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Older adults' preferences for when and how to discuss life expectancy in primary care

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Abstract

Introduction—Life expectancy is important to inform a number of clinical decisions in primary care but its communication is challenging for clinicians.

Methods—This qualitative interview study with 40 community-dwelling older adults explored their perspectives on how and when to discuss life expectancy in primary care.

Results—Most participants did not want to discuss life expectancy longer than 1 year but were open to being offered discussion by clinicians. Suggestions included using health decline as trigger for discussion and discussing with family members instead of patient.

Discussion—Although older adults have varied preferences for the timing and content of life expectancy discussions in primary care, it was generally acceptable for clinicians to offer the opportunity for this type of discussion.

Keywords

Communication; Geriatrics; Life Expectancy; Primary Health Care

Introduction

Research and clinical practice guidelines recommend incorporating life expectancy in the range of years to inform decisions such as cancer screening and glycemic goal in diabetes mellitus treatment for older adults.[1] How to best communicate life expectancy is not clear and primary care clinicians reports discomfort with these discussions.[2] Literature on life expectancy communication often focuses on patients with cancer or at the end of life.[3] A few studies involving older adults not at the end of life assessed *whether* older adults wanted to discuss life expectancy but not *how* or *when* they want the communication to occur.[4–6] This study aims to examine older adults' preferences for how and when to discuss life expectancy in primary care.

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Conflict of interest: none declared.

Methods

We conducted semi-structured in-person interviews with 40 community-dwelling older adults from four clinical programs affiliated with an urban academic medical center. We used maximum variation sampling to recruit participants with diverse age and life expectancies. If someone interested in the study had a diagnosis of cognitive impairment or dementia, we consulted with the person's family members and/or clinician to ensure that the person could provide informed consent and could participate meaningfully in the interview.

Part of the interview explored views about life expectancy and cancer screening; the results are presented elsewhere.[7] Here, we focus on questions that asked older adults whether they want to discuss life expectancy in the range of years with their primary care clinicians, when they want to have such discussions, whether they preferred qualitative or quantitative information about life expectancy, and suggestions for approaching these discussions. Using a brief questionnaire and review of medical record, we collected demographic and health information to predict 4-year and 10-year mortality risks using a validated index.[8] Data collection (December 2015–March 2016) was guided by iterative assessment for theme saturation in the data. One investigator (NS) conducted the interviews, which were audio-recorded and transcribed verbatim. Two investigators (NS, KL) independently coded all transcripts using qualitative content analysis to generate themes and reconciled differences by consensus.

Results

Participants' average age was 75.7 years; 23 were female; 25 were white. They had on average 3.2 chronic conditions and 10.6 medications.[9] Predicted life expectancy was <10 years for 19/40 participants, including 8 with predicted life expectancy <4 years. Over half of the participants (21/40) had high school education or less. Self-reported financial status was "comfortable" for 20 participants, "enough" for 6 participants, and "not enough" for 14 participants.

We found that 13/40 participants said during the interview that they did not want to discuss life expectancy at any time, 13/40 participants said that they wanted to discuss life expectancy only towards the end of life, and only 14/40 participants said that they wanted to discuss life expectancy if it were longer than 1 year (Table). These 14 participants who wanted to discuss life expectancy longer than a year included 12 participants with predicted life expectancy >10 years and 2 participants with predicted life expectancy <10 years. Most participants, however, were amenable to the clinician offering discussion, as long as the patient can decline:

> "You could offer [to discuss life expectancy], I would turn it down but it would not offend me that the doctor offered to talk about it."

Participants had diverse preferences for how to present life expectancy information. Some preferred a more qualitative description without a lot of details while others wanted to know the exact statistics. One participant wanted to hear about mortality risk presented as the

chance of death over a time period but did not want to hear about life expectancy presented as the number of years left to live:

> "Talking about statistically what people with my conditions are doing, when 90% of them have died, that's reasonable, but not specifically to say you've only got 10 years to live."

Suggestions from participants for how clinicians can approach life expectancy discussions mentioned involving family members:

> "This patient may have a family member to accompany them … [the doctor] could just talk about [life expectancy] with another family member."

Another suggestions was to use health decline as a trigger for discussion:

> "The doctor would … bring up [life expectancy] … when the time frame is getting closer and the risks of dying are greater… a person on dialysis rather than a person who is not, or a person with uncontrolled diabetes versus a person who's got control of diabetes."

One participant suggested framing life expectancy in context of existing health conditions:

> "Talk about the risks involve with current conditions and… talk about the possibilities of critical conditions coming up…. Mention the current conditions of the patient and what effect that has on mortality."

Other suggestions included waiting for the patient to initiate and taking into consideration the patient's mental health status.

Discussion

To our knowledge, this is the first study to explore when and how older adults prefer to discuss life expectancy in primary care. Similar to previous studies,[4–6] most of our participants wanted to discuss life expectancy; however, only a minority was interested in such discussions when life expectancy is still more than a year. We found that even those who did not want to discuss life expectancy were open to being offered an opportunity for discussion provided that the patients could say no; similar results have been found in cancer patients regarding end of life prognosis communication.[3]

Previous studies found that more older adults wanted to discuss life expectancy when life expectancy was shorter.[4,6] In contrast, we found that most of the participants who wanted to discuss life expectancy had >10 year predicted life expectancy whereas those participants with limited life expectancy tended to not want such discussions. The discrepancy may be because previous studies used hypothetical or self-assessed life expectancy whereas we predicted life expectancy using a validated index.[4,6,8] Our result needs to be tested in larger populations to better examine preference heterogeneity while adjusting for confounders, but suggests a potential dilemma that patients with more limited life expectancy may be less likely to want to discuss it. Participants had varied preferences for qualitative versus quantitative life expectancy information. The distinction made by participant between

mortality risk and life expectancy, two closely related concepts, points to the importance of framing.

Participants were from clinical programs associated with a single institution and may not represent older adults elsewhere. Having only one interviewer may have impacted data collection and interpretation.

The heterogeneity among older adults' preferences for the timing and content of life expectancy discussions highlight the importance of eliciting patient preference regarding whether and when to have a discussion and how information should be presented. Offering discussion is an acceptable way for primary care clinicians to open the conversation. Suggestions from participants, such as using health decline as a trigger for discussion, can inform future studies to improve the communication around this important topic.

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Table

Older adults' preferences regarding life expectancy discussions in primary care.

Preferred timing to discuss life expectancy	**Example**
Never	*"I can't see where [discussing life expectancy] is helpful…no one wants to know when it's coming so the less they know about when it's coming the better off I think they are."*
Only near end-of-life	*"[Discussing life expectancy] is not necessary unless all signs are pointing to absolutely you are not going to live past 6 months."*
When life expectancy is longer than 1 year	
2–3 years	*"I would want to know within 2 years so that I could get things straightened out… but anything beyond that I would not want to know."*
5 years	*"I think 5 years would give me the time to do the things I may want to do if I have the ability to do them."*
As early as possible	*"As far in advance as possible…[even 10 years]."*
Preferred format of life expectancy information	
Qualitative description	*"If you think… that I might not last another 5 years, just tell me that I'm not doing as well as you had hoped, but … hold off giving a certain number."*
Quantitative information	*"I think the more quantification you can provide the better."*