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Authors

Wong, Theresa W
Lang-Brown, Sean
Romo, Rafael D
et al.

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Prognosis Communication in Late-Life Disability: A Mixed Methods Study

Theresa W. Wong, MD, MPH,* Sean Lang-Brown, BS,^{†‡} Rafael D. Romo, PhD, RN, PHN,^{‡§} Alvin Au-Yeung, MPH,[¶] Sei J. Lee, MD, MAS,^{†‡} Patricia J. Moran, PhD,** Jason Karlawish, MD,^{††} Rebecca Sudore, MD,^{†‡}  Josephine Clayton, MBBS, PhD,^{‡‡§§} and Alexander K. Smith, MD, MS, MPH^{†‡}

IMPORTANCE: Long-term prognosis informs clinical and personal decisions for older adults with late-life disability. However, many clinicians worry that telling patients their prognosis may cause harm.

OBJECTIVE: To explore the safety of and reactions to prognosis communication in late-life disability.

DESIGN: Participants estimated their own life expectancy and were then presented their calculated life expectancy using a validated prognostic index. We used a semi-structured interview guide to ask for their reactions. Qualitative data were analyzed using constant comparative analysis. Potential psychological and behavioral outcomes in response to receiving one's calculated prognosis were recorded and re-assessed 2–4 weeks later.

SETTING: Community-dwelling older adults age 70+ residing in the San Francisco Bay Area.

PARTICIPANTS: Thirty five older adults with a median age of 80 requiring assistance with ≥ 1 Activity of Daily Living.

RESULTS: Self-estimates of life expectancy were similar to calculated results for 16 participants. 15 estimated their life expectancy to be longer than their calculated life expectancy by >2 years, while 4 shorter by >2 years. An overarching theme of, “fitting life expectancy into one's narrative”

emerged from qualitative analysis. Discussing life expectancy led participants to express how they could alter their life expectancy (subtheme “locus of control”), how they saw their present health (subtheme “perceived health”), and their hopes and fears for the remaining years of their lives (subtheme “outlook on remaining years”). Feelings of anxiety and sadness in reaction to receiving calculated prognosis were rare.

CONCLUSIONS AND RELEVANCE: About half of the disabled older adults' self-estimates of prognosis were similar to calculated estimates. Evidence of sadness or anxiety was rare. These data suggest that in most cases, clinicians may offer to discuss prognosis. *J Am Geriatr Soc* 65:2496–2501, 2017.

Key words: prognosis; life expectancy; communication; late-life disability

From the *University of California San Diego, School of Medicine; [†]Division of Geriatrics, Department of Medicine, University of California San Francisco; [‡]San Francisco Veterans Affairs Medical Center, San Francisco, California; [§]University of Virginia, School of Nursing, Charlottesville, Virginia; [¶]Des Moines University, College of Osteopathic Medicine, Des Moines, Iowa; **Osher Center for Integrative Medicine, Department of Medicine, University of California, San Francisco, California; ^{††}Department of Medicine, Division of Geriatrics, University of Pennsylvania, Philadelphia, Pennsylvania; ^{‡‡}Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), The University of Sydney; and ^{§§}Hammond Care Palliative and Supportive Care Service, Greenwich Hospital, Sydney, New South Wales, Australia.

Address correspondence to Alexander Smith, UCSF Division of Geriatrics, 4150 Clement St (181G), San Francisco, CA 94121.
E-mail: Alexander.Smith@ucsf.edu

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Long-term prognosis can help inform clinical and personal decisions for older adults, both by clinicians and patients themselves.^{1,2} Literature on advance care planning in chronic illness and terminal disease suggest a patient preference for incorporating life expectancy into conversations with clinicians,^{3,4} though a recent small study suggested reluctance to discuss life expectancy in the setting of cancer screening cessation.⁵ In practice, however, clinicians' reluctance to discuss prognosis stems from a combination of factors, including: fear of taking away hope, concern for patients' negative reactions, time constraints, inadequate training, and fear of prognostic uncertainty leading to erroneous “foretelling.”^{6–9} The extent to which these concerns are well founded has not been substantiated. The effect of communicating prognostic information to patients with late-life disability has not been studied.

