

Older Adults' Preferences for Discussing Long-Term Life Expectancy: Results From a National Survey

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ABSTRACT

PURPOSE Clinical practice guidelines recommend incorporating long-term life expectancy to inform a number of decisions in primary care. We aimed to examine older adults' preferences for discussing life expectancy in a national sample.

METHODS We invited 1,272 older adults (aged 65 or older) from a national, probability-based online panel to participate in 2016. We presented a hypothetical patient with limited life expectancy who was not imminently dying. We asked participants if they were that patient, whether they would like to talk with the doctor about how long they may live, whether it was acceptable for the doctor to offer this discussion, whether they want the doctor to discuss life expectancy with family or friends, and when it should be discussed.

RESULTS The 878 participants (69.0% participation rate) had a mean age of 73.4 years. The majority, 59.4%, did not want to discuss how long they might live in the presented scenario. Within this group, 59.9% also did not think that the doctor should offer the discussion, and 87.7% also did not want the doctor to discuss life expectancy with family or friends. Fully 55.8% wanted to discuss life expectancy only if it were less than 2 years. Factors positively associated with wanting to have the discussion included higher educational level, believing that doctors can accurately predict life expectancy, and past experience with either a life-threatening illness or having discussed life expectancy of a loved one. Reporting that religion is important was negatively associated.

CONCLUSIONS The majority of older adults did not wish to discuss life expectancy when we depicted a hypothetical patient with limited life expectancy. Many also did not want to be offered discussion, raising a dilemma for how clinicians may identify patients' preferences regarding this sensitive topic.

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INTRODUCTION

Research and clinical practice guidelines increasingly recommend incorporating long-term life expectancy to inform preventive care decisions for older adults.¹⁻¹⁴ For example, for adults with a life expectancy of less than 10 years, guidelines recommend against routine cancer screening⁵⁻¹⁰ and recommend less intensive glycemic goals for diabetes mellitus treatment.¹² The uptake of these guidelines is hindered by a number of barriers, however; one such barrier is that clinicians find it challenging to discuss life expectancy with patients.¹⁵⁻¹⁷ Better understanding patients' preferences around this discussion is important to inform clinical practice.

Most research that has examined patient preferences for discussing life expectancy did so in the context of communicating prognosis among patients with cancer or at the end of life with advanced life-limiting illnesses (ie, weeks to months to live).^{18,19} The relevant time frame for informing preventive care decisions is much longer, however; a life expectancy of less than 10 years is frequently used in clinical guidelines.^{5-10,12} There are also a growing number of older adults who may not have a single terminal condition but have limited life expectancy from multiple chronic conditions and functional impairment.²⁰ Best practices are not well established for

communicating long-term life expectancy in a primary care setting when patients may have less than 10 years to live but are not at the end of life or do not have a single life-limiting illness such as cancer. Only a few studies have examined the perspectives of older adults who do not have cancer and who are not at the end of life regarding whether they want to discuss life expectancy. These studies have found that most participants wanted to have the discussion but often did not further explore their preferences for when or how to do so.²¹⁻²³

We previously conducted a qualitative interview study with 40 community-dwelling older adults and found that although most were receptive to being offered an opportunity to discuss life expectancy, the majority of them did not want to have this discussion if expectancy were more than 1 year.²⁴ As our findings contrasted with those of other studies in the literature,²¹⁻²³ and all took place among relatively small samples with limited generalizability, we sought to test older adults' preferences for discussing long-term life expectancy in a national survey.

METHODS

Study Design and Sample

This cross-sectional survey recruited participants from the KnowledgePanel, which is a probability-based online survey panel representative of US adults.²⁵ Panel members are recruited by random digit dialing and address-based sampling, and are provided with computers and Internet access if needed.²⁵ They are invited to participate in research surveys via e-mail 3 to 4 times a month and receive incentives using a point system. Extensive analyses by independent researchers have found the KnowledgePanel to closely match other nationally representative surveys.²⁶⁻²⁸ Panel members who were at least 65 years old and spoke English were invited to participate in our study, with oversampling of African American panel members. This project was approved by a Johns Hopkins School of Medicine institutional review board.

