

SPECIAL COMMENTARY

ON THE EPIDEMIOLOGY OF 'MYSTERIOUS' PHENOMENA

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In the field of epidemiology, research topics are favored or dismissed depending on whether respective variables under investigation are believed to exist according to current scientific theories. Unconventional independent variables or exposures, such as religiousness and spirituality, and controversial dependent variables or outcomes, such as chronic fatigue syndrome, may be considered unacceptable topics for researchers because they do not fit comfortably into the consensus clinical perspectives of mainstream medical scientists or physicians. Disapproval of research in these and other taboo areas is generally masked by claims that such studies are "pseudoscientific," despite hundreds or thousands of peer-reviewed publications on these topics. In reality, seemingly "mysterious" variables are equally as amenable to epidemiologic research as any other exposure or disease. Similarly, alternative therapies are able to be investigated using existing methods, despite claims to the contrary. Such research is vital for scientific understanding to be expanded into new areas of inquiry. (Altern Ther Health Med. 2001;7(1):64-66)

On one occasion a neighbor found [Mulla Nasrudin] down on his knees looking for something.

"What have you lost, Mulla?"

"My key," said Nasrudin.

After a few minutes of searching, the other man said, "Where did you drop it?"

"At home."

"Then why, for heaven's sake, are you looking here?"

"There is more light here."

—Idries Shah, The Sufis¹

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Research on the efficacy of alternative medical therapies is only one example of a broader category of studies involving phenomena that are not generally accepted or included in mainstream biomedical science. Pushing the envelope, investigating areas in which other scientists have dared not tread, has been an important part of the scientific enterprise since its inception and is pursued today by medical researchers with diverse interests in diverse fields. The field of epidemiology is particularly well suited to this task, because it involves the use of methods that can easily be executed and replicated in the face of conflicting worldviews and opinions about what constitutes an acceptable medical paradigm.

The science of epidemiology is defined as the study of the distribution and determinants of health, illness, and death in human populations; it has 2 main approaches. Descriptive epidemiology is about the first half of this definition: describing the distribution of particular health outcomes by characteristics of person, place, or time, such as how certain types of cancer incidence seem to vary by gender and geographical region and from year to year. Analytic epidemiology addresses the second half of the definition: analyzing the impact of particular exposures, or antecedent factors, on particular outcomes, such as how tobacco smoking seems to be associated with coronary heart disease mortality or how residing near a toxic waste site seems to be associated with the incidence of cancer. Analytic epidemiologic investigations, then, whether involving population or clinical research, are generally designed to identify the relationship between an "X" (ie, an independent variable, such as an exposure or therapeutic intervention) and a "Y" (ie, a dependent variable, such as a health status outcome or rate of disease).²

As with any scientific field, epidemiology has intellectual and ideological boundaries. Certain factors or exposures are considered to be "good"—they are deemed worthy of study and scientists who study them are professionally rewarded. Other factors are "bad"—they are deemed unworthy of study and scientists who pursue them may be marginalized and their research ignored, derided, or dismissed as irrelevant. What constitutes a good or bad topic of inquiry is typically more a matter of worldview than of scientific merit. For those who conduct analytic epidemiologic studies, the good X factors are well known: heredity, the physical environment (some of it, anyway), and physiological and biological processes. Other more psychosocial factors

once considered bad are now becoming good: the social environment, interpersonal relations, health-related behaviors, emotional states, and personality traits. Still, other factors are generally considered so thoroughly unacceptable that even to propose studying them is to invite derision.

In epidemiology, as in other branches of science, powerful forces of social control discourage and disparage the investigation of particular topics. Tenure and promotion committees, funding sources, federal and international agencies, peer-reviewed journals, and professional colleagues have a stake in reinforcing existing definitions of a professional domain, which maintains its boundaries in support of the dominant paradigm. Naturally, this serves to stifle scientific innovation and other unpredictable (and thus uncontrollable) developments. Forbidden topics for epidemiologists include not only certain factors or exposures deemed irrelevant to health and well-being, but also certain health outcomes deemed to be nonexistent. Just as clinical researchers seeking to investigate the efficacy of alternative medical therapies often face numerous barriers, epidemiologists seeking to investigate forbidden X's or Y's may face professional marginalization. And yet, just as the field of alternative medicine has flourished despite these barriers, a growing interest exists in epidemiologic research in areas previously thought to be unworthy of scientific study.

In contemporary epidemiology, controversial X's and Y's are not difficult to find. If anything, they are proliferating. The ultimate in forbidden X's for contemporary epidemiology—it has even been termed the "anti-tenure factor"³—has been the domain of religion and spirituality. Among forbidden Y's, most prominent are a number of unexplained multisymptom syndromes sometimes referred to as "mystery illnesses," such as chronic fatigue syndrome and multiple chemical sensitivity.

Objections to the study of unorthodox X's such as religion and unconventional Y's such as chronic fatigue syndrome are well documented^{4,5}; such objections are not based on any empirical reality. More than 1600 published studies and reviews have explored a connection between religious and spiritual involvement and a multitude of health- and quality-of-life-related outcomes.⁶ This connection has been recognized in scientific publications ranging from *Alternative Therapies in Health and Medicine*⁷ to the *Journal of the American Medical Association*.⁸ Likewise, nearly 3000 published studies and reviews of diverse populations on 6 continents have investigated symptoms or correlates of chronic fatigue syndrome and related conditions.⁹ These studies include recent epidemiologic investigations based on large population samples and published in first-rate peer-reviewed journals such as *Archives of Internal Medicine*¹⁰ and *American Journal of Medicine*.¹¹ One conclusion is inescapable: opposition to the study of certain X's and Y's is not based on empirical evidence; rather, as with the often virulent opposition to research on certain alternative therapies, objections to advancing epidemiologic knowledge of certain seemingly mysterious phenomena are based primarily on ideology—perhaps the result of some nonspecific fear that simply investigating a forbidden factor could bring it an air of legitimacy.

