

Editorial

Epidemiological Abuse

The last quarter of the twentieth century can be described aptly as the "age of epidemiology" in American medicine. It is impossible to watch television or read newspapers, magazines, and journals without being confronted daily with epidemiological information, assertions, and warnings. I include as epidemiological anything that deals with the health of populations and the sciences, especially statistics, that undergird such interests.

One of the paradoxes of modern medicine is that we in America are living longer and healthier lives at the same time we are goaded incessantly to change our lives in order to avoid disease, disability, and untimely death. We seem to derive little comfort from the good news because of the bad. An issue of *Daedalus* in 1977 captured this nuance in its cover title, "Doing Better and Feeling Worse."¹

It is hard, even for conscientious and well-informed persons, to keep a balanced perspective on the magnitude of health risks and potential benefits from following the best advice, especially when the information is compressed into sound bites for television or written by journalists to grab the attention of casual or disinterested readers. Much health information for the public seems calculated to alarm many in order to benefit few; it is presented in the form of advertising hype, excessive simplification, and overkill. It can be terrorizing to hear, for instance, that one can catch AIDS innocently from one's dentist or surgeon in the normal, prudent performance of a technical procedure, even though the likelihood of such an occurrence must be a great deal less than being struck by lightning. (It would subvert my argument to cite statistics to prove the point.)

Family Physicians and Epidemiology

The burden of digesting and responding to epidemiological data falls heavily upon family physicians. We are chided for not screening patients appropriately, missing the diagnosis of common illnesses (especially depression), overlooking rare diseases, and neglecting timely referral of our pa-

tients to other experts. We are urged to discover what our patients do not or cannot choose to tell us — what they deny or acknowledge reluctantly. We are expected to offer anticipatory guidance and patient education, to act the sleuth for hidden morbidity within families, and to assume responsibility for the health of communities in which we practice. I wonder when we will notice that research surveys and questionnaires about our practices are often stacked against us, depending for accuracy upon the caprices of recall and post hoc record reviews. We fill them out obligingly and naively, not having a clear idea of the uses that our answers will serve.

We are told that our patients want and expect more preventive care from us and that we are liable to be sued for failure to diagnose and warn; yet we are constrained to provide only "medically necessary" services by payors who demand one-to-one correlations of ICD and CPT codes and laboratory tests. Moreover, we must deal with insurance plans that severely limit or specifically exclude periodic health examinations, mental health services, treatment of obesity, cosmetic problems, and pre-existing conditions. We are expected, it seems, to bootleg preventive care onto acute care, to perform breast and pelvic examinations on patients who come in for other reasons, to arrange mammography or flexible sigmoidoscopy for patients who visit for monitoring treatment of hypertension or diabetes.

Our critics, some of whom disvalue or misunderstand our work and see no need to expand our training programs, seem oblivious to the fact that, at best, there are only 60,000 of us and even if our practices were models of prevention, we could not serve the entire population.

How should family physicians respond to the contemporary plethora of epidemiological data, recommendations, and warnings? The following examples were gleaned from readily available sources and are not in any way atypical from what crosses our desks in any month. They were chosen to represent a broad sample of topics, wide range of frequencies, and variety of styles of

data presentation and description. I could easily have selected scores of similar examples from the same sources.

Examples of Epidemiological Statements

1. "In 1985, 2,086,000 deaths from all causes occurred in the U.S."^{2 p 6}
2. "Excluding nonmelanoma skin cancer and carcinoma in situ, cancer of the breast accounted for 28 percent of estimated cancer incidence in women in 1989."^{2 p 3}
3. ". . . approximately 11.2 percent of Americans aged 20 to 74 years have IGT [impaired glucose tolerance] compared with 6.6 percent with diabetes."³
4. ". . . one of every 100 of us is schizophrenic, two more are schizoid, eight are phobic, seven are addicted, six are depressed, perhaps five are criminal. Perhaps another five are destructively irrational at any given moment. . . . Add them up. . . . When you are done you have a number, depending on your personal inclination and prejudice, that at any given moment encompasses up to a third of the population."⁴
5. ". . . including patients who have died, the total U.S. HIV prevalence lies between 650,000 and 1.5 million and . . . by 1993 from 390,000 to 480,000 cases of AIDS will have occurred."⁵
6. ". . . as many as one of every four girls in North America may be sexually victimized before she reaches adulthood, [and] recent studies note close to half of all women who have received help in clinical settings were sexually victimized as children" (data from a manuscript submitted to *JABFP*).
7. "It is estimated that cancer of the stomach caused 13,900 deaths in the U.S. in 1989."^{2 p 13}
8. In re dietary beta-carotene and lung cancer risk in Hawaii: "After adjusting for smoking and other covariates, the men in the lowest quartile of beta-carotene intake had an odds ratio of 1.9 (95 percent confidence interval, 1.1 to 3.2) compared with those in the highest quartile of intake."⁶
9. In re eosinophilic-myalgia syndrome and L-tryptophan: "As medical students, we were told that we should always look for common diseases — that when we hear hoofbeats, we