Survey Instrument

Our project was part of a larger survey that also asked questions about cancer screening decision making and communication. Here, we focus on the survey module that examined communication around life expectancy. At the beginning of this module, we stated that doctors can predict how long, on average, a person is expected to live based on the person's health and the doctors' knowledge of how long other people with similar health lived. We then described a hypothetical patient with serious health conditions and limitations in daily activities who was not imminently dying but whose doctor believed might not live as long as other people of the

same age (Supplemental Appendix, available at <http://www.annfam.org/content/16/6/530/suppl/DC1/>). We used a hypothetical scenario to make the question applicable and standardized. We chose this particular scenario because we were interested in understanding whether older adults want to discuss long-term life expectancy before they are at the end of life.

The first part of the module asked the participants, if they were the hypothetical patient, whether they would like to discuss how long they may live with the doctor and the reasons for their response. In our previous qualitative study with 40 community-dwelling older adults, we had explored reasons for wanting to discuss or not to discuss life expectancy.²⁴ Based on this prior work, the potential reasons for wanting to discuss life expectancy in the survey included "because it will help better plan [hypothetical patient]'s life" and "because it is important to be honest and open"; the potential reasons for not wanting to discuss life expectancy included "because the doctor cannot predict how long a person may live" and "because the information may worry or depress [hypothetical patient]."²⁴ In addition to these choices, the participant could also choose "other reasons" with open-ended responses.

We then asked the participants several follow-up questions around life expectancy communication, including, if they were the hypothetical patient, whether it was acceptable for the doctor to offer an opportunity to discuss life expectancy, which the patient could decline; whether they wanted the doctor to discuss life expectancy with the patient's family or friends; and whether they wanted to discuss life expectancy in the context of a specific clinical decision about stopping cancer screening. All of these were yes-no questions.

Next, we asked at what time point the hypothetical patient's life expectancy should be discussed. Using a technique called contingent valuation,^{29,30} each participant was presented a series of yes-no questions about whether the doctor should discuss how long the hypothetical patient is expected to live. The only difference among the questions was that we varied the estimated life expectancy of the hypothetical patient, ranging from 1 month, 3 months, 6 months, 12 months, 2 years, 5 years, 10 years, to 20 years. To avoid starting point bias, the estimated life expectancy presented in the first question was randomized. If the participant chose to discuss life expectancy, then a longer estimated life expectancy was presented in the next question until the participant chose to not discuss life expectancy or the longest life expectancy option was presented. Conversely, if the participant chose to not discuss life expectancy, then a shorter estimated life expectancy was presented in the next question until the participant switched to discussing life expectancy

or the shortest life expectancy option was presented. Lastly, we examined the participant's preferred way to describe a life expectancy of 5 years: qualitatively, as "in the range of a few years," vs quantitatively, "about a 50-50 chance to live another 5 years."

Demographic information about the Knowledge-Panel members including age, sex, race/ethnicity, and education was already known. We collected other characteristics, including self-reported health and func-

tional status, which were used to estimate life expectancy³¹; self-perceived chance to live another 10 years; past relevant experiences, specifically, history of life-threatening illness and history of discussing life expectancy of a loved one³²; belief that doctors can predict life expectancy²¹; and other factors that may influence willingness to discuss life expectancy: decision-making role,³³ importance of religion,³⁴ physician trust,³⁵ health literacy,³⁶ and numeracy.³⁷ We pilot-tested our ques-

tionnaire with 10 older adults not included in the study and iteratively revised the instrument based on their feedback.

