

Using disease-specific mortality in discussions with patients

I applaud *Canadian Family Physician* on its planned series of articles on prevention in primary care, beginning with the “Better decision making in preventive health screening” article in the July issue.¹

However, although I agree with most of the article, I disagree with the authors’ claim that disease-specific mortality is an appropriate outcome measure to evaluate cancer screening.

I suggest that the core of the issue is this: disease-specific mortality’s appropriateness is dependent on whether the reduction in disease-specific mortality is matched by the reduction in overall mortality. If overall and disease-specific mortalities are similarly reduced by the screening, then disease-specific mortality data are useful at the population level. However, if we are considering discussions with individual patients in daily practice, disease-specific mortality does not improve the data we bring to discussions with our patients about the likelihood of mortality.

More important, when disease-specific mortality for a cancer is reduced by screening but overall mortality is not, it means that we have simply traded death from that specific cancer for death from another illness. Further, it suggests that the screening and treatment process for the cancer with lower disease-specific mortality actually causes an increase in disease-specific mortality for other illnesses—something that we have suspected in prostate cancer.

Taking this to its logical conclusion, when considering interventions that reduce disease-specific mortality but do not also reduce overall mortality, we will find ourselves talking with patients about which disease they would prefer to die of. That is an unusually nuanced qualitative decision, one I have found that my patients are ill prepared to contemplate. My experience is that in such conversations patients fall prey to the cognitive error of “availability bias,” whereby they are most influenced by what they have seen in their personal lives. And that means that our attempt to collaboratively discuss options deteriorates into the patient choosing anecdote over evidence. Although I am willing to attempt such conversations, I doubt that the overall well-being of anyone is improved by trying to pick a mortality-causing disease.

As such, I would urge the Canadian Task Force on Preventive Health Care to distinguish between using disease-specific mortality for the purpose of establishing population-level guidance and its suitability for use by front-line family physicians in discussions with patients.

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Competing interests

None declared

Reference

1. Bell NR, Grad R, Dickinson JA, Singh H, Moore AE, Kasperavicius D, et al. Better decision making in preventive health screening. Balancing benefits and harms. *Can Fam Physician* 2017;63:521-4 (Eng), 525-8 (Fr).

Response

Dr Dermer highlights a central issue in decision making on preventive cancer screening: How appropriate are overall mortality and disease-specific mortality as outcome measures?¹ This issue is important for family physicians because these measures provide the information needed for discussions with patients on the potential benefits associated with screening. The potential benefits need to be weighed against potential harms. Further, screening decisions occur in an environment where many patients and physicians overestimate the benefits of screening and there are strong messages from professional organizations and advocacy groups emphasizing the value of screening.

In his letter¹ regarding our article,² Dr Dermer adds to previous debate on the advantages and disadvantages of overall mortality and disease-specific mortality as outcome measures to inform decision making in preventive cancer screening.³⁻⁶ In contrast to Dr Dermer, who questions the use of disease-specific mortality, we believe that both disease-specific mortality and overall mortality can inform decision making in preventive cancer screening when the quality of evidence and the limitations of each of these outcome measures is considered.

We agree that overall mortality is conceptually appealing as a benchmark outcome measure because it answers the crucial question of whether screening improves overall survival.^{3,4,6} However, there are several important limitations to this particular outcome measure.^{3,4,7} First, because of the very large number of potential causes of mortality, detecting the influence of any one factor

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on overall mortality would require data from an exceptionally large number of people. In this context, preventive screening trials might generate reasonably precise information on disease-specific mortality, but they are generally underpowered to determine with any precision the likely influence on overall mortality. Examples include screening for colon or prostate cancer. No trials of screening for colon cancer have examined results from more than 192 000 patients. However, it has been estimated that a trial powered to detect overall mortality for colorectal cancer would require 4.1 million participants and cost upward of \$1 billion.^{3,8} Political, financial, and logistic barriers would make it extremely difficult to conduct such a trial. Second, overall mortality is population specific and might be highly influenced by nontumour factors, such as age and comorbid conditions, that make it difficult to compare across populations or geographic regions.⁷ Finally, overall mortality might not provide information on the potential benefits of treatment related to the specific cancer for which screening is offered.^{5,7}

Measurement of disease-specific mortality attempts to answer the question of whether early detection has a true effect on the natural course of the disease. This outcome measure can provide a strong rationale to participate in screening that has the potential to prevent cancer death for the screened condition. Disease-specific mortality avoids competing causes of mortality and allows comparisons across time periods and regions.^{5,7} Disease-specific mortality also has substantial limitations. First, there are often difficulties in assigning the cause of death, especially in patients with multiple comorbid conditions, which can lead to bias. Second, it is difficult to measure harms, including death, resulting directly from screening itself. Therefore, there should be transparency in the manner in which deaths related to the invasive processes of screening and overdiagnosis are identified and reported in cancer screening trials.^{3,6,7}

How then should family physicians consider overall mortality and disease-specific mortality in decision making about preventive cancer screening? In circumstances where both disease-specific mortality and overall mortality show no benefit or there is an increase in overall mortality, clearly we should not offer screening. In other situations where both overall mortality and disease-specific mortality show benefit it would be reasonable to consider preventive cancer screening, but only after consideration of the associated harms and benefits. Finally, when there is benefit in disease-specific mortality without any demonstrated benefit in overall mortality, we should consider a process of shared decision making, which reflects the uncertainty about benefits, potential harms, and values and preferences of individual patients.

We disagree with Dr Dermer on the concern that patient preferences and values represent a problem for shared decision making. We believe that in achieving a patient-informed decision, it is the role of family physicians to elicit those values and preferences and then ensure that these values and preferences are considered in the context of objectively presented evidence on harms and benefits. This is especially important in circumstances where there is a close balance between harms and benefits, uncertainty about the presence of benefits, and potential variation in patient preferences and values. These discussions are likely to be most effective when supported by well designed patient decision aids or other knowledge translation tools that present information on the benefits and harms of screening in a format that is easily understood by patients.

We thank Dr Dermer for raising this important issue in preventive cancer screening and providing his insights and thoughts for others to consider. We invite further discussion and comments on this issue.

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Competing interests

None of the Canadian Task Force on Preventive Health Care members has any relevant financial conflicts of interest to disclose.

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