

Delivering Patient-Centered Cancer Screening



Easier Said Than Done

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Integrating Patient-Centeredness With Prevention

Despite a consensus around the importance of both prevention and patient-centeredness, integrating these two concepts into “patient-centered prevention” will not be easy. There are times when decision making about preventive care simply cannot be patient-centered. For instance, policy decisions about whether to reduce the salt content of food products cannot be patient-centered in the way that individual decisions about screening tests can be patient-centered. There are also times when prevention should not be fully patient-centered—as when individual decisions can directly affect other people’s health (e.g., childhood immunizations). However, there are many contexts where moving toward the delivery of more patient-centered prevention is not only possible but highly desirable. One such context is cancer screening. Yet, implementing population-based cancer screening programs that are also patient-centered will require that the healthcare, public health, and policy communities overcome two key challenges.

Mr. Joyce and Mr. Beckett: Two Key Challenges to Overcome

The challenges to delivering patient-centered cancer screening are not only conceptual but also logistical. [Table 1](#) describes two patients who are considering cancer screening, Mr. Joyce and Mr. Beckett (fictional patients who represent a composite of several patients for whom the authors have cared), each of whom highlight a key challenge for patient-centered cancer screening:

1. limited use of available cancer risk models that could be used to individualize information about

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0749-3797/\$36.00

<http://dx.doi.org/10.1016/j.amepre.2015.08.003>

benefits and harms of screening (a logistical challenge); and

2. informed screening decisions that may go against our personal preferences and sense of professional obligation (a conceptual challenge).

Patient-centered care has been defined as “care that is respectful of and responsive to individual patient preferences, needs, and values.”¹ Respecting a patient’s autonomy and right to choose is clearly necessary for patient-centered decision making. However, patient preferences cannot be reliable if they are based on inaccurate information. Thus, patient-centered screening seeks to support patient autonomy by eliciting preferences that are based on the most accurate information available for an individual. Average information is sometimes the best we have available for communication and decision making. However, we often have available more-precise, individualized information that we simply do not use. Validated models to individualize risk communication are currently available for most cancer screening tests, but only rarely in the form of accessible tools for clinicians to use at the point of care. Mr. Joyce’s example emphasizes why access to individualized benefit–harm information can be so important for cancer screening decisions.

On average, groups of 70-year-olds (like Mr. Joyce) benefit from continued colon cancer screening (U.S. Preventive Services Task Force Grade A Recommendation). Based on this average information, Mr. Joyce and his provider might conclude that repeat screening is a good choice. But these recommendations fail to consider factors well known to influence the potential benefit of screening, such as comorbidities, family history, and prior screening history.² Given his age, comorbidities, previously normal colonoscopy, and the lag time to benefit from colon cancer screening, Mr. Joyce is unlikely to benefit from another screening colonoscopy. Using personalized quantitative information that takes these factors into account, Mr. Joyce and his provider are likely to arrive at a very different conclusion: that continuing to screen for colon cancer is not a good choice.

Illustrating the second challenge, Mr. Beckett’s decision to forego lung cancer screening despite evidence of

Table 1. Vignettes Describing Two Key Challenges to Delivering Patient-Centered Cancer Screening

Challenge	Vignette
Lack of individualized risk–benefit information	Mr. Joyce is a 70-year-old retired welder. He retains a positive outlook despite difficulty managing his diabetes and heart failure. During a routine visit, his doctor notes he is due for colon cancer screening, having had a normal colonoscopy 10 years ago. He isn't at all concerned about colon cancer, but is amenable to screening "as long as my doctor thinks it's a good idea." But Mr. Joyce's doctor isn't sure how helpful screening is likely to be. He wishes he had better information about the risks and benefits for someone like Mr. Joyce. Ultimately, Mr. Joyce and his doctor decide to follow the status quo and undergo repeat screening.
Discomfort with an informed patient's judgment not to be screened	Mr. Beckett is a 58-year-old engineer and an avid fly-fisherman. Despite smoking a pack of cigarettes every day for 40 years, he quit 3 years ago and has no significant health issues. During a recent visit, his doctor used a decision support tool to provide him with individualized risks and benefits of lung cancer screening. After a discussion, Mr. Beckett decided not to get screened. He acknowledged the potential mortality benefit, but felt this benefit was not big enough to outweigh the potential harms, which include false positives, invasive follow-up testing, and potential overtreatment. Mr. Beckett's doctor accepts this decision but feels a bit uncomfortable with it because it differs from his personal view about the balance between benefits and harms.

Note: Mr. Joyce and Mr. Beckett are fictional patients who represent a composite of several patients for whom the authors have cared.

benefit may cause discomfort for clinicians, public health organizations, patient advocacy groups, and policymakers who support this intervention. In addition to medical–legal concerns and other factors that may incentivize clinicians to order screening tests, clinicians and policymakers often hold strong beliefs about the value of population-based cancer screening.³ To a large extent, clinicians have considered cancer screening to be a simple decision for patients who meet eligibility criteria, requiring little thought prior to a strong recommendation to “get screened.”³ Supporting this assertion, a 2013 survey of patients found that discussions on the pros of cancer screening occurred less frequently than for other common decisions in primary care—and that discussions about the cons of screening were virtually nonexistent.⁴ Using decision support tools to provide individualized estimates of benefits and harms may seem unnecessary to those who hold such a view. As a result, moving toward more patient-centered models of care has remained elusive, even as the policy environment increasingly supports shared decision making in clinical care. We and others argue that it is an ethical imperative to adequately inform patients about common and important benefits and harms prior to ordering a cancer screening test.^{5,6} Moreover, without a collective shift in mindset on cancer screening, the medical, public health, and health policy communities will not be willing to even begin the hard work of delivering patient-centered cancer screening.

Shift in Mindset #1: Moving From Persuasion to Information

Current approaches to cancer screening reflect the population-focused perspective of public health.³ When consensus emerges that screening provides a statistically

significant population benefit, efforts often focus on increasing uptake through enhancing basic awareness and creating social pressure. Such messaging tends toward simplicity over complexity, generalization over individualization, and persuasion over information. In the U.S., the ubiquity of persuasive messaging has fostered the view that age-based screening is a moral obligation.⁷ Individual preferences and values are not entertained under such approaches. Full and transparent disclosure of both benefits and harms is rare.⁴

By contrast, patient-centered approaches to screening strive to give patients a clear understanding of potential benefits and harms and then help them make a decision that aligns with their preferences. But such approaches may lead some patients like Mr. Beckett to decide against screening. The language we commonly use to discuss such decisions—for example, “the patient refused screening”—reflects our underlying discomfort with these decisions. But most average-risk people are not destined to get any single cancer. Thus, most will not benefit from any given screening test (e.g., there is a 95% probability of not benefiting from colon cancer screening over the average person's lifetime). Given this fact, openly discussing the absolute benefit of cancer screening could plausibly lead to less utilization. A valid concern of this approach is that, rather than reflecting his core preferences, Mr. Beckett's decision could be based on a misunderstanding of the evidence, or he could be biased by emotional and cognitive factors. Thus, some may find it difficult to fully endorse this approach. Fortunately, survey instruments to measure the extent to which decisions are informed and reflective of a patient's expressed values and goals are being developed for a number of cancer screening tests.⁸

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