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Perspective

200TH ANNIVERSARY ARTICLE

The Burden of Disease and the Changing Task of Medicine

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Article

Figures/Media

Metrics

6 References

130 Citing Articles

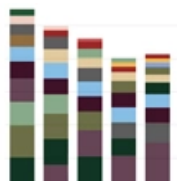
3 Comments

Introduction



AT FIRST glance, the inaugural 1812 issue of the *New England Journal of Medicine and Surgery, and the Collateral Branches of Science* seems reassuringly familiar: a review of

Interactive Graphic



Top 10 Causes of Death in the United States, 1900–2010.

angina pectoris, articles on infant diarrhea and burns. The apparent similarity to today's *Journal*, however, obscures a fundamental discontinuity (1812a, b, c; see *Historical Journal Articles Cited*). Disease has changed since 1812. People have different diseases, doctors hold different ideas about those diseases, and diseases carry different meanings in society. To understand the material and conceptual transformations of disease over the past 200 years, one must explore the incontrovertibly social nature of disease.

Disease is always generated, experienced, defined, and ameliorated within a social world. Patients need notions of disease that explicate their suffering. Doctors need theories of etiology and pathophysiology that account for the burden of disease and inform therapeutic practice. Policymakers need realistic understandings of determinants of disease and medicine's impact in order to design systems that foster health. The history of disease offers crucial insights into the intersections of these interests and the ways they can inform medical practice and health policy.

Epidemiologic Transitions



The DEATHS preceding were caused by Diseases and Casualties as follows, viz.

Abscesses	-	-	1	Hernia, or Rupture	-	3
Aneurism	-	-	1	Jaundice	-	10
Apoplexy	-	-	13	Inflammation of the bowels	-	1
Burns or Scalds	-	-	6	_____ of the stomach	-	1
Cancer	-	-	5	Killed by lightning	-	1
Casualties	-	-	15	Insanity	-	1
Childbed	-	-	14	Intemperance	-	2
Cholera Morbus	-	-	6	Lockjaw	-	2
Colic	-	-	2	Mortification	-	11
Consumption	-	-	221	Old Age	-	26
Convulsions	-	-	36	Palsy	-	12
Cramp in the stomach	-	-	2	Pleurisy	-	8
Croup	-	-	1	Quinsy	-	15
Debility	-	-	28	Rheumatism	-	1
Decay	-	-	20	Rupture of blood vessels	-	1
Diarrhea	-	-	15	Small-Pox, (at Rainsford's Island)	-	2
Drinking cold water	-	-	2	Sore throat	-	1
Dropsy	-	-	21	Spasms	-	2
_____ in the head	-	-	23	Stillborn	-	49
Drowned	-	-	13	Suicide	-	1
Dysentery	-	-	14	Sudden death	-	25
Diarrhea or Indigestion	-	-	15	Syphilis	-	12
Fever, bilious	-	-	7	Teething	-	15
_____ pulmonic	-	-	46	Worms	-	11
_____ inflammatory	-	-	24	Whooping Cough	-	14
_____ putrid	-	-	6	White swelling	-	2
_____ typhus	-	-	33	Diseases not mentioned	-	48
Flux infantile	-	-	37			
Gout	-	-	3			
Hæmorrhage	-	-	4			
				Total,		942

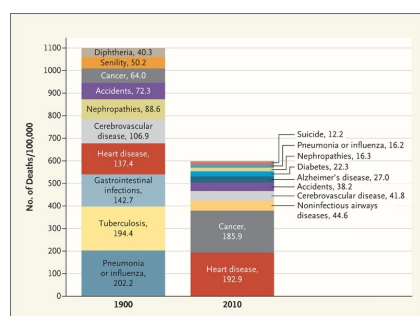
Causes of Death in 1811. Abstract of the Bill of Mortality for the Town of Boston.

In addition to angina, diarrhea, and burns, early *Journal* issues examined gunshot wounds, spina bifida, tetralogy of Fallot, diabetes, hernia, epilepsy, osteomyelitis, syphilis, cancer, croup, asthma, rabies, and urethral stones. Although some case reports describe patients who might walk into a clinic today, others are nearly unrecognizable. Apoplexy, a syndrome of fainting spells that might mean stroke, seizure, or syncope today, was understood to arise from a “nervous sympathy” by which the stomach influenced the head (1812d). Doctors agreed that even a near miss by a cannonball — without contact — could shatter bones, blind people, or even kill them (1812f). Reports of spontaneous combustion, especially of “brandy-drinking men and women,” received serious, if skeptical, consideration (1812g). And physicians were obsessed with fevers — puerperal, petechial, catarrhal, and even an outbreak of “spotted fever” in which some patients were neither spotted nor febrile (1812e). The bill of mortality from 1811 (see [figure](#)) contains both the familiar and the exotic (1812h). Consumption, diarrhea, and pneumonia dominated the mortality data, but teething, worms, and drinking cold water apparently killed as well.

