, especially when they have a good relationship with the patient. Although some PCPs thought prognostic information would be more highly valued by patients with greater educational attainment, we did not find different themes by patient educational attainment. A systematic review of patient preferences for discussing life expectancy also did not find that educational attainment or other characteristics influenced patient interest in these conversations.¹²

Several PCPs in our study felt that discussing long-term prognosis would be useful as part of a larger discussion on patient values. Initiatives such as the Institute for Healthcare Improvement's Age-Friendly Health System, incorporate geriatric principals (4 M's of Geriatric care: Matters Most, Medication, Mobility and Mentation) into a care model bundle that highlights a discussion with older adults as the first 'M.'³¹ To facilitate, Tinetti et al. have developed myhealthpriorities.org to help patients think about and identify what matters most to them.³² Future studies should explore whether understanding one's long-term prognosis improves identification of priorities. Boyd et al. developed a framework for medical decision-making for patients with multiple chronic conditions which³³ recommends asking patients their understanding of their health or about how their illness will affect them over the next few months to years. Yet, the framework gives little guidance on how to communicate long-term prognosis. The first three lines of our script for introducing long-term prognosis could be modified based on the medical intervention being considered and the lag-time to benefit from this intervention to be used within this framework.³⁴

Several PCP participants recommended an approach to discussing long-term prognosis similar to the best practices for discussing prognosis at the end-of-life,^{35,36} such as identifying a standardized time or 'triggers' to have

these conversations (e.g., in the context of clinical decision-making) and asking patients' permission to discuss long-term prognosis. At the end-of-life experts also recommend that clinicians explore patient emotion and worries; however, discussing the emotional aspects of the conversation was not brought up by participants when discussing long-term prognosis. Experts have suggested that discussing long-term prognosis with adults >75 may not be as emotionally laden but this needs to be explored in future work.³⁷

In training clinicians for discussing prognosis at the end-of-life, experts recommend using example scripts, case reviews, and practice.³⁶ Schoenborn and colleagues have used such approaches to train medical residents to discuss 4–5-year prognosis with older adults.³⁸ The training which included three small group sessions and a clinical exercise increased residents' confidence to have these conversations and led to them being more accurate prognosticators. Dr. Schoenborn also developed an asynchronous curriculum to teach PCPs how to use life expectancy in deciding when to stop cancer screening in older adults.³⁹ The training led to an immediate increase in PCPs' self-efficacy to estimate patient life expectancy and to discuss stopping screening but no change in PCP behavior. These findings suggest that PCPs find long-term prognosis estimates useful but will likely need to learn, discuss, role play, and practice some of the strategies we have identified to go beyond estimating prognosis to actually discussing long-term prognosis with older adults.

This study has several limitations. It was conducted in one geographic area and patient participants were English-speaking limiting the generalizability. The majority (64%) of patients reached by phone chose not to participate; possibly due to discomfort with the topic. Also, only adults >75 were included; future work will need to study if the same strategies for discussing long-term prognosis are useful with adults <75. Further, PCPs who participated in each focus group worked together and may have been hesitant to express conflicting viewpoints. Finally, cancer screening decision-making was offered as the rationale for studying how to discuss long-term prognosis; participants may have suggested different language for these discussions for a different clinical context.

Long-term prognosis discussions are increasingly recommended for high quality patient-centered care of older adults.^{36,39} Figure 2 provides a visual summary of our findings including a summary of factors that increase the likelihood of productive long-term prognosis conversations with older adults and suggestions to clinicians on how to begin and conduct these conversations. Future studies will need to test the effect of these strategies in diverse practices.

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CONFLICT OF INTEREST

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

AUTHOR CONTRIBUTIONS

All authors meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Dr. Schonberg conceived of the study and acquiesced, analyzed, and interpreted the data. Shivani K. Jindal conceived of the study, analyzed, and interpreted the data. Adlin Pinheiro analyzed and interpreted the data for this study. Maria Karamourtopoulos and Alicia R. Jacobson acquiesced data for this study. Mary Beth Hamel and Alexander K. Smith conceived of the study and analyzed and interpreted the data. All authors drafted the work or revised it critically for important intellectual content and gave final approval of this manuscript.

SPONSOR'S ROLE

The sponsor had no role in the design, methods, subject recruitment, data collections, analysis and preparation of article.

DATA AVAILABILITY STATEMENT

Data were entered into NVivo 11 (QSR international) qualitative software. The data are not publicly available to maintain participant confidentiality but are available from the corresponding author on reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

Text S1: Semi-Structured Interview Guide for Patient

Text S2: Semi-Structured Interview Guide for Primary Care Providers (PCPs).

Text S3: Code Dictionary.

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