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Title
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Permalink
https://escholarship.org/uc/item/4vx9h6qv

Journal
Journal of the American Geriatrics Society, 61(2)

ISSN
0002-8614

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Publication Date
2013-02-01

DOI
10.1111/jgs.12098

Peer reviewed

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J Am Geriatr Soc. Author manuscript; available in PMC 2014 February 01.

Published in final edited form as:
J Am Geriatr Soc. 2013 February ; 61(2): 264–269. doi:10.1111/jgs.12098.

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“Every Patient is an Individual”: Clinicians Balance Individual Factors When Discussing Prognosis with Diverse Frail Elders

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Abstract

Background—Prognostic information influences testing and treatment guidelines for frail older adults. Yet little is known about the clinician choice to discuss or not discuss prognosis with their frail older patients.

Design—Qualitative interview study.

Setting—Primary care clinicians were recruited from nursing homes, community-based clinics, and academic medical centers.

Participants—Three geriatric nurse practitioners, 9 geriatricians, 5 general internists, and 3 family medicine physicians with a mean age of 44 years and mean 12 years in practice. Seventeen clinicians had patient panels with 80% community dwelling outpatients, 13 had patient panels with 50% of patients 85 or older, and 16 had patient panels with 25% of patients in a minority group (Asian, African-American, and/or Hispanic/Latino).

Measurements—Clinicians were asked to describe their practice of discussing long-term (<5-year) and short-term (<1-year and 3-month) prognosis. Responses were analyzed qualitatively using constant comparison until thematic saturation was reached.

Results—Clinicians reported individualizing the decision to discuss prognosis with their frail older patients based on clinical circumstances. Common reasons for discussing prognosis included: (1) patient had a specific condition with a limited prognosis; (2) to give patients time to prepare; (3) to promote informed medical decision making; and (4) when patients or families prompted the conversation. Common reasons not to discuss included: (1) maintaining hope and avoiding anxiety; (2) cognitive impairment or patient unable to understand prognosis; (3) respect for patients’ cultural values; and (4) long term prognosis too uncertain to be useful.

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Conflict of Interest: The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this paper.

Author Contributions

Ms. Thai assisted with the design of the study, collected and analyzed the data, and prepared the manuscript.

Dr. Walter provided critical revisions of the manuscript.

Dr. Eng supported data collection and provided critical revisions of the manuscript.

Dr. Smith designed the study, analyzed the data, prepared the manuscript, and provided supervision on all phases of the study.

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Conclusion—Clinicians caring for frail older adults are generally willing to discuss short but not long term prognosis. Clinicians balance individual factors when deciding whether or not to discuss prognosis.

Keywords

Prognosis; Geriatrics; End-of-Life

INTRODUCTION

Discussing prognosis is an important attribute of good clinical practice. Studies show clinical decisions are influenced by patients' life expectancy (1). While certain tests and treatments are routinely recommended for older patients, those with limited life expectancy may not live long enough to benefit (1–5). Guidelines increasingly recommend that clinicians use prognosis to help frail older adults make decisions about chronic disease management and screening interventions (1, 6).

Studies show a majority of frail older adults with serious illness would want to know their prognosis in order to make medical decisions (7, 8). Previous studies on communicating prognosis focus primarily on ethnically homogenous groups of patients and patients with specific terminal illnesses, such as cancer (9–11). Yet, little is known about clinicians' attitudes toward discussing prognosis with frail older patients of ethnically diverse backgrounds.

A qualitative study was conducted to identify the factors that influence clinicians' decisions to discuss or not to discuss prognosis with their frail, older patients. This study explores why short- and long-term prognosis is discussed or not discussed, with specific probes about the role of culture.

METHODS

Study Design and Sample

This qualitative study used semi-structured in-person interviews with clinicians who care for frail older patients in outpatient and nursing home settings. Subjects included geriatric nurse practitioners, geriatricians, family medicine physicians, and general internists. We purposively sampled subjects who care for diverse populations of elders.

The research team contacted eligible participants, described the study to them, and 20-minute interviews were scheduled with interested individuals. Clinicians were interviewed at their work site and asked to complete a short demographic survey that included questions about their clinical practice.

