A medical early warning system

Jerome P. Kassirer

Recent threats to the health of the public from virulent micro-organisms have illustrated blatantly how inept we are at getting critical medical information into the hands of the physicians who need it. In the days and weeks following the first case of anthrax infection in the United States that occurred after the events of September 11, 2001, newspapers and cable news networks were far more helpful than any coordinated medical information network in informing physicians about the characteristics of the organisms, the clinical manifestations of the infections, and preventive and therapeutic approaches. Our old reliance on articles published on paper weeks to months after acceptance by biomedical journals, on word of mouth and on mail alerts from government agencies no longer suffices ever since bioterrorism, formerly a taboo subject, became a reality, and when epidemics of deadly, highly communicable, difficult-to-treat diseases such as Ebola virus threaten to spread. Even before these threats, the occurrence of drug-resistant infections in various locales in the world never captured enough attention, in part because of the lack of an effective communication system.

Until recently, no simple method of disseminating information critical to the health of the public existed, but now it does: a combination of email, “push technology” and the World Wide Web assures at least the capability to deliver the news to those who may need it and to capture epidemiologic data from those who collect it. Unfortunately, we are nowhere near to implementing such an early warning system. There are 2 serious obstacles. On the information-sending side, the responsibility for coordinating the data and deciding what should be broadcasted is not vested in a single federal or international agency. On the information-receiving end, a great many physicians are still ill-equipped to receive relevant data even though most doctors in developed countries have computers in their offices or homes. We have effective early warning systems for climate change, problems with food production and aerial attacks, and a developing international effort in infectious diseases. Even though the concept of multiple networks of computers for the dissemination of information vital to global public health was suggested several years ago, there has been little progress toward this goal. Perhaps recent revelations about shared risks will spark this effort.

Where do journals fit into an early warning system for diseases? Journal editors are often among the first to identify potentially dangerous trends and are in a unique position to speed up the process of peer review and publication of material that they perceive to be essential to protect the public. In this issue (page 1137), William Ghali and colleagues report how they examined papers published in the New England Journal of Medicine and in The Lancet that received accelerated review and publication (so-called “fast-tracking”) and compared these with somewhat similar papers in the same journals that were not fast-tracked. Taking the acknowledged limitations in study design and a minimal sample size into account, few substantial differences in the urgency or public health importance of the papers were apparent. The authors thus criticize editors of 2 of the top general medical journals for making several inappropriate judgements when selecting papers for prepublication dissemination or accelerated publication. Joining the chorus of researchers who study medical journals’ practices, they call for more standardization among journals, in this case for selecting papers for the “fast track.”

In my view, making such selections has been, and should continue to be, a judgement call. The experience with the first early warning medical study posted on the World Wide Web aptly illustrates this point. In the summer of 1997, we received a report at the New England Journal of Medicine of an unusual valvular disease in patients taking the diet drugs fenfluramine and phenteramine (fen-phen), but it consisted of case studies of only 24 patients. There were no controls, not even case controls. Despite this limitation, we thought that the cases certainly were worth publishing. We rushed the manuscript through editing and, with our permission, the authors at the Mayo Clinic, Rochester, Minn., called a press conference and simultaneously posted the paper on their Web site (ours, then only one year old, was not adapted yet for such transmission). Why the rush, given that the evidence that causally linked fen-phen to valvular disease was so tentative? Simply because at that time the drugs were being taken by millions of people around the world. Fen-phen clinics were sprouting up, and ads for the pills were appearing every day in newspapers, magazines and on telephone poles. Waiting another 9 weeks until the journal was published on paper to announce this drug complication, we thought, would expose fen-phen users to excessive risk. We were quickly criticized. The data weren’t sufficiently convincing for such action. We were scaring the public. We were grandstanding to gain publicity.
ingly, the US Food and Drug Administration removed fenfluramine from the market shortly thereafter. During my tenure as editor, other decisions to publish papers on the New England Journal of Medicine’s Web site involved similar judgements whereby I had to weigh the quality and importance of the data against the risk to the public in waiting for the presses to finish their work.

Let’s not kid ourselves: guidelines and standards are no substitute for good judgement. Standardization is fine for most consumer products, but the trend over the past decade by many journal editors to conform to sets of rules undermines the uniqueness and the personalities that have distinguished some of our best medical journals. Too much standardization could produce a homogenized product, with all journals in danger of regressing toward a mediocre mean. Moreover, in some instances, newly proposed standards are substantially inferior to time-tested ones, as they permit editors to have financial conflicts of interest and to disqualify themselves from decisions in which they have such an interest.10 Because sentiment in small, close editorial staffs tends to favour each other’s best interests, I believe that objectivity can be compromised by allowing any editor to have a financial interest in an industry whose products are described in submitted manuscripts. For this reason, I believe that editors of journals should have no financial conflicts of interest. Parenthetically, I permitted none during my tenure at the New England Journal of Medicine.

With a few exceptions, journals continue to zealously guard their contents until they appear on paper. It does not have to be that way. Most journals now have Web sites and, in principle, could publish their material electronically as soon as the manuscripts are accepted for publication and edited. Most do not do this, of course, because journal owners fear that some readers will drop their subscriptions and read only online, or that many will skip the paper version and thus ignore the money-making ads that cover the publishers’ costs and contribute to their profits. Because most journals do not offer the full text of their material online even months after publication on paper, any researcher who is trying to get access to critical material is hamstrung.11 MEDLINE allows access to titles, and sometimes to abstracts, but unless a writer has subscriptions to multiple journals that permit online searching of their archives, there is no alternative to copying down titles and trundling off to a library to look up each article.11 How primitive in the Information Age!

Threats of lethal diseases and bioterrorism force us to consider new ways to alert and inform physicians and public health officials about how to protect individuals and populations. At present, medical information remains a commodity hoarded by a relatively small number of publishers, yet in fact it is a public good, paid for largely by the public. Now that we have the tools to disseminate late-breaking, critically important medical information, we need to explore not only how we can get such information to the point of need far more rapidly and efficiently, but also how we can convince publishers to act in the common good by including their closely guarded content in such an electronic network.

It is time to stop relying on the media for medical messages.

Dr. Kassirer is Professor Adjunct of Medicine, Yale University School of Medicine, New Haven, Conn.

Competing interests: None declared.

References


Correspondence to: Dr. Jerome Kassirer, 21 Squirrel Rd., Wellesley MA 02481, USA; fax 781 237-8189; JPKassirer@aol.com