

# The risks of information in health care: do we need a new decision aid?

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As teachers of medical courses and professionals who work in a challenging environment for public health and day-to-day clinical decisions, we are concerned about how up-to-date medical knowledge that is presented in scientific papers is translated into clinical directives or public health decisions. To illustrate, we refer to screening for breast, colon and prostate cancer. The common message that may be derived from these examples was summed in *The New York Times* in 2007 (1), as follows: "Nobody likes to be at the mercy of an expert, especially of those who charge for their services and whose trustworthiness can be hard to assess. Mechanics are a common source of this frustration, but there are many others: doctors, plumbers, financial advisers, real estate agents and technical support people, to name a few."

## The three scenarios

In November 2012, Bleyer and Welch described the limited value of Breast Cancer Screening (BCS) in women 40 years of age or older over the last 30 years (2). The authors expressed doubts regarding the benefit of BCS but concluded with the message that BCS is effective. Subsequently, several letters to the editor were published. French scientists addressed an important discrepancy in the results derived from epidemiologic versus randomized trials (3), i.e. the marginal benefit found in Bleyer and Welch's study and in several European epidemiologic studies contrasts with the clear benefit of mammography derived from several randomized trials. Colleagues from the Nordic Cochrane Center emphasized the considerable harm associated with over-diagnosis of breast cancer and stated that breast cancer screening should be avoided (4). Lannin claimed that Bleyer and Welch should have interpreted their results differently to more clearly describe the identified marginal benefit of mammography

(5). The Society of Breast Imaging classified the Bleyer and Welch paper as a flawed analysis (6). This society asserted that the known 25%-30% reduction in breast cancer mortality contradicts the results reported by Bleyer and Welch.

The broad spectrum of interpretations reflects the need for a new culture of scientific discussion, as expressed by the authors' reply to these comments (7). Three important aspects of the original NEJM paper should be addressed. First, it clearly showed that the implementation of mammography screening increased the annual detection rate of *early* breast cancer cases from approximately 120 to 240 cases per 100,000 investigated women (2). In other words, the detection rate doubled. In absolute numbers, the results indicated that approximately 80,000 additional women per year are diagnosed with breast cancer in each of the larger European countries, including France, Germany, Italy and the United Kingdom, due to BCS. Second, Bleyer and Welch showed that *late* stage disease includes the following two subgroups of breast cancer patients: those in the *regional late stage*, which may be treated effectively, and those in the *distant late stage*, which remains quite difficult to treat. Third, the influence of BCS on the incidence of regional late stage and distant late stage disease differed. The incidence of regional late stage disease was increasing prior to the implementation of screening (and other methods not discussed here) but has been decreasing since the implementation of screening. By contrast, the incidence of distant late stage disease was the same before and after the implementation of screening and other innovations. From a critical point of view, screening causes an impressive effect, i.e. the detection of an additional 120 cases of early breast cancer per 100,000 women. However, thus far, no data indicate that this impressive effect adds any measurable benefit to the management of breast cancer. In reality, this impressive effect is used to justify surgery, radiotherapy and several types of adjuvant therapies but does not lead to a survival benefit. The benefit observed in regional late stage disease exists but is not influenced by screening. Furthermore, the calculated life expectancy of breast cancer patients has increased since the introduction of screening. It should be stressed that the same calculated effect can be demonstrated when a large number of women are diagnosed with 'benign' breast cancer that will never proceed to distant late stage disease. By increasing the proportion of 'benign' breast cancer cases through more aggressive tests,

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calculated life expectancy will increase even if no treatment is available for any breast cancer patient. Bleyer and Welch (2) were accurate in their data presentation and discussion of harm caused by over-diagnosis; however, they did not seem to accept that their data showed more harm than the expected benefit.

The second scenario is related to colon cancer screening, which is widely recommended by experts (8-11). Most of these experts claim that existing data confirm a reduction in mortality from colon cancer due to screening. However, a detailed analysis of the existing literature demonstrated that the quality of the reports that support screening for colon cancer is insufficient to justify the risks of screening (12).

A third scenario—screening for prostate cancer—also warrants a critical review. In an e-mail to our group, Professor Richard J. Ablin recently stated that when he first described the Prostate Specific Antigen (PSA) approximately 40 years ago, he never expected that his discovery would harm millions of men and waste billions of dollars. His warnings have been rather ineffective (13-15).