Data Collection

Twenty clinicians were interviewed using a common interview guide (Online Appendix). The guide was modified iteratively as more interviews were completed to clarify topics of interest. Researchers asked participants open-ended questions exploring factors that made them more or less likely to discuss prognosis with frail older patients, with specific probes about discussing long-term (<5-year) and short-term (<1-year and 3-month) prognosis and the role of culture. Participants were also asked how prognostic information should be communicated and the methods and factors they use to estimate prognosis in clinical settings.

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Data Analysis

Interviews were recorded and transcribed. Interviews were analyzed using NVivo 8 software (QSR International). Data were analyzed using a system of constant comparative analysis; data were reviewed reiteratively to identify new themes (19–21). The multidisciplinary research team, consisting of representatives from the fields of medicine, geriatrics, ethics and public health, coded several transcripts to develop a common codebook. A single researcher then coded the remainder of the transcripts (JNT). Throughout the coding process, codes were added as new themes emerged. A second investigator (AKS) reviewed the transcripts and codes were modified and data re-coded to reflect the new coding scheme. When no new themes emerged, saturation was reached, and no further interviews were conducted. The Committee on Human Research of the University of California, San Francisco and the San Francisco Veterans Affairs Research and Development committee approved this study.

RESULTS

Characteristics of Participants

Participants included 20 primary care clinicians who care for large, diverse panels of frail elders in outpatient and nursing home settings. Three were geriatric nurse practitioners and 17 were physicians (9 geriatricians, 5 general internists, and 3 family medicine physicians). The mean age of participants was 44 years; 80% were female. The self-identified race/ethnicity of participants was Asian (n=9), White (n=7), Latino (n=3), and 1 reported other race/ethnicity. The average years in practice of participants were 12 with a range from 1 to 33 years. Seventeen clinicians reported that community dwelling outpatients comprised 80% of their panel, 13 had patient panels where 50% were 85 or older, and 16 had patient panels with 25% of patients from a minority group (Asian, African-American, and/or Hispanic/Latino).

Overview

All but one participant said they would discuss long-term prognosis with their frail older patients under individualized circumstances, but rarely did so in practice. In contrast, all participants expressed a willingness to discuss short term prognosis and stated that they did so routinely in practice. Participants described specific clinical situations that would prompt a discussion about how long a patient might have to live. Responses were categorized as "Reasons to Discuss," "Reasons Not to Discuss," "How to Discuss," and "How to Estimate."

Reasons to Discuss Prognosis

Poor Short-term Prognosis—Clinicians stated that they were more willing to discuss prognosis if they felt their patients had a worsening health condition signifying a poor short-term prognosis. One Geriatrician observed that she was more likely to discuss prognosis with, "People who have lots of co-morbidities, who have been in and out of the hospital, who have a decline in their function." Clinicians repeatedly emphasized using their patients' decline in functional status or worsening of symptoms as a trigger to discuss prognosis (Table 1).

Promotes Informed Medical Decisions—Clinicians were more likely to raise the issue of prognosis if they felt that telling a patient his or her prognosis would help with making informed medical decisions. The following quote is illustrative: "I think that the easiest way to talk about it often is when we're talking about screening and when an appropriate time is to stop screening, because we usually think about the benefits of screening being only if

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someone really has 5 years or more to live" (Geriatrician). Participants' responses indicated that prognosis enabled shared decision-making, allowing patients to maintain their autonomy. In addition, discussing prognosis was important for surrogates who needed to make medical decisions on patients' behalf (Table 1).

Allows Patients to Get Their Lives in Order—Clinicians said that they were more likely to discuss prognosis with their patients if they felt it would help them prepare for the end of life. For example, one Geriatric Nurse Practitioner described it as allowing her patients to prepare in whatever way was most meaningful to them: "Generally, I want to frame it in a way so that they can wrap up their lives, say goodbye, or just figure out all of their affairs." Clinicians generally felt that discussing prognosis helped patients make decisions to meet their remaining life goals (Table 1).

Patients or Their Families Prompt the Conversation—Another reason clinicians gave for discussing prognosis was if it were patient- or family-prompted. One Geriatrician shared: "Either they mention something about a friend or a neighbor who has gotten sick and passed away or they talk about a deceased spouse or something that comes up that is kind of an 'in' to bringing up the subject." Clinicians felt it was appropriate to discuss prognosis when it was patient-initiated because it gave them a gauge for how patients felt about the subject: "It's so much more helpful in a sense when patients ask directly because it almost implies their permission to speak frankly" (Family Medicine Physician).

