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Supplementary Text S1: Patient Semi-Structured Interview Guide

As we've discussed, I have a series of questions that I want to cover, but these are all open-ended questions so the style of the interview will be much more like a conversation than like a survey or questionnaire. Throughout the interview you should feel free to raise any issues that you think are important. Now we are going to share some information on cancer screening that you may not have heard before. We would like to hear your thoughts on this information.

We know that it takes 10 years on average before a woman aged 75 or older has a chance of benefitting from having a mammogram or a colonoscopy. This means that a woman who has a mammogram or colonoscopy today may lower her chance of dying from cancer in 10 years. This is because most cancers found on a mammogram or colonoscopy are slow growing so it may take years before these cancers actually affect an older woman's health. Many times, a woman may die from another health problem before a breast or colon cancer would affect her life. Therefore, doctors are increasingly being encouraged to talk to their patients about their chances of living 10 years when helping women decide whether or not they want to keep getting tests to look for cancer.

1. What do you think about doctors talking to their patients about their chance of living 10 years when discussing stopping cancer screening.
2. How would you feel if your doctor asked you if it would be okay to talk about how long you may have to live?
 - a. Probe: How would you feel if your doctor talked to you about your chances of living 10 years?
3. Have you ever talked to your primary care doctor or another health care professional about how long you may have to live?
 - a. If so, how did the conversation come up?
 - i. What did your doctor say?
 - ii. How did you feel?
4. Have you ever talked to your family about how long you may have to live?
 - a. If so, how did the conversation come up?
 - b. What did your family say?
 - c. How did you feel?
5. Have you ever talked to another professional, e.g. a financial planner or member of the clergy about how long you may have to live?
 - a. If so, how did the conversation come up?
 - b. What did the financial planner/clergy member say?
 - c. How did you feel during or after this conversation?
6. Have you thought about how long you may have to live on your own?
 - a. What made you think about it?
 - b. Would you consider bringing this up to your primary care doctor?
 - c. Why or why not?
7. If your doctor wanted to talk to you about how long you may have to live, how would you feel about this?
8. How could the information be useful for you?/Is there any way this might be unhelpful? Please explain.
9. Has your doctor talked to you about your plans or thoughts on your future?

Now we are going to show you some potential scripts for doctor's to use when discussing stopping cancer screening with their patients. We would like your feedback on these scripts.

Here are the original scripts we presented to patients, the final scripts are in the manuscript

I. Options for introducing the topic:

Example A (asking patients if they want to know more about their prognosis): *“As my patients start to get older, some of them want to talk about how much time they might have left so they can prepare for the future, though no one can know for sure. Is that something you’d like to talk about?”*

Example B (acknowledging that the decision to stop cancer screening depends on life expectancy): *“Sometimes when I talk to patients about stopping cancer screening, they get worried about their health or that something has changed. Nothing has changed but I wanted to use this time to ask you whether it would be helpful to you to talk about your life expectancy, or how long you may have to live. We doctors think prognosis is really important so that we don’t order tests that can only harm you and not benefit you. Do you have any questions about how much time you might have left?”*

Example C (referring to risk calculators): *“I wanted to let you know that there are now calculators available to help doctors estimate how long their patients may live. I wanted to ask you if you would be interested in learning more about how long you may have live from these calculators. Some of my patients are interested in how long they may have to live to prepare for the future.”*

II. Communicating prognosis

Objectives: To learn from participants how to communicate prognosis and what language to use

Example A (asking patients what they know about their prognosis): *“No one knows exactly how long someone may have to live. I do not have a crystal ball but there are tools to help doctors estimate how long patients may have to live. But before I get into that, I wanted to ask you, what are your thoughts on how long you may have to live?”*

Example B (discussing life expectancy): *“Based on what I know about your health and your age, I would estimate that your life expectancy is around 10 years. It could be more or it could be less. But if I had to give my best guess, that is what I would say. No matter what, I will do whatever I can to help you live as long as possible in the best health as possible.”*

Example C (discussing prognosis): *“Based on what I know about your health and your age, I would estimate that there is a 50/50 chance that you will live another 10 years. No matter what, I will do whatever I can to help you live as long as possible in the best health as possible.”*

Example D (when patient is not interested): *“That is fine. We do not have to discuss your prognosis. I wanted to offer you this information in case it would be helpful to you. I completely understand that you do not want to discuss this and I will continue to do whatever I can to help you live as long as possible in the best health as possible.”*

III. What to say after providing prognostic information

A. Example: *“What are your thoughts? Is this information helpful to you? I am here for you to help you will all of your medical decisions. I wanted you to have all the information that I have.”*

If patient shares decision making with family: *“I am also happy to talk to your family and answer any of their questions.”*

Final Questions and Thoughts: *We’ve now covered all of the questions that I had. So one of my last questions would be whether there is anything else you can think of that I should have asked?*

Reiterate Confidentiality and Express Thanks: *If there is nothing else that you can think of, I want to thank you very much for taking the time to speak with me and to share your experience. And I want to reiterate once again that all of your comments will be treated as strictly confidential. The information you have shared will be combined with the responses from other interviews for analysis and will not be associated*

with you personally in any way. This has been enormously useful, so thank you once again for your time and your cooperation, it is deeply appreciated.

