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Maximizing Informed Cancer Screening Decisions

Louise C. Walter, MD and

Division of Geriatrics, San Francisco VA Medical Center and the University of California, San Francisco

Carmen L. Lewis, MD, MPH

Division of General Medicine and Clinical Epidemiology, University of North Carolina School of Medicine

Most public health campaigns and quality improvement initiatives in the United States have focused on maximizing cancer screening rates rather than on maximizing informed cancer screening decisions. For example, while it is nearly impossible to read a magazine, ride public transportation, or watch television without seeing a public service announcement promoting some form of cancer screening, very few of these announcements provide accurate, balanced information about the pros and cons of screening. Most communicate a 1-sided message that cancer screening is always the right thing to do (1). While such messages have the positive effect of reducing screening disparities among persons who are likely to benefit, these messages have the detrimental effect of discouraging meaningful discussions about the risks and benefits of screening with persons in whom screening efficacy is less clear (e.g., persons with advanced age or multiple comorbidities). Similarly, performance measures that equate ordering a screening test with high quality health care discourage clinicians from discussing the risks of screening with patients and minimize the importance of informed cancer screening decisions (2).

However, interest in informed decision making for cancer screening has been growing over the past decade, catalyzed by public controversies about the utility of certain cancer screening tests, like prostate-specific antigen (PSA), and what age to start and stop cancer screening. The result has been an increasing call for patients to understand the risks and benefits of cancer screening tests, clarify personal values about them, and to make informed decisions about whether to undergo screening. Yet, clinicians often find it difficult during a busy office visit to discuss the complex consequences of cancer screening tests with patients. This is especially true when definitive evidence about benefits and harms is lacking, as is the case for screening mammograms in women aged 70 years or older.

In this issue of the ARCHIVES, Mathieu and colleagues (3) take a step forward in promoting informed decisions about screening mammography in the elderly by developing and testing a decision aid to help 70-year-old women understand the potential pros and cons of continuing mammography and make a choice that is consistent with their values and preferences. A major contribution of the decision aid is its clear presentation of the potential risks of screening using event rates per 1,000 women and including the possibility of over-detection and over-treatment of breast cancer that may occur as a result of screening. Interestingly, during pilot testing of the decision aid clinicians thought information about over-detection, false-positives, and follow-up imaging and biopsies should be removed because it may worry women. Women, on the other hand, wanted to know these risks so the information remained in the decision aid. Certainly, if the objective is to maximize informed

decisions (rather than maximize screening rates), women need to be given balanced information about both potential benefits and risks of screening.

Mathieu and colleagues (3) also found that clearly presenting potential risks and benefits of mammography to 70-year-old women who have been regularly screened did not reduce their intentions to continue screening. Ninety-five percent of women randomized to read the decision aid remained positive towards screening. But is this high enthusiasm for screening among elderly women appropriate? Possibly, since there is no evidence that the potential benefits of mammography suddenly cease at age 70. Randomized trials do not provide direct evidence for or against screening mammography in women aged 70 years or older because they were not included in the trials in sufficient numbers. Indirect evidence supporting screening in older women includes their higher absolute risk of dying from breast cancer and the increased accuracy of mammography in older women (4). Therefore, most guidelines recommend continuing screening mammography unless a woman has comorbid conditions that limit her life expectancy to less than 5 years (4). Since approximately 90% of 70-year-old women will live 5 years or more (5), high levels of intent to continue screening do not seem unreasonable in this age group and do not indicate a failure of informed decision making.

However, more work will need to be done to develop decision aids for older adults that provide individualized information about potential risks and benefits of screening tailored to a person's health status and prognosis rather than based solely on a person's age. For example, the decision aid by Mathieu and colleagues (3) does not distinguish how risks and benefits of screening differ for a healthy 70-year-old woman versus a frail 70-year-old woman in poor health. Yet, we know that detecting breast cancer at an early stage does not improve the survival of elderly women with multiple comorbid illnesses (6). In addition, based on the lag-time between screening and breast cancer survival benefit, older women who have a life expectancy less than 5 years have little chance to benefit from screening (7). Women with limited life expectancies also are at greater risk for having clinically insignificant breast cancer detected by screening, which may lead to over-treatment and associated complications (8). Explaining how the consequences of screening depend on health status and life expectancy will become increasingly important for decision aids addressing cancer screening decisions among persons over age 70 years since individual variability in health status and life expectancy increases with advancing age.

In addition, if we are going to maximize informed decision making we need to be able to measure it. Ideally, measures of informed decision making should capture several domains, including improved knowledge and more realistic expectations of the outcomes of stopping or continuing screening; clarity about which benefits and risks matter most to the person; participation in decision making at the level the person desires; and making decisions about screening that are consistent with the person's values and preferences (9). Mathieu and colleagues (3) used a composite measure of several domains including knowledge (score > 5 out of 10 on knowledge questions), clearly defined values (low decisional conflict), and intent to continue or stop screening (not undecided) to conclude that their decision aid resulted in a greater proportion of women making an informed decision about whether to continue or stop mammography compared to usual care (73% vs. 49%). Perhaps performance measurement systems, like the Health Plan Employer Data and Information Set or Veterans Affairs, which currently measure the quality of care by the rates of mammography, should consider including measures of informed decision making. Such measures would classify patients who make informed decisions to decline screening as having received good quality care, in contrast to current measures that misclassify such patients as having received poor care because they were not screened (2). In addition,

measures of informed decision making would reward clinicians for having discussions with older patients about the benefits and risks of cancer screening.

Although we still have a long way to go to maximize informed cancer screening decisions, it is a worthy goal. Currently, many patients do not make informed decisions about cancer screening because they overemphasize potential benefits of screening while downplaying potential harms (9). This might explain why very elderly women in poor health continue to undergo screening mammography, even when the risks are substantial and the benefits are remote (10). Decision aids are a promising tool to promote informed decision making, although many questions remain unanswered about the optimal presentation of quantitative information and the integration of decision aids into medical practice. For example, most elderly patients want to share test-related decision making with their clinicians, which will require systems that reimburse clinicians for the complexity and time requirements of these discussions (9). However, there is little doubt that the future will bring increased attention to informed decision making with the advent of new screening technologies that can identify disease earlier and earlier and the increasing demand for individualized care. Further evaluation of strategies to best address the information needs of the diverse elderly population is needed to ensure that older adults are not left behind when it comes to maximizing informed decision making.

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