Reasons Not to Discuss Prognosis

Maintain Hope and Avoid Anxiety—Clinicians were reluctant to discuss prognosis if they felt it would undermine hope and generate anxiety (Table 2). For example, one general internist noted that discussing prognosis conflicted with her role of enabling patients to maintain hope: "They may know but they don't necessarily want to hear me say it as their doctor. Because sometimes it feels like my job is to prolong life for them. They're worried that my saying that might mean, 'She's throwing in the towel.'"

Patient Unable to Understand—Clinicians shied away from discussing prognosis when they felt that a patient's cognitive impairment would prevent him or her from understanding the significance of the prognosis. One clinician observed: "The ones who are not as intact, they either don't have enough capacity to actually comprehend the information or it just doesn't make sense to them" (Geriatric Nurse Practitioner). Clinicians also felt that patients would not be able to grasp medical concepts or would misunderstand the clinical value of a prognosis (Table 2).

Respect for Patients' Cultural Values—Clinicians reported balancing patient- and family-factors as well as considering their perceptions of their patients' culture when deciding whether to talk about prognosis. Some clinicians noted that in certain cultures, families preferred keeping prognostic information from the patient: "I think the U.S. mainstream cultural approach is often full patient autonomy – give them all the information, let them make decisions. Certainly, in other cultures, I've been told quite emphatically, 'Don't let Mom know how badly she's doing. Talk to us about it; Mom doesn't want to know'" (General Internist). Clinicians also observed that in some Asian cultures, it was ominous to talk about death, thus clinicians tried to respect their patients' cultural values by avoiding discussions about their limited life expectancies (Table 2). Participants also spoke about the importance of a shared cultural background: "I think sometimes when there's race discordant or ethnicity discordant care, there can be a mistrust of providers. That's something I think can influence the information we give or the information that we're given by our patients" (Geriatrician).

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Long-term Prognosis is Too Uncertain to be Useful—While all but one clinician were willing to discuss long term prognosis, clinicians reported that in practice they rarely did so, particularly the non-Geriatricians. The most common reason for not sharing a long-term prognosis (<5 years) was clinicians' uncertainty on the usefulness or significance of the information (Table 2). One General Internist expressed this finding best: "I actually don't know what it means. If I was to see a doctor and he or she was to say, 'Well, you have 5 years to live on average, based on what we know.' This doesn't mean very much to me. In fact, it doesn't mean anything at all to me. Five years is a long time."

How to Discuss Prognosis

When asked how prognosis should be communicated, several themes emerged: acknowledge uncertainty, involve family, and discuss within the context of the patients' health and advance care planning. Several respondents acknowledged that because clinicians' ability to prognosticate accurately is oftentimes poor, they usually disclose this uncertainty to patients. One Geriatrician shared: "I actually always tell them, 'Doctors are wrong more often than they're right about this but here's why I think we should be talking about it.'"

How to Estimate

While some clinicians reported the use of published prognostic indices and life-tables, other clinicians reported using their clinical experience and intuition to prognosticate. These clinicians reportedly based life expectancy estimates on patients' functional status, pattern of decline, and overall health condition. One Geriatrician reported: "I feel like there are just some patients that as physicians we call it the eyeball test. We see the patient, we don't have to look at their vital signs or labs – we just sort of know that they are declining and that their time is not long." Moreover, clinicians reported that it was easier to give a prognosis for patients with specific medical conditions, such as advanced dementia or cancer, than patients without a clearly dominant and fatal condition.

DISCUSSION

This study found that clinicians were generally willing to discuss prognosis with frail elderly patients, but only in specific and individualized clinical contexts. Clinicians balanced individual factors, such as patients' culture, medical condition, and specific life goals, when making the decision to discuss prognosis and how to frame the conversation. Moreover, clinicians were less likely to disclose long-term prognosis.

Clinicians were often prompted to discuss prognosis when a patient experienced a functional decline, repeated hospitalizations, worsening symptoms, or diagnosis with a terminal condition such as advanced cancer or dementia. These health events are important "triggers" for these clinicians to initiate prognostic conversations with the frail elderly.