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

Discussions on Stopping Cancer Screening in Older Adults PRIMARY CARE CLINICIAN FOCUS GROUP INTERVIEW GUIDE*

INTRODUCTION

OPENING

Thank you for choosing to participate in this interview. As we've discussed, I have a series of questions that I want to cover, but these are all open-ended questions. There are no right or wrong answers. Throughout the interview you should feel free to raise any issues that you think are important.

Begin recording.

EXPLORATION

How would you feel about talking to an older patient about his/her life expectancy when talking to patients about stopping cancer screening (e.g., mammography/colonoscopy)? How would you approach this topic? What language would you use?

What makes talking to patients about their life expectancy in these situations hard? What makes it easier?

How do you estimate patient 10-year life expectancy? What tools do you use?

There are now several methods available to help estimate older adults 10-year life expectancy or prognosis (show Appendix C):

1. *Prognostic indices*: The Lee-Schonberg index (show ePrognosis) considers a patient's age, sex, body mass index, function, mobility, history of cancer, diabetes, emphysema, heart failure and smoking, number of hospitalizations in the past year, and perceived health. Adults with >50% risk of mortality within 10 years based on their score on this index are considered to have an estimated life expectancy <10 years.

2. *Life table approaches*: Cho et al. have examined the impact of specific comorbid diseases on older adult's life expectancy. For example, Cho et al. found that a 75 year old woman with diabetes has a life expectancy of 11.4 years, while a 75 year old woman with congestive heart failure (CHF) has a life expectancy of 7.0 years.

What do think of these tools? Would you find these tools helpful? Why or why not? What do you like/dislike about these tools? Which do you prefer? How changes if any would you suggest to make ePrognosis easier for you to use?

How do you think assessment of prognosis should happen in practice? How would it affect work flow?

To facilitate discussion:

"Suppose Ms. Jones came to see you. Ms. Jones is a 77 year old female with a history of diabetes, myocardial infarction, former smoker, who feels that her health is fair. She uses a cane to get around and her son helps her buy her groceries. Her last mammogram was two years ago and her last colonoscopy was 10 years ago."

Would you discuss this patient's life expectancy with this patient? Why or why not?

How would you estimate the patient's life expectancy?

C. Feedback on Example Scripts:

We have developed example scripts/language for discussing prognosis with an older adult like Ms. Jones.

I. Options for introducing the topic:

Example A (asking patients if they want to know more about their prognosis): *“As my patients start to get older, some of them want to talk about how much time they might have left so they can prepare for the future, though no one can know for sure. Is that something you’d like to talk about?”*

Example B (acknowledging that the decision to stop cancer screening depends on life expectancy): *“Sometimes when I talk to patients about stopping cancer screening, they get worried about their health or that something has changed. Nothing has changed but I wanted to use this time to ask you whether it would be helpful to you to talk about your life expectancy, or how long you may have to live. We doctors think prognosis is really important so that we don’t order tests that can only harm you and not benefit you. Do you have any questions about how much time you might have left?”*

Example C (referring to risk calculators): *“I wanted to let you know that there are now calculators available to help doctors estimate how long their patients may live. I wanted to ask you if you would be interested in learning more about how long you may have live from these calculators. Some of my patients are interested in how long they may have to live to prepare for the future.”*

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Example A (asking patients what they know about their prognosis): *“No one knows exactly how long someone may have to live. I do not have a crystal ball but there are tools to help doctors estimate how long patients may have to live. But before I get into that, I wanted to ask you, what are your thoughts on how long you may have to live?”*

Example B (discussing life expectancy): *“Based on what I know about your health and your age, I would estimate that your life expectancy is around 10 years. It could be more or it could be less. But if I had to give my best guess, that is what I would say. No matter what, I will do whatever I can to help you live as long as possible in the best health as possible.”*

Example C (discussing prognosis): *“Based on what I know about your health and your age, I would estimate that there is a 50/50 chance that you will live another 10 years. No matter what, I will do whatever I can to help you live as long as possible in the best health as possible.”*

Example D (when patient is not interested): *“That is fine. We do not have to discuss your prognosis. I wanted to offer you this information in case it would be helpful to you. I completely understand that you do not want to discuss this and I will continue to do whatever I can to help you live as long as possible in the best health as possible.”*

III. What to say after providing prognostic information

A. Example: *“What are your thoughts? Is this information helpful to you? I am here for you to help you will all of your medical decisions. I wanted you to have all the information that I have.”*

If patient shares decision making with family: *“I am also happy to talk to your family and answer any of their questions.”*

Please let me know your reaction and thoughts. What do you like or dislike about the scripts? What language would you change?