We therefore conducted a mixed-methods study of community-dwelling older adults with late-life disability to: (1) investigate the reaction of older adults to long-term

prognostic information, and (2) investigate how self-estimates of prognosis compared with calculated estimates.

METHODS

Study Design and Sample

Clinicians referred 78 participants from four geriatric clinics in the San Francisco Bay Area. Fifty-nine eligible participants were approached; thirty-five agreed to participate. Eligible participants were community-dwelling; age 70+; requiring assistance in an Activity of Daily Living; speaking English, Spanish, or Mandarin; and able to participate in a 45-minute interview. Interviewers were native speakers of the participant's primary language. Participants were informed of the option to see and discuss their own calculated prognosis during the consent process. Potential participants were excluded if they were unable to complete the teach-to-goal consent technique that tested understanding of the study contents.¹⁰

Data Collection and Measures

In-home interviews were conducted using a semi-structured interview guide (see Supplemental Materials). The interview guide was developed initially as a team and revised iteratively for clarity and focus on emerging themes. Participants were first asked how they would prefer to receive communication of their life expectancy. Participants were given four options: with a doctor present, either (a) verbally, (b) visually, or (c) both, or (d) at home without a doctor present. Next, based on a 0 to 30-year timeline, participants were asked to circle the shortest, longest, and most likely number of years they thought they may live. Interviewers then offered to present a calculated estimate of the participant's life expectancy with a visual presentation, designed on previous literature (Figure 1).^{11,12} The Lee Index, validated for individuals older than 50 years, was used to generate calculated life expectancy estimates.^{13,14} This index uses information about age, sex, physical function, and chronic illness to predict years until death for people with similar characteristics. The Lee index captures uncertainty in prognosis by providing a best and worst case (25% and 75% survival), as well as a most-likely life expectancy (50% survival).

Participants were given the option to see their calculated prognosis, and if they chose to do so, their reactions were discussed qualitatively using open-ended questions. We then asked participants to respond to 10 statements about potential emotional and behavioral outcomes from receiving one's calculated life expectancy using a 5-point Likert scale from "Not at all" to "Extremely" (See Table 2 for list of statements). A follow-up phone interview was conducted 2–4 weeks later to re-assess psychological and behavioral outcomes (see Supplemental Text S2).

Data Analysis

Interviews were audio-recorded, professionally transcribed and translated, and verified for accuracy by the interviewers. Throughout the project, field notes and memos were written to capture the analytic process and identify areas



Figure 1. Visual aid used to present life expectancy. Interviewers presented life expectancy to participants using this image template. The worst, most likely and best case times were calculated for each participant using the Lee index, a validated prognostic tool for individuals older than 50 years.^{11–14} [Color figure can be viewed at wileyonlinelibrary.com]

needing further explication. Coding was done through constant-comparative analysis¹⁵ and managed using NVIVO qualitative analysis software.¹⁶ Theoretical saturation¹⁵ was achieved when the research team of four people agreed the interviews provided no new data that advanced the analysis. The research team represented expertise in geriatric medicine, gerontological nursing, palliative and end-of-life care, ethics, and qualitative methods.

Three members of the research team independently coded the first five interviews. They then met and discussed the codes, coming to a consensus on the interpretation of the data and developing a uniform codebook. Subsequent transcripts were coded by a single member of the team, with a second member repeating the coding of 20% of selected transcripts. The entire team met once a week to review the coding and emerging themes and achieved an 80% concordance in coding through verbal agreement. All disagreement was resolved through consensus.