Several clinicians, particularly the geriatricians and geriatric nurse practitioners, described the importance of discussing long term prognosis with frail elderly patients in the context of tests and treatments with a long lag-time to benefit, such as cancer screening. Clinicians who generally did not disclose long-term prognosis made their decision for compelling reasons: lack of meaning or usefulness of this information to patients, and inability to estimate long-term prognosis accurately. In our previous research, we found that two-thirds of frail elderly patients would want to discuss a 5-year prognosis with their clinician, primarily so they could prepare personally, spiritually, and financially for the end of life (8). Taken together, these findings suggest a need to educate clinicians about the general preference of many elderly patients to discuss prognosis, and the need for accurate, accessible tools for clinicians to estimate long-term prognosis. A compendium of prognostic indices was

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recently launched to allow clinicians to readily access prognostic information in clinical practice (www.eprognosis.org).

These data from clinicians seem to suggest that discussions of prognosis are fairly common; yet data from patients would suggest otherwise. In our previous study of frail elders from diverse backgrounds, we found that only 1 out of 60 subjects reported that her clinician discussed prognosis. In a study of 214 older adults with advanced chronic conditions and functional limitations and their clinicians, in 46% of clinician-patient pairs clinicians reported discussing prognosis but patients reported no such discussion took place (7). The reasons for this discordance are unclear, and are a ripe topic for future research. On the one hand, it is possible that clinicians are disclosing prognosis, yet the prognosis is either not heard, understood, or processed. On the other hand, it may be that clinicians over-report their practice of discussing prognosis because they feel it may be socially and professionally desirable to report conducting such discussions.

We specifically interviewed clinicians who care for diverse populations of older adults because evidence suggests that culture may play a strong role in decision-making around discussions of prognosis (8, 16–18). This study found that clinicians considered patients' culture as one of many individual factors to weigh when making the decision to discuss prognosis. Notably, some clinicians described a reluctance to discuss prognosis among Asian elders, as it could be viewed as portending bad luck, taking away hope, or being disrespectful toward that person's culture. However, clinicians may do a great disservice to their patient when they withhold prognostic information based on assumptions about their patients' preferences derived from cultural stereotypes, rather than directly asking about preferences for prognostic information.

This study was not designed to be representative of all clinicians caring for frail older adults. However, this study was intended to gain in-depth perspectives from the lived experiences of clinicians. The use of long-term prognosis among primary care clinicians who care for frail, older patients requires further study. Prognostic discussions may prompt a conversation regarding the option of forgoing screening or treatment for patients who are unlikely to benefit. On the other hand, as some clinicians in our study noted, long-term prognostic information may not be accurate enough to be useful. This is an empirically testable hypothesis, and the next step in this path of research is a larger intervention study of the acceptability and outcomes of prognosis discussions on clinical decision making in diverse communities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Funding Sources: Dr. Smith was supported by a pilot grant from the Center for Aging in Diverse Communities, grant no. P30-AG15272 of the Resource Centers for Minority Aging Research program funded by the National Institute on Aging, National Institutes of Health. Additional support provided by the National Center for Research Resources UCSF-CTSI (UL1 RR024131), Atlantic Philanthropies, the Society of General Internal Medicine, the John A. Hartford Foundation, and the Association of Specialty Professors.

Sponsors' Role: The sponsors had no role in the design or conduct of the study, data management or analysis, or manuscript preparation.

