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# "Planting the Seed": Perceived Benefits and Strategies for Discussing Long-term Prognosis with Older Adults

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## Abstract

**Importance:** Many clinicians do not discuss long-term prognosis with their patients due to uncertainty associated with the prognostic estimate and fear of causing psychological harm. For clinicians with experience discussing long-term prognosis, there are limited descriptions of the perceived benefits of having these conversations, as well as of preferred communication strategies.

**Objective:** To characterize the goals and approaches of clinicians with experience discussing long-term prognostic information with older adults.

**Design:** We used a semi-structured interview guide containing two key domains of perceived benefits and strategies to explore why and how clinicians choose to discuss long-term prognosis with patients. Long-term prognosis was defined as life expectancy on the scale of years. Clinician responses were analyzed qualitatively using the constant comparisons approach.

**Setting:** Clinicians from home-based primary care practices, community-based clinics, and academic medical centers across San Francisco.

**Participants:** Fourteen physicians, including eleven geriatricians, and one geriatric nurse practitioner with a mean age of 40 years and mean 9 years in practice.

**Results:** Perceived benefits of discussing long-term prognosis included (1) *establishing realistic expectations for patients*, (2) *encouraging conversations about future planning*, and (3) *promoting shared decision-making through understanding of patient goals of care*. Communication strategies included (1) *adapting discussions to individual patient preferences* and (2) *engaging in multiple conversations over time*. Clinicians preferred to communicate prognosis both in words and with a visual aid, though most did not know of a suitable visual aid.

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**Conclusion:** Engaging in tailored, longitudinal discussions of long-term prognosis aids clinicians in anchoring conversations about future planning and preparing patients for the end of life.

## Keywords

Prognosis; life expectancy; communication; goals; strategies

## INTRODUCTION

The majority of older adults and caregivers prefer to have conversations with clinicians about prognosis.[1–5] Studies show understanding of prognosis may influence how older adults plan financially, spend time with family, and make medical or health-related decisions.[4,6] Despite such preferences, however, conversations about prognosis, and in particular long-term prognosis, or life expectancy on the scale of years, occur infrequently in clinical practice.[2,3,6]

Clinicians have reported numerous barriers to incorporating discussions of long-term prognosis into the care of older adults.[7–10] Such barriers include uncertainty surrounding the prognostic estimate, desire to maintain hope and avoid anxiety, concern related to lack of patient understanding, and some patient preferences to avoid explicit discussions of life expectancy.[7–11] Even clinicians who use long-term prognosis for medical decision-making disagree if discussing prognosis with patients is necessary.[7]

Clinicians' reluctance may stem from lack of a framework or best practices for how to discuss long-term prognosis. To explore why and how clinicians discuss long-term prognosis with patients, we conducted semi-structured interviews with clinicians experienced in caring for older adults. We aimed to identify major goals that clinicians hope to accomplish by discussing long-term prognosis and techniques and approaches they utilize to most effectively engage patients in these conversations.

## METHODS

### Study Design and Sample

Eligible clinicians were primary or palliative care practitioners caring for older adults with dependencies in activities of daily living. Clinicians were known to the researchers and purposefully recruited due to their expertise in prognosis communication and likelihood to provide substantive, qualitative descriptions of potential positive outcomes of long-term prognosis discussions and actionable strategies to achieve these outcomes.

Fifteen clinicians practicing in San Francisco, CA were interviewed, including eleven geriatricians, two palliative care specialists, one family medicine physician and one geriatric nurse practitioner. The average age of the sample was 40 years and average time in practice was nine years (time in practice standard deviation 9 years). Eleven clinicians were female and four were male. Thirteen practiced in outpatient settings and two in home-based primary care settings. Clinicians estimated that patients in their panels were on average 82%

community-dwelling, 26% receiving home visits, 53% 85 years or older, 27% female, and 47% from a minority population.