Data Collection and Analysis

A total of 1,272 eligible KnowledgePanel members were invited to participate in November 2016. The KnowledgePanel provided survey weights that adjusted for nonresponse and for oversampling of African American panel members to produce nationally representative estimates. We applied the weights in all analyses.

Participant characteristics were analyzed descriptively. The primary outcome was wanting to discuss life expectancy in the hypothetical scenario. Univariate and multivariate logistic regression analysis was used to identify participant characteristics associated with this outcome. All variables with $P \leq .05$ in univariate analysis were included in the multivariate model. Responses to follow-up questions were summarized descriptively. In the contingent valuation analysis, we examined the proportion of participants who wanted to discuss life expectancy over the range of hypothetical life expectancies tested. All statistical analyses were performed using STATA version 13 (StataCorp, LLC).

RESULTS

A total of 878 participants (69.0% of those invited) completed the questionnaire (Table 1). The majority of participants were

Table 1. Participant Characteristics

Characteristic	All (N = 878)	Preference for Discussing Life Expectancy		P Value
		Wanted to Discuss ^a (n = 363)	Did Not Want to Discuss ^a (n = 515)	
Age, mean (SD), y	73.4 (6.1)	73.5 (6.1)	73.3 (6.2)	.70
Female sex, No. (%)	462 (55.1)	177 (51.9)	285 (57.4)	.20
Race, No. (%)				
White	575 (77.2)	261 (80.9)	314 (74.7)	.15
African American	214 (8.7)	68 (6.3)	146 (10.4)	
Other	89 (14.1)	34 (12.8)	55 (14.9)	
Educational level, No. (%)				
<High school	61 (14.4)	13 (9.6)	48 (17.7)	<.001
High school	268 (33.2)	80 (26.2)	188 (37.9)	
<4-year college	243 (24.2)	104 (25.9)	139 (23.0)	
College graduate or postgraduate degrees	306 (28.3)	166 (38.2)	140 (21.5)	
Health literacy, ^{b,36} mean (SD)	13.1 (2.1)	13.2 (2.2)	13.0 (2.0)	.33
Numeracy, ^{c,37} mean (SD)	13.8 (3.5)	14.4 (3.4)	13.4 (3.6)	<.001
Predicted life expectancy, ³¹ No. (%)				
>10 years	631 (68.9)	262 (69.7)	369 (68.4)	.76
<10 years	197 (31.1)	81 (30.3)	116 (31.6)	
Self-perceived life expectancy, No. (%)				
≥10 years	762 (83.4)	322 (84.7)	440 (82.5)	.54
<10 years	110 (16.6)	41 (15.3)	69 (17.5)	
Belief that life expectancy can be predicted, ²¹ No. (%)				
Disagree	446 (47.3)	155 (39.5)	291 (52.6)	<.001
Neutral	308 (38.6)	132 (39.1)	176 (38.2)	
Agree	122 (14.2)	74 (21.4)	48 (9.2)	
Has had life-threatening illness, ³² No. (%)	252 (29.3)	120 (33.4)	132 (26.5)	.09
Has discussed life expectancy of a loved one, ³² No. (%)	240 (24.8)	156 (40.7)	84 (14.0)	<.001
Complete trust in doctor, ³⁵ No. (%)				
Disagree	81 (8.6)	26 (7.0)	55 (9.7)	.53
Neutral	231 (27.6)	98 (27.6)	133 (27.6)	
Agree	565 (63.8)	238 (65.4)	327 (62.7)	
Preferred decision-making role, ³³ No. (%)				
Make own decisions	533 (62.5)	220 (62.0)	313 (62.9)	.83
Shared or leave to doctor	337 (37.5)	141 (38.0)	196 (37.1)	
Religion is important, ³⁴ No. (%)	633 (70.8)	242 (65.5)	391 (74.5)	.02

^a Responses to the hypothetical scenario. See Methods for description.

^b Possible range 3 to 15; higher scores indicate better health literacy.