Analysis of Concordance

Concordance between participants' self-estimated and calculated life expectancy was defined as a difference of 2 years or less. During the qualitative analysis, 2 years reflected the point where participants perceived that their

personal estimates were or were not in agreement with their calculated estimates. We compared the qualitative responses of those who were concordant with those at the extreme ends of discordance.

RESULTS

Study Participants

Thirty-five older adults were recruited. Ages ranged from 70 to 96, with a median age of 80 (Table 1). The sample was predominantly white ($n = 26$), male ($n = 20$), and English-speaking ($n = 29$). Twenty-seven participants would prefer to have their doctor communicate their prognosis, and six would prefer to view the information on their own (Table 1).

Concordance between Estimated and Calculated Life Expectancies

Sixteen participants' estimates of most-likely life expectancy were within 2 years of their calculated most-likely estimate (46% concordant; Figure 2). Fifteen participants' estimates of most-likely life expectancy were longer than their calculated life expectancy by more than 2 years (43%), while four participants' estimates of most-likely life expectancy were shorter by more than 2 years (11%). Thirty participants' (86%) estimated life expectancy ranges overlapped with their calculated life expectancy (Figure 2).

Table 1. Sample Characteristics ($n = 35$)

Characteristic	Value (%)
Median age (years)	80
Age range (years)	70–96
Female (n)	15 (43)
Race/ethnicity (n)	
White	26 (74)
African-American	1 (3)
Chinese	4 (11)
Latino	3 (9)
Other	1 (3)
Language spoken (n)	
English	29 (83)
Spanish	4 (11)
Mandarin	2 (6)
Health-related factors (n)	
Diabetes mellitus	14 (40)
Cancer	9 (26)
Lung disease	11 (31)
Heart failure	9 (26)
Current smoker	4 (11)
BMI <25	7 (20)
Difficulty bathing without assistance	16 (46)
Difficulty managing finances	11 (31)
Difficulty walking several blocks	31 (89)
Difficulty pulling or pushing large objects	29 (83)
Preferred Life Expectancy Communication Method (n)	
Doctor in Words	11 (31)
Doctor in Words & Visually	16 (46)
View Themselves	6 (17)
Unclear	2 (6)

Overview of the Qualitative Findings

Participants' responses to learning their calculated life expectancy reflected the degree of concordance with their own estimate and how well the calculated result aligned with their life narrative, or their views on their life course and health. The overarching theme of "fitting life expectancy into one's narrative" along with three subthemes emerged from the data. Participants constructed their life narratives through the combined lens of three key perspectives, which became the three sub-themes: locus of control, perceived health, and outlook on remaining years.

Locus of Control

Participants spoke of varying degrees of control over their lives. Some saw their lives as influenced by factors outside of their control, while others believed control came from within them. Several spoke of both. Participants who believed their life expectancy was completely out of their control referenced the will of God or uncontrollable circumstances. One participant said, "Nobody knows. Only God knows how long." On the other end of the continuum, many participants strongly believed their life expectancy was determined by their own behavior, and as such they had the power to affect their lifespan. As this participant described, "I think there is probably a good deal of control that I still have over the lifespan depending on how I treat myself."

Perceived Health

Participants saw themselves as having either stable or deteriorating health that led them to estimate that they had more or less time to live, respectively. One participant, for example, pointed out the positive aspects of her health, "I feel that I'm still able to go out and do things." In contrast, another participant acknowledged his physical decline, "There's no question my abilities have deteriorated considerably compared to what they were." Participants extrapolated the progression of their current health condition to the future, frequently valuing quality of life, not just quantity, as one participant explained, "I wanna live and I wanna have a full life and not [just] exist."

Outlook on Remaining Years

In thinking about the next several years, participants revealed their attitudes toward their own mortality. Some participants took an optimistic view on their remaining time, looking forward to living a full life and achieving their goals. One participant said, "I hope to live another seven years so I can see my grandkids all grow up." Some foresaw more difficulties and unresolved concerns, particularly participants in poor health. Most expressed a balance of appreciating the present circumstance while accepting the imminent possibility of death, as summarized by this participant, who said, "The next one or two years I'm looking forward to, but I'm ready to go if God took me tonight."

