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Discussing Long-term Prognosis in Primary Care Hard but Necessary

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Primary care practitioners (PCPs), including physicians and nurse practitioners, strongly influence whether older adults are screened for cancer, treated aggressively for diabetes mellitus, and/or given statins for primary prevention of cardiovascular disease. Meanwhile, guidelines¹ increasingly encourage PCPs to consider patient life expectancy when deciding whether to recommend these and other medical interventions to older adults. For example, several organizations recommend that older adults with less than a 10-year life expectancy not be screened for cancer.² The rationale for this recommendation is that these patients will not live long enough to experience the possible life-prolonging benefits of cancer screening. Instead, screening these patients only puts them at risk of the harms associated with the tests, including anxiety resulting from false-positive test results, overdiagnosis (detection of tumors that are of no threat), and complications from workup and/or treatment of cancer.³ Despite the guidelines and the risks of cancer screening, nearly half of older adults with short life expectancies are screened for breast (women only) or colon cancer.⁴ One reason for this overuse of cancer screening and other medical interventions among older adults with short life expectancy is that PCPs tend to avoid discussing prognosis with older adults.

To better understand PCPs' attitudes and experience estimating and discussing long-term prognosis with older adults, Schoenborn et al⁵ interviewed 28 PCPs with busy clinics in 17 different rural, urban, and suburban practices affiliated with Johns Hopkins Community Physicians. Long-term prognosis was loosely defined as a prognosis in the range of years. Although PCPs considered long-term prognosis important and factored it into their clinical recommendations, they admitted that they rarely discussed prognosis with their patients. The participants identified multiple barriers to discussing prognosis with older adults including feeling uncertain about their prognostic estimates, having inadequate time during clinic visits, a lack of societal or cultural value for prognostic information, concerns about how patients would react to the information, and limited training on how to communicate prognosis. The PCPs believed that a strong physician-patient relationship and having patients express interest in their prognosis made these conversations easier. Overall, the

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PCPs believed that talking to their patients about their prognosis is important but is hard to do and is therefore not commonly done.

Communication about prognosis has been primarily studied between oncologists and patients with cancer near the end of life. In oncology, physicians are encouraged to prepare for end-of-life discussions by establishing what the patient and family know about the prognosis, determining how much the patient wants to know about the prognosis, and readiness to engage in the discussion, delivering the information clearly, responding to emotion, establishing goals of care and treatment priorities, and formulating a plan.⁶ These same principles will likely be a useful starting point for PCPs when discussing prognosis with older adults with 5- to 10-year life expectancy. Intuitively, a PCP in the Schoenborn et al⁵ study reported using a practice recommended by experts in palliative care when discussing prognosis with patients. The PCP introduces the topic of long-term prognosis by asking patients how long they think they will live and then adjusts the patient's estimate based on clinical knowledge and information from population data.

Key to the discussion is the ability to estimate prognosis. Although many PCPs in the Schoenborn et al⁵ study noted that they used their “gestalt” when estimating prognosis, multiple studies⁷ suggest that using risk calculators in addition to clinical judgment improves prognostication. Calculators that estimate a patient's probability of mortality over a specific time frame (eg, 10 years) are available on the website [ePrognosis.org](http://eprognosis.org) (<http://eprognosis.ucsf.edu/>) and can be used to help estimate patient prognosis. Patients found to have a less than 50% chance of being alive in 10 years according to these calculators are estimated to have a less than 10-year life expectancy. Ideally, for ease of use in time-strapped primary care, patients could be asked to complete the questions necessary to estimate their prognosis before a clinic visit. Prognostic information could then be made readily available to PCPs in electronic medical records.

However, even when PCPs feel confident in their estimates of patient prognosis, data presented by Schoenborn et al⁵ suggest that PCPs have difficulty discussing prognosis with patients. Based on our own experience, we have developed video examples of how to speak with older adults about their prognosis in several different clinical scenarios: when recommending that a patient no longer undergo screening for colorectal cancer, when relaxing hemoglobin A_{1c} targets for those with diabetes mellitus, and when discussing goals of care in the setting of advanced heart failure. These videos are available on the ePrognosis website.