^c Possible range 3 to 18; higher scores indicate better numeracy.

women (55.1%) and were white (77.2%), with an average age of 73.4 years. Compared with responders, nonresponders were similar in age ($P = .85$) and education ($P = .19$), but were more often female (59.3% vs 52.6%, $P = .03$) and less often non-Hispanic white (49.6% vs 65.5%, $P < .001$).

The majority of participants, 515 (59.4%), did not want to discuss how long they might live in the presented hypothetical scenario. Those who did and did not want to discuss life expectancy were not significantly different in age, sex, race, health literacy, numeracy, predicted life expectancy, self-perceived life expectancy, physician trust, and decision-making role (Table 2). Rather, the factors that were significantly

and independently associated with wanting to discuss life expectancy included higher educational levels (odds ratio with more than college education, 2.18; $P = .004$ across categories), being neutral or believing that doctors can accurately predict life expectancy (odds ratios = 1.59 and 3.06; $P < .001$ across categories), and past experience with either a life-threatening illness (odds ratio = 1.50; $P = .02$) or having discussed life expectancy of a loved one (odds ratio = 3.98; $P < .001$). In addition, reporting that religion is important was associated with lower odds of preferring to discuss life expectancy (odds ratio = 0.69; $P = .03$).

Participants' reasons for wanting and not wanting to discuss life expectancy are summarized in Table 3.

Additional reasons mentioned in open-ended responses for wanting to have this discussion included believing that it would help the family plan or might help identify what could be changed to extend life. Some participants reported that they "just want to know." Additional reasons for not wanting to discuss life expectancy included believing that it may negatively affect the person's quality of life and that only God can know how long someone lives. Among the 515 participants who did not want to discuss life expectancy in the hypothetical scenario, the majority also did not think that the doctor should offer discussion (59.9%), did not want the doctor to discuss life expectancy with family or friends (87.7%), and did not think life expectancy should be discussed in the context of stopping cancer screening (78.7%) (Table 3).

We found that the longer the hypothetical patient was expected to live, the smaller the proportion of participants who wanted to discuss life expectancy (Figure 1). A sizable minority (16.5%) did not wish to have this discussion even when it was 1 month. At the other extreme, some (11.4%) wanted to discuss life expectancy even when it was 20 years. But the largest share

Table 2. Factors Associated With Preferring to Discuss Life Expectancy

Characteristic	Unadjusted Odds Ratio (95% CI)	P Value	Adjusted Odds Ratio (95% CI) ^a	P Value
Age, per year	1.01 (0.98-1.03)	.62	–	–
Female sex	0.80 (0.61-1.05)	.11	–	–
Race		.05		.55
White	Ref		Ref	
Black	0.56 (0.33-0.93)		0.80 (0.45-1.43)	
Other	0.79 (0.53-1.17)		0.82 (0.53-1.28)	
Education		<.001		.004
<High school	Ref		Ref	
High school	1.27 (0.80-2.01)		1.09 (0.66-1.82)	
Some college	2.06 (1.28-3.33)		1.66 (0.96-2.85)	
>College	3.26 (2.05-5.19)		2.18 (1.25-3.80)	
Health literacy, ³⁶ per point (scale 3-15)	1.05 (0.98-1.12)	.15	–	–
Numeracy, ³⁷ per point (scale 3-18)	1.09 (1.05-1.14)	<.001	1.04 (0.99-1.09)	.11
Predicted 10-year mortality ^{b,31}	0.81 (0.46-1.43)	.47	–	–
Self-perceived 10-year mortality ^b	1.08 (0.62-1.87)	.78	–	–
Doctors can accurately predict life expectancy ²¹		<.001		<.001
Disagree	Ref		Ref	
Neutral	1.36 (1.01-1.83)		1.59 (1.14-2.21)	
Agree	3.10 (2.05-4.69)		3.06 (1.93-4.86)	
Has had life-threatening illness ³²	1.39 (1.04-1.86)	.03	1.50 (1.07-2.09)	.02
Has discussed life expectancy of a loved one ³²	4.22 (3.05-5.85)	<.001	3.98 (2.82-5.62)	<.001
Complete trust in doctor ³⁵		.36		
Disagree	Ref		–	–
Neutral	1.38 (0.80-2.37)		–	–
Agree	1.44 (0.87-2.39)		–	–
Prefers shared decision making or leaving decision to doctor (vs making own decisions) ³³	1.04 (0.79-1.37)	.79	–	–
Religion is important ³⁴	0.65 (0.48-0.87)	.004	0.69 (0.49-0.97)	.03