What other information or tools would you need to talk to older adults with <10 year life expectancy about stopping cancer screening?

CONCLUSION

Final Questions and Thoughts

Are there any other issues or concerns that require further discussion or have not been addressed?

Reiterate Confidentiality and Express Thanks

I want to thank you very much for taking the time to speak with me and sharing your experiences. And I want to reiterate once again that all of your comments will be treated as strictly confidential. The information you have shared will be combined with the responses from other interviews for analysis and will not be associated with you personally in any way. This has been enormously useful, so thank you once again for your time and your cooperation, it is deeply appreciated.

If you have additional thoughts, please let us know. We are happy to meet with you individually to discuss this topic in more depth. Please also feel free to email us any thoughts you may have.”

Supplementary Text S3: Code dictionary

Discussing life expectancy (>5 years):

<i>I. Attitudes</i>	Examples/Details
a. Unhelpful^{1,2}	Too far into the future/not the way older adults think
i. Sounds negative/patronizing	
ii. anxiety provoking/loss of hope¹⁻³	
b. Helpful	10-year prognosis is helpful
i. at end of life	Would want to know with very short life expectancy
ii. planning for the future²⁻⁴	Would want to know to help plan for the future
iii when prognosis is long/good	Useful when you want to get patients screened
c. Uncertain if helpful¹	
d. Perceptions of own mortality	Thoughts about their own life expectancy/loss of function/how they want to die
e. Patient information preferences⁴	Does patient want to know/not want to know their prognosis
<i>2. Norms</i>	
a. Not what PCPs do/should do³	PCPs should not/would not or should/would talk to patients about life expectancy
b. Discuss with family^{2,3}	
<i>4. Self-Efficacy (i.e., Barriers/Facilitators)</i>	
a. Communication challenging¹	
i. Communication easy	
b. Estimating prognosis challenging	
i. Estimating prognosis easy	
c. Prognostic tools helpful	
i. Unhelpful^{3,5}	
d. No training/training can help¹	Not trained for these conversations/training may help communication
e. Depends on PCP/patient relationship	
<i>5. Transitioning from quantity to quality/values</i>	Transitioning to a focus on quality of life rather than more tests to increase quantity
<i>6. Other discussing life expectancy</i>	Something that feels like a theme that does not fit into an above code

How to change the scripts:

<i>1. Too negative/anxiety provoking</i>	Do not like "how much time you have left", do not like "at your age", cold, Use this code when specifically referring to text in the scripts
<i>2. Not OK with hearing a number</i>	Not ok to talk about a specific life expectancy, or OK if it is long
<i>3. Ask about preferences for prognostic info</i>	Likes being asked for preferences around prognostic info before being asked.
<i>4. Specific language for life expectancy</i>	
<i>5. Confusing language on prognosis</i>	
a. good	Language on prognosis is not confusing
<i>6. Other suggestions</i>	Something that feels like a theme that does not fit into an above code

References for codes from literature review:

1. Schoenborn NL, Bowman TL, 2nd, Cayea D, Pollack CE, Feeser S, Boyd C. Primary Care Practitioners' Views on Incorporating Long-term Prognosis in the Care of Older Adults. *JAMA Intern Med.* 2016;176(5):671-678.
2. Thai JN, Walter LC, Eng C, Smith AK. Every patient is an individual: clinicians balance individual factors when discussing prognosis with diverse frail elderly adults. *J Am Geriatr Soc.* 2013;61(2):264-269.
3. Ahalt C, Walter LC, Yourman L, Eng C, Perez-Stable EJ, Smith AK. "Knowing is better": preferences of diverse older adults for discussing prognosis. *J Gen Intern Med.* 2012;27(5):568-575.
4. More JM, Lang-Brown S, Romo RD, Lee SJ, Sudore R, Smith AK. "Planting the Seed": Perceived Benefits of and Strategies for Discussing Long-Term Prognosis with Older Adults. *J Am Geriatr Soc.* 2018.
5. Thomas JM, Fried TR. Defining the Scope of Prognosis: Primary Care Clinicians' Perspectives on Predicting the Future Health of Older Adults. *J Pain Symptom Manage.* 2018; 55(5):1269-1275.