Influence of Concordance

The strength of participants' reactions reflected how concordant their estimate was with the calculated estimate.

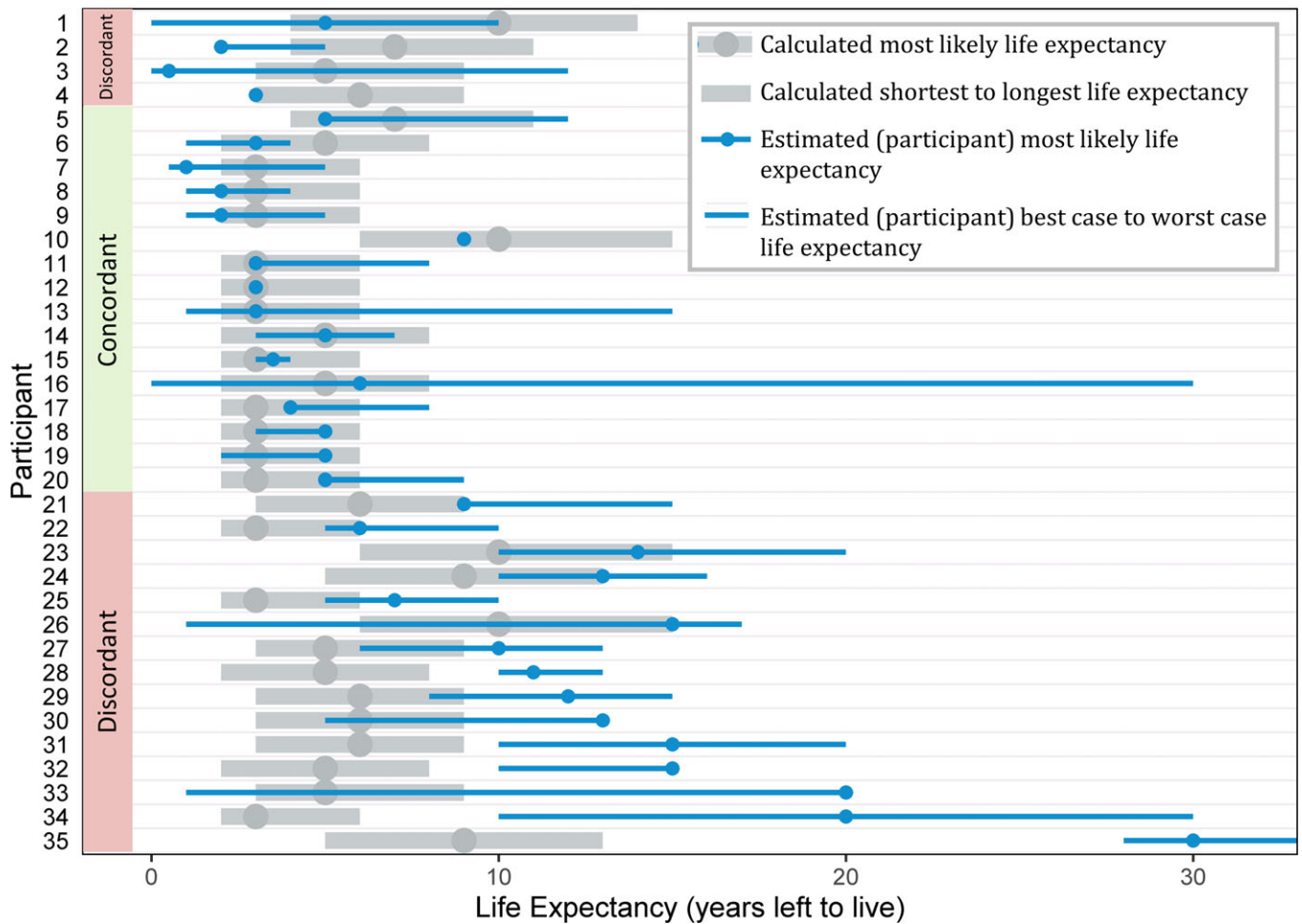


Figure 2. Concordance in life expectancies. The participants’ estimated life expectancies and their life expectancies calculated by the Lee Index are plotted, with bars representing the worst to best case ranges of each estimate.^{13,14} Participants whose estimates were discordant and shorter than their calculated life expectancies are at the top of the figure (participants 1–4), and participants whose estimates were discordant and longer than their calculated life expectancies are at the bottom (participants 21–35). [Color figure can be viewed at wileyonlinelibrary.com]

For those with concordant estimates, the information was taken in stride and resulted in short, affirmative reactions. A participant with a concordant estimate (participant 14 in Figure 2) acknowledged her understanding of the prognostic information and accepted it, saying, “I live in the moment. I live knowing that I am mortal.” However, even when agreeing with a concordant calculated prognosis, not all participants accepted the validity of prognostication, as this participant (participant 11 in Figure 2) made clear, “Nobody can guarantee the future.”

Those with discordant estimates had more varied and stronger reactions that usually involved rejecting their calculated estimates. In the most extreme case, a 70-year-old participant (participant 34 in Figure 2) gave himself a 20-year life expectancy while the Lee index yielded a best-case estimate of 6 years. The calculated estimate was so far afield from any aspect of his life narrative that he could not accept it: “I’m going to be rock and rolling for a long time. . . [I am] taking all my medicines, you know.” Participants’ reasons for not accepting discordant calculated life expectancies included their assessments of their health as well as personal beliefs.

Even participants whose calculated life expectancy exceeded their own estimates sometimes did not accept