Ref = reference group.

^a Only variables having $P \leq .05$ in univariate analysis were included in multivariate analysis.

^b Analyzed as continuous variables with range of 0 to 1 in the regression model. For example, one person's 10-year mortality risk may be 0.02 or 2%, and another person's 10-year mortality risk may be 0.92 or 92%. Here, the odds ratio is per 1 unit of mortality risk, ie, comparing 100% mortality risk with 0%.

Note: Preference expressed in the hypothetical patient scenario. See Methods for description.

(55.8%) wanted to have this discussion when expectancy was less than 2 years.

When presented with the 2 phrases to describe a life expectancy of 5 years, slightly more than one-half of the participants (51.1%) preferred the more quantitative description: "about a 50-50 chance to live another 5 years." The rest preferred the more qualitative description of "in the range of a few years."

DISCUSSION

Life expectancy discussions may inform a number of decisions for older adults, who are a fast-growing segment of the population.³⁸ This study is, to our knowledge, the first to assess older adults' preferences for discussing life expectancy outside of the context of cancer or end of life in a large national sample. We found that most participants did not wish to discuss life expectancy in a hypothetical scenario depicting a patient who had serious illnesses but was not imminently dying.

This result contrasts with those of previous studies involving smaller convenience samples, in which 55% to 66% of participants wanted to discuss life expectancy.²¹⁻²³ Several reasons may contribute to the different finding in our study. First, our study population was younger, healthier, or both when compared with participants in most prior prognosis communication studies because we aimed for a nationally representative sample, whereas prior studies often focused on older adults with serious illnesses.^{18,19,22,23} Different age cohorts may also have different social and cultural values that influence how life expectancy is considered. Second, our survey asked about a hypothetical patient rather than asking about participants themselves, which may result in different responses. The reasons participants gave for their response (either wanting or not wanting to discuss life expectancy) are consistent with those seen in other studies.^{21,23,24} The preferences for discussing life expectancy did not differ by age, predicted life expectancy, self-perceived life expectancy, health literacy, or numeracy, and they did not change substantially when we asked about a specific clinical context

(eg, stopping cancer screening) even though we had expected that this factor may make life expectancy more salient, understandable, or both to older adults. Rather, the preferences for discussing life expectancy were associated with past experiences and whether one believed that life expectancy can be predicted.

This is also the first study, to our knowledge, to quantify the preferred timing for discussing life expectancy. We found that as estimated life expectancy increased, fewer participants believed that it should be discussed. This result is consistent with those of 2 other, smaller studies.^{22,23} The time at which at least one-half of the participants were willing to discuss life expectancy was between 1 and 2 years. Preference regarding how to describe life expectancy was evenly split between the qualitative description and the more quantified one, whereas patients with cancer more often prefer qualitative descriptions.³⁹