### The voice of a communication expert

Several years ago, the former editor of *British Medical Journal*, Professor Richard Smith, addressed this problem from the editor's perspective in a series of articles in which he stated the following (16,17): "Medical journals are a confluence of medicine, science and journalism - and might be expected to have the values of all three. Sometimes, however, these values conflict." According to Richard Smith, we are in an abysmal state, as thousands of biomedical journals are publishing mediocre research for a profit. In other words, we all are driven by commerce, i.e. the need to make a profit. Mediocre research may be contaminated with fraudulent or spun research.

Smith proposed open access publications and the emphasis of ethical and evidence-based practice as solutions to this problem. We believe that these solutions are the correct strategies but are not sufficient to change the present situation. Unless we develop a new way of thinking, we will not be able to change the direction of the present development in any society. We are currently driven by commerce and making a profit for ourselves or for our companies. This goal and the related attitudes, skills and knowledge lead to inconvenient long-term effects in health care.

These long-term effects may occur in the health care system unless we shift from commercialization to economization. Economization refers to balancing (monetary and non-monetary) costs and consequences of alternative actions. The goal of economization is to identify the optimal solution for the patient's health problem. The essential difference between economization and commercialization is the target. Although both strive for profit, commercialization focuses on one's "own profit" or "own company profit", whereas economization addresses "patient profit."

This differentiation is applicable to day-to-day practice. Economic decisions guarantee that the benefit from health services will be higher for the patient than for any other player in the system, whereas commercial decisions ensure that at least one player in the system other than the patient will benefit most from a particular health service. This observation leads back to *The New York Times* article: "Nobody likes to be at the mercy of an expert ..." The

distinction between economic and commercial decisions is not supported by statistical data; rather, it is based on societal values, which differ across cultures. We conducted a series of experiments that confirmed that the interpretation of scientific papers is more influenced by one's personal belief regarding long-accepted assumptions than by the quality of the study design or presented data (18-20).

### Possible solution to the problem

The acceptance of a scientific fact can only occur through extensive discussion with multiple partners. Considering the pressure on scientists, practitioners and public health decision makers, it is not sufficient to state that screening must detect life-threatening disease (2). In the case of screening programs, we must consider significant conflicts of interest. Therefore, we must focus on the most reliable endpoint of screening, reduced mortality. Mortality from any type of cancer will be reduced only if screening enables effective treatment that reduces the incidence of life-threatening disease. As discussed by Bleyer and Welch, the incidence of life-threatening breast cancer has not been reduced since 1976. Furthermore, approximately 90% of diagnosed prostate cancer is not life-threatening. Finally, the research on colon cancer is poor and, thus, cannot be accepted as valid support for the effectiveness of screening. The good news is that regional advanced breast disease can be effectively treated; however, these treatments do not depend on efficient screening methods.

We conclude that these screening programs do not influence survival but may induce 'perceived safety' (21) in patients who believe that screening is beneficial and physicians who act in the best interest of the patient. Angelina Jolie's recent campaign that advocates for additional money for breast cancer screening of members of affected families is associated with a high risk of mismanagement. Genetic screening can provide information that is otherwise unavailable; however, the important question is whether this new information will improve health. Recent progress in telemedicine will lead to a tremendous increase in information (22). As most individuals will be able to generate new health care data, two risks will increase, the risk of generating more uncertainty than safety and the risk of dramatically increasing the demand for medical consultations.

The example of telemedicine demonstrates that the difficulty is likely not confined to medical journals, but may also extend to opinion leaders in health care. Most of this trouble is related to conflicts of interest (23). We typically consider conflicts of interest as unethical relationships between scientists and practitioners and the pharmaceutical industry. Conflicts of interest can also emerge from unprofessional conceptions, uncritical use of medical tests, the high vulnerability of patient trust and confidence and the fact the health care services are often provided and evaluated by the same individuals. Thus, conflicts of interest are evident throughout health care systems. Consequently, the future challenge is not avoiding these conflicts of interest, but addressing them. Transparency and scientific validity will be the core principles in the management of conflicts of interest. Progress will not typically emerge from mainstream viewpoints, but may emerge from a fair discussion of controversial opinions.

Graduate institutions should teach students how to develop such controversial opinions by providing the



opportunity to discuss examples such as cancer screening and telemedicine in the context of public health decisions. Because young professionals have less prejudice against new statements, less incongruity with previously learned knowledge and fewer conflicts of interest, their perspective is typically more accurate than that of long-time professionals.

## ■ AUTHOR CONTRIBUTIONS

Thomaz TG, Constâncio TI, Silva-Júnior AG, and Nóbrega ACL took part in the discussion group. Porzsolt F was the leader of the group and had the original idea for the manuscript.

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