IN 1959, A RURAL COUPLE TOOK THEIR 9-MONTH-OLD SON, “JOHN,” TO BE TESTED FOR SOMETHING THEY HAD NEVER HEARD OF BEFORE, HEMOPHILIA. THEY HAD JUST READ AN ARTICLE ABOUT THE DISEASE IN Reader's Digest1 AND WONDERED IF JOHN’S BRUISING AND LISTLESSNESS COULD BE EXPLAINED BY THE UNFAMILIAR BLEEDING DISORDER. SOON THEREAFTER, JOHN WAS DIAGNOSED WITH HEMOPHILIA A, A COAGULATION DEFECT THAT REQUIRED COUNTLESS DOCTOR VISITS AND PAINFUL BLEEDING CRISSES THROUGHOUT HIS CHILDHOOD.

While John was in his 20s, the first report about an unusual disease affecting homosexual men appeared in the scientific literature.2 Later identified as the disease caused by the human immunodeficiency virus (HIV), AIDS has since received tremendous mass media coverage.3 Perhaps partly as a result of how AIDS was depicted in the press, patients with hemophilia and other groups associated with HIV became modern-day pariahs among some members of the public, who responded with fear and discrimination against them.4

John, who eventually tested positive for HIV, entertained the idea of submitting a more detailed account of his experiences for this issue of MSJAMA. However, 20 years after AIDS first hit the press, John decided that publishing his story would invite unwelcome scrutiny of him and his family, especially by those in his community who still live in irrational fear and ignorance of the transmissibility of HIV.

This true story illustrates the enormous impact—both positive and negative—that magazines, television, radio stations, daily newspapers, and other communication entities that comprise the “mass media” can have on an individual’s health and life. Every day, physicians face the myriad effects of the mass media on their patients’ perceptions of health care and medical science. This issue of MSJAMA explores some challenges and opportunities that arise as a result of disseminating scientific and medical information to the public.

To better understand how the mass media shapes the public’s perception of medicine, it is important to quantify the public’s response to media coverage and critically analyze the contents of this coverage. Gail Geller, Barbara A. Bernhardt, and Neil A. Holtzman discuss the mass media’s role in influencing the public’s perception of genetics research. Lisa Schwartz and Steven Woloshin lend a critical eye to the health claims made in some medical advertisements.

While misrepresentation of medical information by mass media can have negative consequences, the use of mass media to educate the public about medicine has an enormous potential to do good. Physician and reporter Miriam Shuchman discusses examples of good reporting that has resulted in positive changes in the health care field.

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The Mass Media Are Primary Sources of Health and Science Information for Many Americans, Including Scientists and Physicians. Discoveries of new disease-related genes have appeared regularly in the print and broadcast media. In our survey of the public’s perception of the media coverage conducted immediately following the announcement of the near-completion of the sequencing of the human genome in June 2000, over half of the respondents reported some exposure to media coverage of the event.

Despite widespread media coverage, the public may not be well informed about genetic discoveries. Media stories may omit important facts that can lead to misconceptions among the public about the applicability of genetics research. For instance, media reports may neglect to mention that the discovery of major susceptibility genes for common diseases such as breast and prostate cancer probably pertains to only those patients with early onset and a strong family history of the disease in question. Moreover, mass media reports about the discovery of genes for rare diseases may inappropriately extrapolate the results to common diseases or fail to highlight the long lag time between the discovery of a disease-related gene and the development of tests and treatments for the disease.

On the other extreme, media coverage that focuses on the negative aspects of genetic discoveries may lead consumers to fear their application. For example, the media commonly report on the dangers inherent in genetic research such as insurance or employment discrimination, and the possibility of genetic enhancement and “designer babies.” In our survey, the most frequently mentioned concerns about the sequencing of the human genome were privacy violations/discrimination (15.7%) and cloning (13.5%). The concern about cloning is interesting in light of the results of our content analysis of all media coverage immediately following the announcement about the sequencing of the human genome, which revealed the complete absence of any discussion of the subject. Nevertheless, there have been widespread media reports of plans to attempt human cloning, which may have colored the way people interpret news about other genetic discoveries.