### Data Collection and Measures

Interviews were conducted by two interviewers (JMM, SLB) using a semi-structured interview guide including questions from two domains: (1) perceived benefits of discussing long-term prognosis and (2) communication strategies that clinicians use to achieve desired outcomes. Long-term prognosis was described to clinicians as "life expectancy on the scale of years, distinct from short-term prognosis, which is on the scale of months and often discussed in the context of conversations about hospice". The concept of a trial was used as a launching point for discussion of pros and cons of discussing long-term prognosis. Clinicians were asked to rate 11 hypothetical outcomes measuring benefits and harms on a Likert scale in response to the question: "How important would the following trial endpoints be in convincing you that discussion of long-term prognosis is (or is not) a worthwhile intervention?" Open ended follow-up questions were asked after each outcome to characterize the perceived benefits of discussing long-term prognosis that influenced clinicians' ratings and what strategies they use to achieve these outcomes. Clinicians were also asked to choose one of four options for presenting life expectancy to their patients: 1) Explain it in words 2) Show the information visually 3) Explain it in words and present the information visually or 4) Allow the patient to view the information alone (without you, the clinician, present).

### Data Analysis

Qualitative analysis was performed using constant-comparative analysis.[12] Interviews were audio-recorded and professionally transcribed. We used NVIVO qualitative analysis software for open coding of the interviews.[13] Two team members (JMM, SLB) met after independently coding the transcripts to create a codebook and assign final codes through discussion until consensus. Axial codes and themes were discussed by four team members (JMM, SLB, RDR, AKS). Interview recruitment ended when theoretical saturation[12] had been reached and no new themes emerged from new interviews.

## RESULTS

### Overview of Qualitative Findings

Clinician responses were subdivided into two domains, "perceived benefits" and "strategies". Three themes that emerged from qualitative analysis of perceived benefits were: (1) *establishing realistic expectations for patients*, (2) *encouraging conversations about future planning*, and (3) *promoting shared decision-making through understanding of patient goals of care*. Two themes that emerged from analysis of communication strategies were (1) *adapting discussions to individual patient preferences* and (2) *engaging in multiple conversations over time*. Clinicians also expressed a desire for the development of visual aids to assist with life expectancy communication.

**Perceived Benefits**

**<u>Establishing realistic expectations for patients:</u>** Clinicians emphasized a major goal of discussing long-term prognosis was to assist patients in understanding what to expect in the future, both in terms of their medical care and health progression (Table 1). One clinician explained, "My hope is that, in the long run, the patient and family are able to have realistic expectations and have their expectations met by the medical system."

**<u>Encouraging conversations about future planning:</u>** Another perceived benefit of discussing long-term prognosis was the potential of using long-term prognosis to introduce conversations about future planning. Types of future planning regularly mentioned included advance care planning, financial planning, and living situation planning (Table 1). Highlighting the importance and challenge of initiating advance care planning conversations, one clinician stated: "the response I would hope for [from a discussion of long-term prognosis] is just an openness to discussing advanced directives." Another clinician noted, "I have had a lot of conversations with people about money. Which is not something that I thought I would be doing when I went to medical school. But caring for a loved one is expensive".

**<u>Promoting shared decision-making through understanding of patient goals of care:</u>** Clinicians also consistently characterized long-term prognosis discussions as a means to clarify goals of care (Table 1). One clinician shared, "I think prognosis leads to a discussion about what makes patients tick, what they care about, and how our medical care can help facilitate that." Clinicians expressed that long-term prognosis discussions empower clinicians to more effectively make decisions in collaboration with patients and family members by ensuring that everyone understands the prognosis, allowing the clinician to demonstrate their investment in the patient's wellbeing by asking about goals of care (Table 1).

**Strategies**

**<u>Adapting discussions to individual patient preferences:</u>** We found clinicians that discuss long-term prognosis tailor their discussions to individual patient preferences. Clinicians first established patient desire to discuss long-term prognosis: "First and foremost, I just want to make sure that the patient actually wants that information, and is ready to hear that information, and that we do it in a way that's sensitive". Several clinicians also described adapting discussions of long-term prognosis to their patient's level of education (Table 2).