This ideological objection manifests principally in disputes

over what a respective exposure variable or health-outcome variable "is." Investigators into the epidemiology of more "respectable" variables who disparage the study of mysterious X's or Y's do so by making "is"-based assertions: "There's no such thing as chronic fatigue syndrome. It's just a term used to lend medical credence to the symptomatic manifestations of depression or hypochondriasis." "People who believe in God or religion are just fantasy-prone or disturbed. That stuff isn't real." Such statements are put forth, regularly, as rationale for quashing or ignoring research on these topics. Resolving these sorts of epistemological issues is not something that epidemiology—or medical science in general—is capable of addressing. Yet such issues are also completely irrelevant for epidemiologic research.

By focusing on observable or otherwise measurable phenomena, epidemiologic research methods are entirely capable of documenting the distribution and determinants of mysterious phenomena, irrespective of whether some ideologues believe they are "real" or "good." For most working epidemiologists, observables include biological characteristics of people, environments, and disease agents; for medical epidemiologists and clinical scientists, they also include signs and symptoms; and for social and behavioral epidemiologists, they also include behaviors, attitudes, beliefs, psychological states and traits, and social-structural characteristics. Each of these categories includes reliably and validly measurable phenomena. These measurable phenomena in turn include the most forbidden X's and Y's, as witnessed by the scores of validated religious and spiritual measurement instruments¹² and the development of a case definition for chronic fatigue syndrome by the Centers for Disease Control and Prevention.¹³

Ideologues may not "approve" of these developments, but apparently fewer scientists are listening to them. According to the recent report of an expert panel convened by the National Institutes of Health, "[t]he unorthodoxy of a construct, conceptually speaking, is not a particular barrier to its psychometric validation and use in subsequent analyses."^{14(p 1089)} In epidemiology, as in alternative medicine, these words are beginning to be taken to heart.

For epidemiologists, documenting the distribution or determinants of mysterious phenomena is no more or less tractable than doing the same for currently acceptable phenomena. This maxim bears underscoring, especially in light of the tendency of professional debunkers to dismiss ideologically or politically out-of-favor research with terms such as "pseudoscientific." A few brief points summarize the status of mysterious phenomena for epidemiologic research:

1. If patients, research subjects, or members of a community sample report a phenomenon or experience, then it can be studied epidemiologically.
2. Self-reports, clinical diagnoses, symptoms, and signs are equally amenable to epidemiologic study. Self-reports are reliable and valid markers of health and illness, and symptoms are as quantifiable as signs.
3. Political or ideological disfavor is of no relevance to the capability of a variable to be studied epidemiologically.

4. Investigation of mysterious X's and Y's, by definition, is the best way to advance epidemiologic knowledge. Impeding such investigation by interfering with the study of potentially modifiable risk factors and preventable diseases may extract a cost in human lives.

5. The epidemiology of mysterious phenomena points to the future of health-related research, much as therapies currently defined as "alternative" are useful markers of the future of clinical practice.

As the field of complementary and alternative medicine continues to grow, efforts will be made by powerful forces to co-opt the field and reign it in. These efforts will be made by governmental, academic, and corporate entities with a financial stake in maintaining the status quo, or, if this becomes impossible, in regulating, managing, and controlling change. A principal means of achieving this change will be through the sanctioning of certain avenues of research and the labeling of other avenues as explicitly or implicitly "out of bounds." This trend can already be seen in the not-so-subtle shift in funding priorities of the National Institutes of Health for alternative medicine from the exciting, cutting-edge basic science and clinical material included in the Chantilly Report¹⁵ to the medical-model-safe clinical trials supported by the new regime at the National Center for Complementary and Alternative Medicine.

Although political and ideological motives typically underlie and drive these sorts of developments, they are often supported by appeals made to the need for "good science." Good science (ie, sound scientific methodology and execution) should actually be the central criterion by which all scientific investigations are evaluated. But, as defined by the mainstream, good science often excludes—by definition—investigations that go too far in challenging or overthrowing conventional thinking. Mysterious phenomena must remain mysterious phenomena, lest they become understood and potentially reshuffle people's conceptions of medical reality. This is never stated outright; rather, it is implied that such "good" studies are good because they alone are conducted according to the highest standards of scientific methodology. When well-executed studies of disfavored research topics are derided as "bad" on the grounds of methodological inferiority, what is really meant is that the study of certain phenomena is beyond the pale.

Mysterious phenomena are not beyond the pale. Investigation of once mysterious X's and Y's, by epidemiologists or any other type of medical scientist, is precisely how advances are made in public health and medicine. This has been true throughout the history of medicine and science, and it is just as true today. Epidemiologists investigating such forbidden factors as religiousness and such taboo outcomes as chronic fatigue syndrome are squarely in the mainstream of the epidemiologic research tradition, whether the mainstream wishes to acknowledge it or not. Judging from the increased research interest in the epidemiology of other mysterious X's (eg, hope, love, forgiveness) and Y's (eg, Gulf War illness, fibromyalgia, multiple chemical sensitivity), more scientists are ignoring the pull of conformity and are pushing forward, the mainstream be damned.

Research into uncharted scientific territory is an honorable—if not always honored—tradition in scientific research. Barriers to these efforts are often rooted in the ever-present tendency to protect and preserve the status quo by discouraging areas of inquiry that threaten what appear to constitute medical and scientific axiomatic principles. Yet truly new insights can only come from looking where we have not looked before, down paths that are not already well lit.

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