Some social scientists have argued that such unbalanced coverage can lead the public to believe that traits, behaviors, and diseases are biologically determined. Others have attempted to refute this claim based on evidence that the media are no more likely to attribute disease to genetic causes now than they were 2 decades ago, despite recent increases in media coverage. The impact of media coverage of genetics on public behaviors, such as willingness to participate in genetic research, is less well understood. Nevertheless, population research will be necessary to evaluate genetic testing, prevent its misuse, and help to realize its benefits.

Members of the public will need to be knowledgeable about the issues at stake in the Human Genome Project and in scientific and medical research in general in order to make well-informed and ethically sound decisions about their participation in genetics research, and the use of new genetic technologies. Since much of the public’s knowledge about genetics will probably continue to come from the media, it is important to understand the factors that influence how media reports are generated.

Literature on genetics reporting suggests that the news-making process is complex and multifactorial. Research with positive results may get reported more than often than research with negative results. For example, stories reporting a gene associated with alcoholism got much more coverage than the stories that could not confirm the association. Biomedical scientists and journalists may also have different standards of newsworthiness, communication styles, and visions of the media’s role in reporting science news. Scientists generally do not consider research findings newsworthy until they are endorsed by peers as part of the peer review process. These different approaches may result in media reports that are confusing to the public.

In order to improve reporting, researchers have been encouraged to educate news “gatekeepers” (such as editors and producers) about the true importance of a medical discovery, and scientists and science writers have been encouraged to make themselves available to each other, and to check press releases for accuracy and clarity. Whether these suggestions will be adopted, can improve the accuracy of media reports, or whether physicians can influence media coverage of genetics remains to be seen.

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Efforts to market medicine to the public have greatly expanded in the last several years. In addition to seemingly ubiquitous direct-to-consumer drug advertisements, medical centers increasingly advertise services such as cancer care or surgical procedures. Recently, a number of companies have begun soliciting patients to order their own tests, from simple blood tests to advanced imaging studies. As medicine becomes increasingly commercialized, the prominence of direct-to-consumer marketing efforts is likely to grow.

Ideally, medical advertisements would promote informed decision making by educating consumers about medical conditions, tests, and treatment options. Unfortunately, such ads often present medical information in a way that exaggerates disease risk and thus the value of the marketed products in reducing that risk. The purpose of this essay is to help physicians critically read medical advertisements so they are better prepared to respond to patients with misconceptions about advertised claims. We analyze 3 actual advertisements to illustrate how to approach messages about disease risk, screening, and medication.

How Many People Get or Die From a Disease?

“This year 180000 Americans will be found to have a brain tumor, 21000 of which originate in the brain. The others are of ‘metastatic origin’ . . . Brain tumors are the second-leading cause of cancer death in children under the age of 15.”

This example, from a company marketing brain imaging to the public, uses a common strategy to exaggerate risk. The message begins with attention grabbing large numbers, but it provides little context to make sense of them. To understand a message about disease risk, readers need to know the population at risk and how this risk compares to other risks.

In the example, the population at risk appears to be the entire US population. The 180000 brain tumors (and 21000 primary brain tumors) occur among approximately 275 million Americans. By highlighting the numerator (ie, number of tumors) without mentioning the denominator (ie, total number at risk), the reader’s attention is focused on a large number instead of a small proportion. Explicitly providing this denominator would probably change how readers perceive their risk of having a brain tumor. A clearer expression of the reader’s risk of having a primary brain tumor might say: “This year 0.07% of Americans (7 in 10000) will be found to have a brain tumor.”

The original message also notes that brain tumors are “the second leading cause of death among children under the age of 15.” This alarming phrase further exaggerates risk by suggesting that death from brain cancer is common during childhood. To realistically assess the magnitude of the threat, readers need information not provided in the ad: How often do children die before the age of 15, and what proportion of these deaths are attributable to brain cancer? Despite what the ad suggests, on average, a child’s chance of dying of any cause by age 15 is small (about 1%). Injuries are the single largest cause of deaths in this age range and account for 40% of all deaths in childhood. Compared with a risk of 1 in 10000 of dying before age 15 of a brain tumor, the risk of death from injury is about 16 times that of death from brain tumor.