**<u>Engaging in multiple conversations over time:</u>** Clinicians emphasized they intend discussion of prognosis to be ongoing conversations they return to over the course of multiple visits. One clinician described how making prognosis a continuing conversation made it easier to have difficult conversations when acute illnesses arise, "I think one of the hopes is that [discussing long-term prognosis] sets the stage for and sort of helps break down barriers … so that when things change or even a few years down the road you could have a similar conversation". Ongoing conversations were maintained strategically by some providers, who described a process a few called "planting the seed" in which clinicians invite patients to discuss a concrete item related to life expectancy at a future visit, for

example, "I typically plant the seed with the advanced directive, 'I'd like to talk to you about this but we don't have to talk about it right now.'" Clinicians believed "planting the seed" for future conversations encourages behavior change through reinforcement. In addition, clinicians who saw discussing life expectancy as a process did not expect patients to take immediate actions after discussing prognosis (Table 2).

**Engaging multiple senses using visual aids:** Ten of fifteen clinicians preferred to be able to communicate prognostic information both in words and visually, though most participants did not currently use or have access to a suitable visual aid (Table 2). One clinician explained the value of presenting prognostic information in multiple ways was it could lead to more patients understanding the information than if it was presented in only one format: "I deal with people who have a varying amount of health literacy, and often memory, vision and hearing impairment. So, I think trying to engage as many senses as possible when conveying information is good."

**Rating hypothetical outcomes of future study of long-term prognosis**—Among eleven hypothetical outcomes of a future trial of long-term prognosis that clinicians rated using Likert scales, "engagement in advance care planning", "financial planning", and "living arrangement planning" were reported as the most important positive outcomes in convincing clinicians that long-term prognosis discussion would be worthwhile. "No response or reaction from the patient" and "patient disagreement with presented prognosis" were rated as the least important negative outcomes in convincing clinicians that long-term prognosis was not worthwhile.

## DISCUSSION

We highlight clinicians' perspectives on long-term prognosis communication, including perceived benefits and preferred communication strategies and modes of delivery of prognostic information. Clinicians experienced in discussing long-term prognosis use these conversations to establish realistic expectations for patients, facilitate preparation and planning for the end of life, and promote shared decision-making. Clinicians employ common strategies when having discussions about long-term prognosis, such as individualizing content and extending conversations over multiple visits.

Our findings have implications for the development of best practices for long-term prognosis communication.[8] Studies of communication training show that clinicians can become more skilled at communicating serious news through training.[14–18] Building on our previous work, we propose here a framework (Figure 1) to help guide practitioners who care for older adults in addressing common discussion topics during the final decades of life.[19] Clinicians should use life expectancy to prioritize topics rather than age, due to the heterogeneity of prognosis based on age, and consider using validated prognostic calculators available at ePrognosis.org.[20] Notably, advanced care planning is anchored to prognosis, and can be addressed continuously. Introducing the topic of long-term prognosis as a way of helping patients prepare for their long-term financial future may be a way to begin these conversations that older adults welcome.

Clinicians in this study agreed discussions should be tailored to individual patients. Therefore, the framework should be flexible and encourage clinicians to adapt conversations to the diverse histories, perspectives, and experiences older adults bring to these conversations, and not assume that a one-size-fits-all approach is effective. We note clinicians reported caring for a high proportion of patients from minority groups, but did not mention any strategies of communication or practices related to cultural values. Further research could examine how prognosis communication can be adapted for older adults from diverse communities.

Most clinicians in this study desired visual aids to supplement conversation about long-term prognosis to increase patient understanding. Wong et al. found that 46% of patients would prefer to have prognosis presented with a visual aid and verbal explanation.[5] Seventeen percent would prefer to view prognosis without a doctor present, presumably receiving all information from a visual aid.[5] While the use of a visual aid was prompted in our question, the preference of most patients and clinicians for having one demonstrates an opportunity to improve communication by developing visual aids to accompany discussion frameworks.

The transferability of our findings is limited by the small size of our cohort of clinicians and characteristics of clinicians interviewed. We did not intend to capture perspectives representative of all clinicians, only those with significant expertise in prognosis communication to identify the best goals and strategies to evaluate in further research. Given the relative homogeneity and small sample size of our cohort, a priority of future research of clinician attitudes regarding long-term prognosis communication must be recruitment of providers with more diverse backgrounds, clinical practices, and patient populations. Our findings may be limited because clinicians self-reported perceived benefits and communication strategies. Clinicians may use strategies unconsciously, and the benefits they describe may merely be associated with long-term prognosis communication and not facilitated by it.