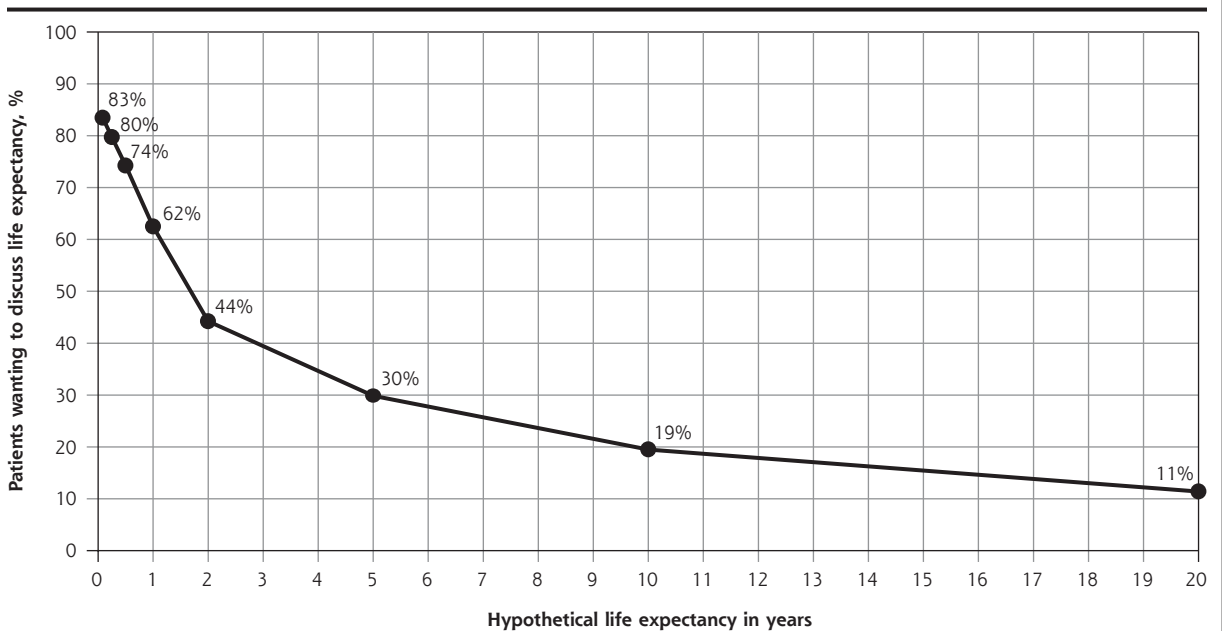
Recognizing that not everyone wants to discuss life expectancy, we were particularly interested in exploring how to approach those who would not want

Table 3. Participants' Reasons and Preferences Around Discussing Life Expectancy

Reason/Preference	Wanted to Discuss Life Expectancy ^a (n = 363)	Did Not Want to Discuss Life Expectancy ^a (n = 515)
Reason for wanting to discuss life expectancy ^b		–
Help patient better plan life	270 (72.3)	
Important to be honest and open	151 (42.2)	
Other	16 (4.6)	
Reason for not wanting to discuss life expectancy ^b	–	
Doctors cannot predict life expectancy		302 (56.7)
May worry or depress patient		272 (52.2)
Other		43 (9.7)
Acceptable for the doctor to offer to discuss life expectancy?		
Yes, as long as I can say no	344 (94.8)	222 (40.1)
No, the doctor should not have brought up the topic at all	16 (5.2)	291 (59.9)
Want the doctor to discuss life expectancy with family or friends?		
Yes	198 (57.9)	65 (12.3)
No	164 (42.1)	450 (87.7)
If the doctor recommends stopping cancer screening due to limited life expectancy of the patient, should doctor then discuss life expectancy with the patient?		
Yes	305 (84.5)	114 (21.3)
No	58 (15.5)	401 (78.7)
How should the doctor describe life expectancy of about 5 years?		
In the range of a few years	174 (49.2)	255 (48.7)
About a 50-50 chance to live another 5 years	188 (50.8)	252 (51.3)

^a Responses to the hypothetical scenario. See Methods for description.

^b Participants could choose more than 1 reason; therefore, percentages do not add up to 100%.