their calculated life expectancies. A participant in his early 80’s (participant 2 in Figure 2) had a calculated estimate of 7 years, but his own estimate of 2 years fit better with his perception of his life: “My health isn’t that great. . . and I take a million pills. . . I know I should be doing more exercising, but I’m lazy.”

Some participants accepted the calculated life expectancy over their own, whether it was for the better or worse. One participant (participant 22 in Figure 2) was saddened by a shorter calculated life expectancy but then remarked, “You know what? [this is] not a shock. I can see it happening [because my health has been deteriorating].” Another participant (participant 24 in Figure 2) was emboldened by getting a shorter calculated estimate, reflecting on how she would adjust her perception of the length and quality of her future, “You know death is certain and all this, but now I think that [the calculated life expectancy] makes me more focused on really living.”

Emotional and Behavioral Outcomes

Overall, hearing the calculated prognosis had little positive or negative impact on participants as detected using

Table 2. Psychological and Behavioral Outcomes

Time of Interview	Prompt: Knowing my calculated life expectancy ...	1 Not at all (n)	2 A little bit (n)	3 Somewhat (n)	4 Very Much (n)	5 Extremely (n)	Mean response
Initial Interview (n = 33)							
Makes me:							
	Feel anxious	24	5	2	1	1	1.48
	Feel sad	26	5	1	1	0	1.45
	Think of my faith/religion	18	2	4	5	4	2.24
	Want to spend more time with family	10	4	6	8	5	2.81
I will change the way that I:							
	Exercise	22	4	4	3	0	1.63
	Smoke	32	1	0	0	0	1.03
	Drink alcohol	32	1	0	0	0	1.03
	Take medications	30	2	1	0	0	1.18
	Make medical decisions	23	4	3	3	0	1.57
	Plan financially	25	3	5	0	0	1.39
Follow-Up (n = 29)							
Makes me:							
	Feel anxious	24	3	0	2	0	1.31
	Feel sad	19	9	0	1	0	1.41
	Think of my faith/religion	23	0	1	3	2	1.66
	Want to spend more time with family	16	2	4	3	4	2.21
I will change the way that I:							
	Exercise	22	3	2	2	0	1.45
	Smoke	27	0	2	0	0	1.14
	Drink alcohol	28	1	0	0	0	1.03
	Take medications	25	2	2	0	0	1.21
	Make medical decisions	21	1	6	1	0	1.55
	Plan financially	26	1	2	0	0	1.17