## CONCLUSION

Perceived benefits of communicating long-term prognosis include informed long-term planning and shared decision-making. Clinicians believe prognostic information can be tailored to reduce risk of harm. The goals and communication strategies highlighted in this study are the basis for a model of long-term prognosis discussion, which we will continue to refine in our future work.

## ACKNOWLEDGEMENTS

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## IMPACT STATEMENT

1. We certify that this work is novel.

2. This work identifies potential benefits and strategies for discussing long-term prognosis that can be used to develop best practices for life expectancy communication with the goal of improving decision-making among older adults.
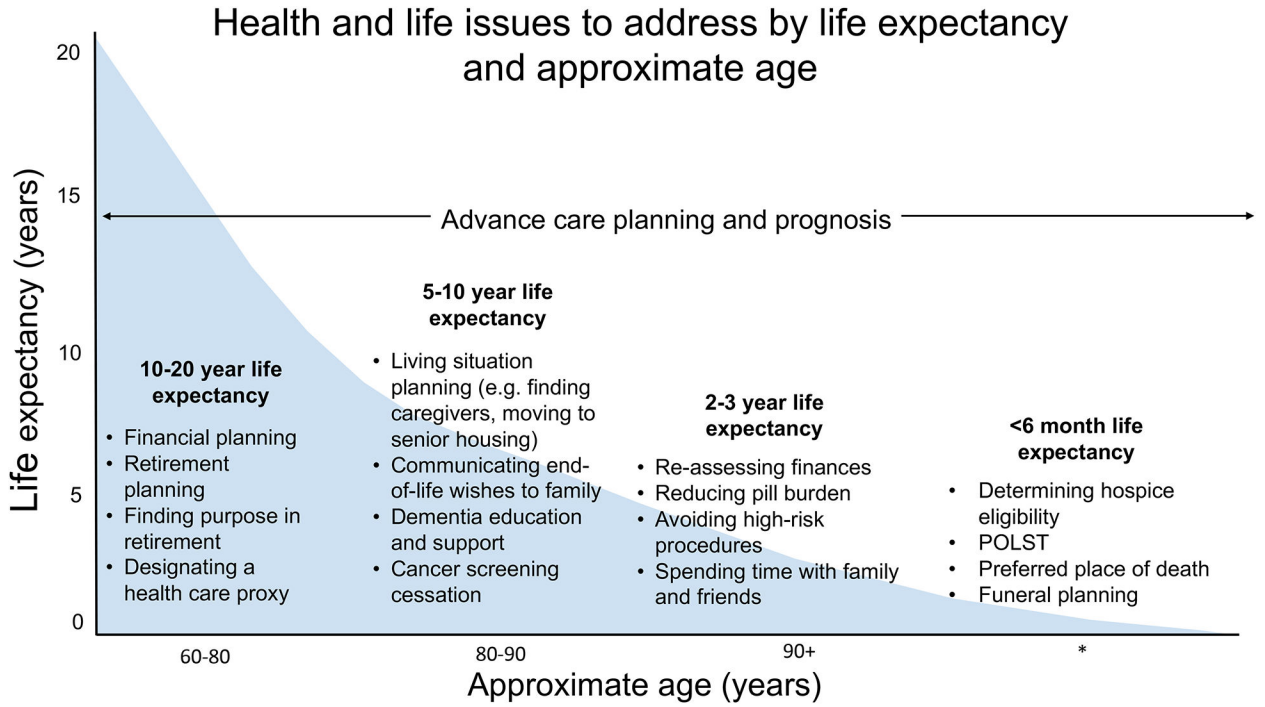
**Figure 1.**
Proposed framework for achieving desired outcomes and strategies for long-term prognosis communication beginning at age 60. This framework provides recomendations for the incorporation of the goals described by clinicians in this study and other important health and life issues into clinical practice. Clinicians should use prognosis to prioritize topics rather than age if possible, due to the heterogeneity of life expectancy based on age. The authors recommend using ePrognosis.org[20], an interactive online repository of personalized prognosis calculators, to estimate prognosis. Of note, advanced care planning is anchored in prognosis, and should be addressed throughout.
* At no age is life expectancy less than 1 year.[21]