What Is the Benefit of Early Detection?

“CT [computed tomographic] scans—when used in conjunction with an analytical model developed here—can detect lung cancer five to seven years before an x-ray, when the tumor is no bigger than a grain of rice. This early detection breakthrough could raise the lung cancer survival rate from a discouraging 12% to as high as 80%.”

This advertisement uses the 5-year survival metric (ie, the proportion of cases alive 5 years after diagnosis) to suggest that screening can dramatically improve prognosis in lung cancer. Specifically, it suggests that the chance of surviving 5 years after diagnosis is 12% for people who are not screened, and 80% for those who are.

This advertisement is misleading because the comparison is inherently biased in favor of screening. Consider the effect of lead time bias. Imagine a person with an advanced lung cancer causing cough, hemoptysis, and weight loss; these symptoms prompt medical attention and a diagnosis of lung cancer is made in 1997. Despite treatment he dies in 1999. Now imagine that CT screening detected the tumor at an earlier stage in 1995, two years before the development of symptoms. Because treatment could not affect the progression of his tumor, despite the fact that it was diagnosed earlier, he still dies of lung cancer in 1999. In the first case, survival from time of diagnosis was 2 years; in the second, 4 years. Although measured survival improved by 2 years, he died at exactly the same time. Thus, the only thing the screening accomplished was informing the patient earlier that he had an incurable disease. Two other biases—length bias (ie, the tendency of screening to discover relatively less aggressive cancers) and overdiagnosis bias (ie, the fact that some screen-detected cancers would never become clinically significant even without treatment)—also distort comparisons of 5-year survival in favor of screening. Whether or not screening really works, screening tests that identify presymptomatic disease will always improve 5-year survival even if treatment is completely ineffective.
While there is good evidence that CT screening can detect lung cancers before they become symptomatic, there are no data demonstrating improved outcomes. While it seems intuitive that early detection must improve outcomes, this intuition was wrong for lung cancer screening using chest radiographs. Lower mortality rates from a randomized trial—not improved 5-year survival—would constitute proof of the benefit of screening.

The advertisement also misleads consumers by failing to mention 2 potentially harmful consequences of testing: the risks associated with further diagnostic testing, and overdiagnosis. Some people undergoing CT screening have suspicious lesions detected that are not cancer (ie, false positives). In general, cancer is ruled out through a biopsy, which carries significant risks in itself. Patients requiring thorascopy or open lung biopsy need general anesthesia and often require chest tubes. These procedures can be complicated on rare occasions by serious infection or death. A second way that screening can result in harm is through overdiagnosis, which is the detection of lung cancers (sometimes called pseudodisease) that either would not have progressed or would have progressed so slowly that the patient would have died of other causes before ever experiencing symptoms. Treatment of pseudodisease is unnecessary and can only cause harm. Pseudodisease can only be found by screening, and there is no way to know which lesions represent pseudodisease during a patient’s lifetime. Given the current state of knowledge about screening for lung cancer, there is no way to know how many patients who are screened will be injured by unnecessary treatment.

How Well Does Treatment Work?

A frequently published direct-to-consumer advertisement states: “42% fewer deaths from heart attack among those taking ZOCOR.”

This advertisement is a good example of the kind of the numbers readers are likely to see. The 42% reduction in heart attack deaths sounds impressive. But the key question to ask is “42% fewer than what?” Without knowing what number is being lowered by 42%, it is impossible to know the absolute magnitude of the change.

This information is provided in small print at the bottom of the advertisement: “42% reduction based on 111/2221 (ZOCOR) vs. 189/2223 (placebo).” Therefore, ZOCOR lowered the risk of heart attack death in the next 5 years from 8.5% (placebo) to 5% (ZOCOR)—a 42% relative risk reduction (1 - 5%/8.5%) and a 3.5% absolute risk reduction (8.5% - 5%). The impressive figure—42%—reflects the difference between 8.5% and 5%. To understand how well a treatment works, a comparison should be made between the risk of an outcome for people who do not receive treatment (ie, the base rate) with the risk for those who do.

Box. What to Look for in Messages That Market Medicine

How many people get or die from disease?