should not think of zebras. Yet we must be able to recognize a 'zebra'"⁷

10. "An analysis of 115 cases of acute rheumatic fever presenting over two decades (1969-1988) at a New York City hospital suggests that this disease is still a cause for concern. . . . About 10 percent of cases were recurrences of previously diagnosed acute rheumatic fever, suggesting inadequate use of throat cultures for group A beta-hemolytic streptococci or inadequate antibiotic prophylaxis."⁸
11. "All clinicians involved in the care of young, sexually active adults should consider the potential for chlamydial infection in both men and women patients, including those who have no signs or symptoms."⁹

The Nature of Epidemiological Data

It is beyond my intent, and probably my capacity, to critique these items individually. Let us assume that the studies were designed and carried out perfectly by experienced and statistically sophisticated investigators, and that the data are true in the sense of being correct, valid, and reliable. What should I do as a consequence of receiving such information? Should I modify my practice immediately in some way to incorporate these data? Should I file them for reference, awaiting more information and authoritative recommendations from official committees, study groups, and health departments? Should I simply be content with increasing my awareness of what is being studied and written about now? Should I ignore them until something happens to one of my patients that increases the relevance of the data?

The first thing that strikes me is that the information is not all of the same quality and importance. Some of the data appear harder than others, but this distinction is not as helpful as I wish it were. None seems as hard and important as Pasteur's experiments that demolished the theory of spontaneous putrefaction or Banting and Best's demonstration that properly prepared pancreatic extracts dramatically lowered blood glucose in pancreatectomized dogs.

There seems to be a difference in kind of hardness between good epidemiological studies and good laboratory experiments, even when

the former meet the strictest requirements for avoiding bias and the results are unquestionably significant. Banting and Best used about 50 dogs whose pedigrees and demographic characteristics were not specified, and it was unnecessary to repeat their experiment using a standard sample of dogs, controlled, placeboed, and double-blinded. Their results were self-authenticating and convincing in a way that epidemiological studies are not. Their genius was less in research design and mathematical permutations than in discovering the proper way to prepare pancreatic extracts by first tying off the pancreatic ducts.

I am not suggesting that all research must meet Nobel prize-winning standards, but I am confessing that I often feel a measure of skepticism and doubt about epidemiological studies, even when they originate in the CDC. Sophisticated data derived from 2×2 tables do not seem entirely trustworthy or compelling.

Perhaps this is because, in part, epidemiological reporters have so many different ways of presenting data, and the rules for choosing one way over another seem arbitrary. Raw data rarely stand on their own and need to be massaged statistically in varying degrees of complexity before inferences can be drawn. I have noticed a tendency to describe conclusions for their most dramatic effect on readers and hearers. It is quite impressive to learn that X was found three times more frequently in subjects than in controls – it lends itself strikingly to histograms – but the effect is muted when I learn that the raw numbers were 2 and 6 in a study sample of 200. I begin to wonder whether my judgment is being manipulated a bit, not fraudulently, of course, but manipulated all the same. Massaged data seem to have an irresistible vulnerability to become propaganda, i.e., truth used for the purpose of persuasion or action when the motives are not revealed.

Examples 4 and 10 illustrate this point. In 4, I have no reason to doubt the correctness of the individual items of prevalence of mental disorders; they are in the ball park of others' estimates. But when I am invited to add them together and conclude that a third of the population qualifies for a mental disorder, my common sense balks. Is the author asking me to believe that the disorders are mutually exclusive? I doubt that he believes that, but he is so intent on persuading me

of the importance and frequency of mental disorders that he lapses into hyperbole and error. There is nothing necessarily wrong with his intent, but his rhetorical extravagance challenges by credulity.

Example 10, about acute rheumatic fever in New York City, wants to convince me that the disease is making a comeback, probably also in Alabama, and that I should follow official guidelines better in using throat cultures and antibiotic prophylaxis. I do not mind being reminded, but the author's liberty in generalizing one hospital's experience undermines my confidence. Perhaps his recommendations apply only to large cities with poor, overcrowded populations.