quantitative Likert scales. The majority of responses to the statements about psychological and behavioral outcomes were “Not at all” or “A little bit.” Two individuals felt sadness or anxiety (Table 2). At follow-up, it was determined that one participant had misunderstood the question and felt excited, not anxious, about his life expectancy. The other explained that she had an anxiety disorder and that her anxiety was due to unrelated events in her family.

DISCUSSION

About half of the 35 community-dwelling older adults with late-life disability self-estimated prognoses that were concordant (within 2 years) with their calculated estimate. In over 85% of cases, the most-likely years of self-estimated and calculated prognoses overlapped. In all cases, concordant or discordant, participants incorporated their life expectancy into their own life narratives. Discordant prognoses often resulted in stronger reactions than concordant prognoses, especially in the most extremely discordant cases. Still, the overwhelming majority of participants did not report significant psychological reactions or behavioral changes.

In our small sample size, the quantitative outcomes could be preliminarily interpreted in two contrasting perspectives. On the one hand, as the prognostic information affected few participants, clinicians may not need to take time from their busy schedules to routinely discuss prognosis with older patients. Moreover, while strong emotional reactions were rare, patients may reject the calculated life expectancy if it does not fit with their life narrative.

On the other hand, the interview allowed participants to reflect and reconcile the difference between the prognostic information and their own expectations. Patients may still want to discuss life expectancy despite acknowledging that the clinician’s estimate may be inaccurate.² Furthermore, a prior study of chronically ill patients revealed that most preferred to delegate clinical decision-making to their physicians.¹⁷ Thus, with little evidence of psychological harm, clinicians could routinely discuss prognosis to better align patients’ perspectives with objective measures of prognosis, or at the very least open a discussion about patients’ life narratives.

Conversations about prognosis may best take place in a primary care setting, where established patient-clinician relationships are most likely to make patients comfortable sharing their life narratives. Few older adults in this study wanted to view life expectancy information alone, so clinicians should take the responsibility of offering this information to patients in person. Better predictors of functional life expectancy¹⁸ are needed, as many participants expressed concern about quality in addition to quantity of remaining life.

Our finding that learning life expectancy triggers a discussion of one’s life narrative is supported by previous research from several disciplines. We may have observed some of the Hawthorne effect triggering this process in our study: the interviews process may have helped patients process life expectancy information via a well-studied process called life review.^{19–22} Our qualitative themes parallel the functions of narrative in the context of illness and

disability, including making sense of events, asserting control, and transforming identity, as previously identified in health communications research.²³ Participants' desire to keep their life narrative intact also reflects the Continuity Theory, according to which older adults cope with changes associated with normal aging by evoking familiar strategies that maintain internal continuity.²⁴

Limitations are noted. Despite efforts to recruit a diverse sample of older adults and due to a small sample size, we were unable to draw significant conclusions about gender and racial differences. A single team member coded most transcripts, though they were reviewed regularly with the entire multidisciplinary team. The study selected for participants who were prepared to discuss prognosis through the consent process, so they may not have reacted as negatively to the information.

CONCLUSION

The majority of participants would like to have a clinician present when discussing life expectancy. Participants did not react with strong feelings of sadness or anxiety to concordant or discordant calculated life expectancies compared to their own estimates, though several did reject the calculated results. Clinicians may offer to discuss life expectancy with their older disabled patients and expect the patients to tie the information into their life narratives.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Table S1. Table of Qualitative Themes and Representative Quotes

Text S2. Qualitative Interview Guide

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