Our society has tended to avoid thinking about or talking about death, especially when deciding who should be offered medical treatments or tests. However, there is mounting public interest in thoughtful planning for future care. Atul Gawande's best-selling book, *Being Mortal*,⁸ brings attention to the significant need for health care professionals to consider and discuss patients' goals of care and preferences in view of a limited life expectancy. The popularity of this book suggests the public's widespread interest and need for information on this topic. Financial planners routinely estimate and discuss their clients' long-term prognosis when providing financial advice. The time has come for older adults to expect their PCPs to estimate and discuss their long-term prognosis when deciding on

medical interventions. When asked, most older adults report that they would like information on their long-term prognosis to make informed medical decisions and to plan for their future.⁹ By avoiding discussing prognosis, PCPs may be undermining their patients' ability to make informed decisions about their care, especially since many older adults incorrectly estimate their own life expectancy.¹⁰ Currently, many older adults with short life expectancies are receiving diagnoses and treatment for cancers and other diseases that otherwise would not have caused problems or symptoms. Overscreening is particularly concerning since the risks of workup and treatment for cancer and other diseases rise as patients age and become more frail.

Primary care clinicians are well positioned to help patients understand how prognosis affects their likelihood of benefitting or being harmed by different medical interventions. Primary care clinicians often have long-standing relationships with their patients and know their patients well. The strength of these relationships is critical for successfully conducting difficult conversations. Unlike when younger patients are diagnosed with terminal cancer, older individuals often recognize and accept that they are nearing the end of their life span. Because of this self-awareness, prognosis conversations with older adults may not be as emotionally charged as PCPs fear. Instead, discussing long-term prognosis with these individuals may further enhance trust and improve communication within these relationships.

Guidelines encouraging PCPs not to recommend specific tests or interventions to older adults with a less than 10-year life expectancy may be unrealistic if PCPs are unable to discuss that prognosis.² Therefore, it is essential that we develop and adopt thoughtful strategies for communicating prognosis to older adults in primary care. Although prognosis is a sensitive topic, we suspect that PCPs who master the art of discussing long-term prognosis with older adults will likely have more satisfied and trusting patients and may help their patients avoid harm, receive higher quality care, and experience a better quality of life.

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References

1. American Society of Clinical Oncology: ten things physicians and patients should question. [Accessed March 4, 2016] Choosing Wisely website. <http://www.choosingwisely.org/societies/american-society-of-clinical-oncology/>. Published 2016
2. [Accessed May 19, 2015] Choosing Wisely: an initiative of the ABIM Foundation: promoting conversations between providers and patients. <http://www.choosingwisely.org>
3. Walter LC, Schonberg MA. Screening mammography in older women: a review. *JAMA*. 2014; 311(13):1336–1347. [PubMed: 24691609]
4. Royce TJ, Hendrix LH, Stokes WA, Allen IM, Chen RC. Cancer screening rates in individuals with different life expectancies. *JAMA Intern Med*. 2014; 174(10):1558–1565. [PubMed: 25133746]

5. Schoenborn NL, Bowman TL II, Cayea D, Pollack CE, Feeser S, Boyd C. Primary care practitioners' views on incorporating long-term prognosis in the care of older adults [published online April 11, 2016]. *JAMA Intern Med*. doi:10.1001/jamainternmed.2016.0670.
6. Bernacki RE, Block SD, American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med*. 2014; 174(12):1994–2003. [PubMed: 25330167]
7. Knaus WA, Harrell FE Jr, Lynn J, et al. The SUPPORT prognostic model: objective estimates of survival for seriously ill hospitalized adults: Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med*. 1995; 122(3):191–203. [PubMed: 7810938]
8. Gawande, A. *Being Mortal*. Metropolitan Books; New York, NY: 2014.
9. Ahalt C, Walter LC, Yourman L, Eng C, Pérez-Stable EJ, Smith AK. “Knowing is better”: preferences of diverse older adults for discussing prognosis. *J Gen Intern Med*. 2012; 27(5):568–575. [PubMed: 22127798]
10. Romo RD, Lee SJ, Miao Y, Boscardin WJ, Smith AK. Subjective, objective, and observed long-term survival: a longitudinal cohort study. *JAMA Intern Med*. 2015; 175(12):1986–1988. [PubMed: 26502331]