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Table 1

Reasons to Discuss Prognosis

Theme	Description of Theme	Quotes
Poor Short-term Prognosis	Clinicians were more likely to discuss prognosis if they felt their patients' condition was declining, leading to limited life expectancy	"If they have cancer, end stage liver disease or kidney disease and you see them declining more and more, then we start talking about prognosis." (*Geriatrician*)
		"At three months, I start to get a little bit more frank. Because you don't want people to miss out on whatever opportunities to do whatever they need to do if you really think they're going to die in three months." (*Family Medicine Physician*)
Promote Informed Medical Decision Making	Discussing prognosis allows shared medical decision making among clinicians, patients, and their families, while enabling patients to maintain autonomy	"I usually try and work it into a conversation about a medicine or a treatment of something. Or, it can be screening as the reason not to do a mammogram or a colonoscopy." (*Geriatrician*)
		"At least I would want to inform them so they know if they should go forth with more invasive treatment options or should they just go for comfort care because you want their autonomy to be considered into the treatment options and decisions." (*Geriatric Nurse Practitioner*)
		"In those cases I typically ask permission to talk to their children or proxy decision makers because I've found that even when my patient does not want to hear his or her own prognosis that patient typically has a loved one who does want the information and who needs it to make informed medical decisions." (*Geriatrician*)
Allow Patients to Get Their Lives in Order	Prognostic information allows patients to make decisions regarding personal relationships and other aspects of their lives that are consistent with their remaining life goals	"They may change their plan, how to deal with life, how to deal with a family member. They may call their family members, their son or grandchildren, say a final goodbye. So they need some time to be prepared, otherwise they – everybody is shocked and that's not good." (*General Internist*)
		"I think then there's more urgency to make sure that their needs are going to be met as they're dying. If there are things that they still want to do, then they have a chance to do it." (*Geriatrician*)
Patients or Their Families Prompt the Conversation	Clinicians discussed prognosis if the patients or their families asked about life expectancy	"Generally, when I first meet a patient and am establishing their care I talk about their goals of care. We cover advanced directives, we complete a POLST form and sometimes that leads to patient's questions about their own prognosis and/or families' questions about prognosis." (*Geriatrician*)
		"For the other patients, it was more the children asking, "How long do you think my mom has?" or "How long do you think my dad has?" but not so much of the patients themselves." (*Geriatric Nurse Practitioner*)

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Table 2

Reasons Not to Discuss Prognosis

Theme	Description of Theme	Quotes
Maintain Hope and Avoid Anxiety	Clinicians were less likely to discuss prognosis if they felt that it was their role to maintain hope and avoid causing anxiety in patients	‘I mean, they have hope – they may know that they have a terminal disease but they may hope to live out the year to see their granddaughter get married or something like that. The last thing I want to do is destroy that kind of hope.” (*General Internist*)
		“I’m too scared to tell them and make them anxious because they might think, ‘Oh, my God, I have three months.’ So I would just reassure them that, “Well, hopefully, things will get better for you. We’ll try to do everything.” (*Geriatric Nurse Practitioner*)
		“There are some very anxious people who – I talk about their prognosis with them but not as openly or frank – simply because then they get more and more worried about other things. A lot of time is spent feeling more anxious than is necessary.” (*Family Medicine Physician*)
Patient Unable to Understand	Discussing prognosis may not be helpful if patients have cognitive impairment or clinicians felt they were not likely to understand the clinical significance of the prognostic information given	“I think the setting in which I wouldn’t do that specifically with a patient is if they’re severely demented or they wouldn’t understand.” (*Geriatrician*)
		“Others are going to take it as the word of God, and all of a sudden, they’re going to say, ‘My doctor said I’m going to live a year,’ and they don’t listen to the ‘Oh, it’s a probability’ – they don’t hear any of that. All they hear is ‘one year.’ So, are we doing harm by doing this? People really don’t understand these concepts.” (*General Internist*)
Respect for Patients’ Cultural Values	Clinicians described a range of perceptions about patients’ individual culture that impacted their willingness to discuss prognosis, indicating the role of culture in the decision to speak with frail, diverse elders about life expectancy issues	“Occasionally, Latinos as well don’t want the family member to know. They want to keep it from them or whatever.” (*Geriatrician*)
		“Certain cultures in Asia, speaking directly about death could be considered both forbidden and disrespectful – like as if you were wishing a bad thing to happen to that person. Even though I am pretty gentle with my approach, I find that I get really, really indirect with my Asian patients, until I get permission from them to be more upfront” (*Family Medicine physician*)
		“I take care of a lot of former Soviet expatriates and there are very strong cultural prohibitions against talking about prognosis.” (*Geriatrician*)
Long-term Prognosis is Too Uncertain to be Useful	Clinicians felt a 5-year prognosis would be too far out to be certain, therefore, would not help patients make any useful decisions regarding their medical care	“I can’t really speak for other people but I imagine that most would not be able to grasp a five year prognosis. I’m not sure that I would know how that would help me figure out what to do with my life. Plus, I wouldn’t trust a five year prognosis.” (*Family Medicine Physician*)
		“I usually don’t do it if it’s that far out. I generally will tell people – especially if they’re six months or less – if I think they’ve got about a year left I will definitely say something. But, five years, that’s kind of too far out to really predict very well in my opinion.” (*Geriatrician*)