Figure 1. Preferences for discussing life expectancy at various time points.

such discussion. In our previous interview study of older adults, suggestions for how to approach the life expectancy discussion included involving family members and offering opportunity for discussion.²⁴ Here, however, we found that most of the survey participants who did not want to discuss life expectancy also did not want the doctor to discuss their life expectancy with family or friends. We were especially surprised to find that most of those who did not want to discuss life expectancy preferred that the doctor did not offer a discussion, even if they could decline the offer. These participants accounted for almost one-third of the total sample, representing a sizable minority. This finding raises a significant dilemma for clinicians—how can they assess which older adults would want to have a discussion about life expectancy if offering the conversation may not be acceptable to a subset? This dilemma is relevant especially as guidelines increasingly call for using life expectancy to inform clinical decision making.⁵⁻¹⁴ One potential solution is that the clinician may first explore past experiences with illness and life expectancy discussions, and beliefs regarding life expectancy prediction to assess how receptive a patient may be to discussing life expectancy. Specifically, a patient's preference may change over time as his or her health status and experiences change, so assessing those preferences at multiple time points may be important, especially after major health events in the life or family of the patient. Second, our result regarding the preferred timing of life expectancy discussion suggests that approaching the conversation

when the life expectancy is around 1 to 2 years may be acceptable to more patients. Third, a prior study showed that primary care clinicians often considered older patients' life expectancies in clinical decision making even though they did not discuss the life expectancy with patients.¹⁷ Conceivably, clinicians can incorporate patients' life expectancies to inform and guide care recommendations that maximize benefit and minimize harm even in patients who do not wish to discuss life expectancy. The challenge of discerning patient preferences for life expectancy discussion is only one among several barriers that need to be addressed in order to optimally incorporate life expectancy discussions in primary care; other barriers include time constraint, inadequate clinician training in discussing life expectancy, and clinical uncertainty around life expectancy predictions.¹⁵⁻¹⁷ Studies have shown heterogeneous results on how accurately clinicians predict life expectancy. Some studies have found that point estimates are often inaccurate,⁴⁰ but when asked to assign patients to various life expectancy categories (eg, fewer than 2 years, 2-5 years, 5-10 years, 10 or more years), clinicians tend to do better.⁴¹ In addition, there are life expectancy prediction tools available now that use self-reported health and functional status to aid in prediction.⁴²

Our study has several limitations. First, our participants, although matching national data in distribution by demographics, may not be representative of certain subgroups of older adults such as those with low computer self-efficacy. Second, the survey used a hypo-

thetical scenario to assess preference for discussing life expectancy, and participants' responses may not fully reflect actual behaviors. In addition, a single hypothetical scenario likely does not capture the diversity of patient health statuses or the dynamic nature of health trajectories. In the absence of a validated assessment instrument, we chose the scenario to provide a standardized context for participants to consider whether they would like to discuss life expectancy when it is limited but longer than weeks to months. Third, the questions about preferred timing for discussing life expectancy assumed a single transition point at which someone would switch from wanting to not wanting to discuss life expectancy. Fourth, this survey module was part of a larger survey and followed other modules about cancer screening. We do not anticipate the preceding modules to have affected participants' responses described here but cannot fully exclude that possibility. Lastly, our findings could be susceptible to nonresponse bias, but we achieved a relatively high response rate and used poststratification weights to adjust for nonresponse.

In summary, the consideration of long-term life expectancy is important to inform a number of preventive care decisions among older adults; however, whether, when, and how to communicate these considerations to patients are not clear. We have found that when presented with a hypothetical patient with serious illnesses and limited life expectancy, the majority of the older adults in our study preferred not to discuss life expectancy. Moving forward, strategies to approach this sensitive topic may include assessing patient factors that are strongly associated with willingness to discuss life expectancy and offering the discussion when closer to the last year of life.

To read or post commentaries in response to this article, see it online at <http://www.AnnFamMed.org/content/16/6/530>.

Key words: communication; life expectancy; patient preference; older adults; decision making; personalized medicine; vulnerable populations; primary care; practice-based research

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