**Table 1.**

Selected quotes about perceived benefits of discussing long-term prognosis

| Theme | *Description of theme*<br>**Quote** |
|---|---|
| **Establishing realistic expectations for patients** | *Clinicians use long-term prognosis to notify patients of what to expect in the future in terms of medical care and health progression, leading to improved decision-making*<br>"Knowing your prognostic information is one of many pieces of information that will help you make good decisions, if you're able to make good decisions, or if you have the resources with which to make good decisions."<br>"We should help patients prepare for what might happen"<br>"I think any time there is some bigger decision on the table, having a particular intervention or are we gonna stop your statin or whatnot. Again, it's really hard to have that discussion without — you can, but I think it's easier to have the discussion with the shared understanding of prognosis." |
| **Encouraging conversations about future planning** | *Long-term prognosis discussion lends itself to conversations about advance care, financial, and living situation planning*<br>"Often when we're talking about prognosis and the things that we're looking at is trying to have someone designate a healthcare agent or having them fill out their advance directives"<br>"Having an idea of how long you're going to live will probably guide where you should be putting your money down in terms of a long-term model for housing. Whether it's staying at home or needing to start looking external to the home itself." |
| **Promoting shared decision-making through understanding of patient goals of care** | *Discussion of long-term prognosis can elucidate goals of care for patients and promote more collaborative decision-making*<br>"I guess the goals in talking to someone about prognosis or life expectancy will be to help us make the decisions together. There is an inequity in the amount of information that you have as a physician and that the patient has. To make a decision together, it's helpful for everyone to have as much of the same information as possible. It's important for me to understand my patient and their family; what their values are; and what's important to them in their life; and what they want their life to look like. And it's important for them to understand, for me, things that I know because of my medical knowledge."<br>"When I've had these different conversations with different patients, I find it to be a great motivator for them to understand why I am invested in them." |

**Table 2.**

Selected quotes about preferred strategies for discussing long-term prognosis

| Theme | *Description of theme*<br>**Quote** |
|---|---|
| **Adapting discussions to individual patient preferences** | *Clinicians seek permission to discuss long-term prognosis and adapt discussion to individual patient preferences and needs*<br>"We give them the amount of information that they want and ideally, when possible, not too little and not too much. I end up doing a lot of check-ins and asking permission a lot for additional information"<br>"Not all patients want to know, nor should they be forced to."<br>"I think that the conversation is worthwhile if it's information that people want" |
| **Engaging in multiple conversations over time** | *Long-term prognosis discussions occur longitudinally and de-emphasize the importance of immediate behavioral outcomes.*<br>"This is not just a one-time thing. We hope that we can kind of carry on this discussion. Not every time we meet, but certainly kind of keep it open."<br>"I think that my expectations for the immediate outcome of the conversation is usually just to start the conversation."<br>"I think these sometimes have to be iterative, so I wouldn't want to be put off by one conversation not leading to a change in behavior that I was hoping for. I guess there may be a dose effect here, maybe like smoking cessation, right?" |
| **Engaging multiple senses by using visual aids** | *Clinicians would prefer to use visual aids with verbal explanations to make prognosis information understandable to as many patients as possible, but most do not have a visual aid to use*<br>"Currently, I do it by words only. But, as with other things I might explain about the body, including a visual aid just helps make it potentially more clear and potentially more memorable, to the patient. But having said that, I don't have a visual aid that I use."<br>"My general understanding is that if we present information in different ways, that you're more likely to actually achieve understanding, and I do, with all my patients in general practice and geriatrics tend to be low literacy and often non-English speaking, and when we're talking about prognosis, we tend to use a lot of nuance or euphemism even despite best efforts not to, so I think the visual can be really helpful." |