Denominator (calculate the chance of the outcome in the target population)

Time frame (learn over what period of time the risk refers to)

Context (compare how this chance compares to the chance of other events)

What is the benefit of early detection?

Evidence for delayed death—not just earlier diagnosis (lower mortality rates from randomized trials—not improved 5-year survival for cancers detected by screening—constitute proof of the benefit of screening)

Potential harms (false-positive test results and the follow-up testing needed, and the detection of pseudodisease)

How well does treatment work?

Absolute event rates with and without treatment (be aware of reports that present a relative risk reduction without the base rate)

Outcomes that matter to patients (eg, reduced mortality rather than reduced cholesterol)

One way to increase demand for medical services is to promote exaggerated beliefs about disease risk and intervention benefit. A few simple questions may help readers critically evaluate such claims (Box).

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PHYSICIANS AND SCIENTISTS HAVE CRITICIZED JOURNALISTS FOR misleading the public about important medical issues. For example, a 1997 survey of scientists found that the majority of them believed that reporters do not understand statistics well enough to explain new scientific findings, do not understand the nature of science and technology, and are more interested in sensationalism than in scientific truth. These concerns may have been bolstered by misleading reports in the popular press. For instance, sensationalized reports on the hazards of calcium channel blockers may have led some patients to stop taking their prescribed antihypertensive medications, while optimistic coverage of rodent experiments in the field of antiangiogenesis resulted in patients with cancer requesting this unproven treatment from their oncolgists.

Although the reporters failed in these cases to accurately explain scientific information, not medic reports are as careless. Responsible reporting by journalists can illuminate important issues for the general public that might have otherwise remained obscured in the scientific arena. In some cases, investigative reporters have exposed aspects of medicine and medical science that prompted legislative and policy changes in the health care system.

For example, a New York Times probe of fraudulent practices at the Columbia/HCA Healthcare Corp chain of hospitals in March 1997 led to a federal criminal investigation of the company. A Los Angeles Times series on the US Food and Drug Administration’s system of drug approval in 2000 strengthened the claims of those advocating tighter controls at the agency. Extensive coverage by the Washington Post and others of the death of a young patient in a university-based gene therapy experiment resulted in stronger federal protections for patients enrolled in clinical trials. A Boston Globe series on the hazards of placebo-controlled trials in psychiatry was one of several journalistic investigations that resulted in changes in the way psychiatric patients are enrolled in research protocols.

Investigative reporters often rely heavily on anonymous sources who might jeopardize their careers for leaking damning information. These “whistleblowers” also risk being sued once they trust a journalist with sensitive information about their organizations. Journalists can risk exposing their confidential sources when they attempt to substantiate claims by speaking with people who oppose or disagree with the whistleblower. Reporters tread a fine line as they attempt to corroborate information from a whistleblower and try to unearth various aspects of complex issues without exposing their sources. Depending on the situation, reporters can go to great lengths to protect their sources, while others may aggressively pursue stories, even if their sources would prefer not to have their comments exposed. For example, Ralph T. King, a former biotechnology reporter for the Wall Street Journal, interviewed a pharmacist who had been pressured by a drug company not to publish her findings about one of the company’s products. She feared legal action against her if she were quoted in a newspaper. In his lengthy page—one story, King described in detail what the company had done and barely quoted the pharmacist to protect her identity.

On the other hand, reporters are not obligated to grant sources the right to not be quoted on public record, especially if these sources say things to a reporter without first clarifying that what they say will be considered “off the record.” An episode of the news magazine 60 Minutes provides a recent example of a reporter who broadcasted comments made by a source, who subsequently claimed that what he said should have been off the record in the show. In this episode, the executive of a Canadian drug company made derogatory comments about a scientist during the interview with CBS reporter Lesley Stahl. To the apparent surprise of the executive, Stahl asked him about it on the air. He replied, “I said to you I’ll say certain things to you off the record. I might well say things in a private conversation off the record . . .” “We’re reporters, we’re not your pals,” Stahl responded.

Reporters and those in the health care industry may never be “pals.” However, the mass media play an important role by engaging in public service journalism that uncovers problems in medicine and medical science.

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