I have trouble with both big and little numbers in applying them to my practice. I can't comprehend 2,086,000 deaths (example 1). I do not know whether that number is too big or about right for the U.S. population. Should I be amazed or alarmed? If all deaths occurred when patients are under a physician's care, and are evenly distributed, my share should be 3.3 per year; but none of my patients have died in the last year (that I know of), so I am in a quandary. Am I doing better than the average physician in preventing deaths, or is my practice temporarily quirky, and should I not feel bad if next year 6.6 patients die?

Small numbers give me the same problem (examples 7 and 9). I might practice 40 years without having a patient die of cancer of the stomach. As a matter of fact, it's been about 15 years, so I am already over my quota. Should I begin to request more EGDs and biopsies on patients with any sort of upper abdominal symptoms? And what about eosinophilic-myalgia syndrome from L-tryptophan? Need I add this zebra to my list of orphan diseases, which I have already been chided in the public press for overlooking? The author clearly thinks I should.

Information and News

The late Walker Percy made a distinction between information and news in his book, *The Message in the Bottle*.¹⁰ He imagined a person shipwrecked on a strange island who went to the beach daily to collect messages that washed ashore in bottles. Some of the messages were true but irrelevant to his condition of being shipwrecked, such as, "The melting point of lead is 621.5°F." Others were false

like, "Chicago is on the Hudson River," while yet others were extremely relevant and needed confirmation, e.g., "There is fresh water in the interior of the island," or "A hostile party is coming from a neighboring island."

I can sympathize with this parable. I have to separate news from information in the hundreds of articles that come to my attention each year. All appear authoritative, dressed in the garb of science, especially epidemiological science, and they demand something from me. They seem important because peer reviewers and editors have found them worthy of publication, but I cannot respond actively to each one. I have to select those that seem both true and relevant (news) and react passively to the ones that do not affect my practice directly (information).

My processes of selection are neither arbitrary nor neutral in their consequences. Epidemiological data, when they have reached the status of consensus, tend to become coercive. There has always been a connection between preventive medicine and the law, but now there are more subtle sanctions, such as peer-review, quality assurance, liability, lost compensation, and even civil penalties for those who do not conform to current norms of practice.

Family physicians take a beating from epidemiologists, many in our own ranks, for not following guidelines for preventive medicine, early diagnosis, and appropriate referral. The assumption seems to be that we lack knowledge or interest and that these lacks can be remedied through education and sanctions. The truth is that there are many reasons, some complex and systematic, for not diagnosing depression, substance abuse, and child abuse (for instance) in large numbers of our patients.

One of the reasons is that preventive medicine is not the same as family practice. Family physicians do not see their patients in battalions, but one at a time. We have different agendas and relationships, and while we share some forms of scientific knowledge, family physicians also deal heavily in personal knowledge (news) as well as information. Preventive medicine has not yet bridged the gap between the group and the individual. Nobody knows whether everyone should follow the same diet, avoid the same habits, and have the same schedule of diagnostic tests. We recommend applying statistical information universally because we do not know the particular risks of an individual.

But even if we had perfect medical knowledge of individuals at birth, and could prescribe a lifetime schedule of proper medical care, that would not exhaust our possibilities for services to our patients, many of whose problems arise out of their pathogenicity for themselves, the predatory nature of human relationships, and the antipathy of politics and economics to authentic and autonomous human well-being and health.

Conclusion

This editorial is no brief for turning back the clock of progress, but it is a protest against what I believe is a coming era of unprecedented medical control over both physicians and patients, fueled by what experts say is good for them. If medical experts really know that, they must be the first among all experts who can see the end from the beginning — and be responsible for that.

I intend to continue to read epidemiological articles — how can I avoid it if I read journals at all, including this one? — but I do not intend to become knee-jerk compliant to every significant value of *P* or to feel guilty about it! I have always believed that there is a measure of wisdom and perhaps safety in the public's noncompliance with all expert medical advice, such as not getting all prescriptions filled or taking all medications as prescribed. Total compliance might have worse consequences than half compliance.

Moreover, I do not intend to be abused by epidemiological data, most of which need to be taken with at least one grain of salt and often come after the fact. One of my esteemed friends says that for a difference to be a difference, it should make a difference. As yuppies are fond of saying, "I can live with that."

G. Gayle Stephens, M.D.
Birmingham, AL

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