A century later, the infections that filled the *Journal* had been redefined according to specific microbial causes. The *Journal* ran reviews of tuberculosis (1912b), gonorrhea (1912e), and syphilis (1912i). Diphtheria, measles, pneumonia, scarlet fever, and typhoid made frequent cameos, and Massachusetts still maintained a leper colony on Penikese Island (1912d). Tropical infections also fascinated authors, whether worms in immigrants or outbreaks of plague, yellow fever, and malaria in the nation's new tropical empire.

Doctors in 1912 did have some reasons to celebrate. By any account, the previous year had been “the healthiest of which there is any record” (1912a). Nearly every *Journal* issue that year mentioned another centenarian, and coverage of the “overwhelming success” of U.S. athletes at the Stockholm Olympics celebrated American racial vigor (1912f). One editorial, describing progress made since the *Journal*'s early years, rhapsodized about what another century of medical discovery might bring: “Perhaps in 1993, when all the preventable diseases have been eradicated, when the nature and cure of cancer have been discovered, and when eugenics has superseded evolution in the elimination of the unfit, our successors will look back at these pages with an even greater measure of superiority” (1912c).

Such paeans to progress, however, were accompanied by fear of the diseases of modernization. One article described a new problem, “automobile knee,” and decried the prevalence of “persons of extremely indolent habits of life” who no longer walked more “than the few steps that are needed from the chamber to the elevator, from the elevator to the dining-room, or lounging-room, and then to the automobile” (1912j). Long-standing concern about epilepsy, alcoholism, and feeble-mindedness took on new relevance in a society increasingly preoccupied by fears of race suicide and the promise of eugenics (1912g, 1912h). Doctors struggled with cancer, eclampsia, impotence, heart disease (chiefly infectious or valvular rather than atherosclerotic), and arthritis.



Top 10 Causes of Death: 1900 vs. 2010.

During the 20th century, heart disease, cancer, and other chronic conditions assumed more dominant roles (see [bar graph](#)), although outbreaks of infectious disease — from eastern equine encephalitis (1938) and kuru (1957) to legionnaires' disease (1977), AIDS (1981), and multidrug-resistant tuberculosis (1993) — necessitated ongoing vigilance against microbes. New concerns also came to medical attention, from the terrifying consequences of thermonuclear war (1962) to the indolent but devastating effects of environmental pollution (1966) and climate change (1989). Optimism about prospects for the health of future populations persisted but remained tempered by concern about the pathologies of civilization. An

obesity epidemic, feared in 1912, has come to pass. Our previously steady increase in life expectancy has stalled and may even be reversed (2005).

Definitions and Consequences



The material and conceptual dynamism of disease poses challenges: how do we define disease meaningfully, and how do we measure our burden of disease and set health policy priorities? These are deceptively simple questions. The definition of disease in *Merriam-Webster's Medical Dictionary* as “an impairment of the normal state of the living animal or plant body” raises questions: What is normal? What is impaired? We cannot answer by referencing biology alone: the line between the normal and the pathological requires value judgments. As physicians know, not every symptom constitutes a disease. Nor, as anthropologists have shown, is it feasible simply to contrast “disease,” as diagnosed by doctors, with “illness,” as experienced by patients.¹ As contemporary disputes over the definitions of alcoholism, chronic fatigue syndrome, and attention-deficit disorder make clear, physicians are never the sole arbiters of disease.

Any responsible attempt to define disease must account for the phenomenon's complexity. A disease has characteristic signs and symptoms, afflicts particular groups of people, and follows a characteristic course. Doctors name diseases and work to identify their causes and develop ways to prevent and treat them. But patients also ascribe meaning to their suffering and assign responsibility for what went wrong.² And diseases have utility, with concrete consequences for patients, doctors, and their institutions.³ They mediate patients' claims to the sick role and adjudicate access to health care resources. Disease definitions structure the practice of health care, its reimbursement systems, and our debates about health policies and priorities. These political and economic stakes explain the fierce debates that erupt over the definition of such conditions as chronic fatigue syndrome and Gulf War syndrome. Disease is a deeply social process. Its distribution lays bare society's structures of wealth and power, and the responses it elicits illuminate strongly held values.⁴

The complexities and consequences of disease extend to its measurement. Even after a disease has been clearly defined, measuring its frequency, intensity, and relevance is not simple. Since the 17th century, polities have compiled causes of death into annual bills of mortality. Successive generations of demographers and epidemiologists have transformed such statistics into age-adjusted measures of disease-specific mortality and developed measures of morbidity and of the impact disease has on people's ability to lead meaningful, productive lives. But such measures, including disability- and quality-adjusted life-years, reduce the complex experience of disease to a single coefficient.

A population's disease status can also be gauged by lists of common diagnoses at clinics or hospitals, but no single measure definitively characterizes a population's burden of disease. Choosing among metrics is as much about values and priorities as about science, and it directly affects health policy. Whereas advocates of

clinical and research funding for cardiovascular disease might use mortality data to support their claims, mental health advocates can cite morbidity measures in seeking greater resources. Data on causes of childhood mortality would justify certain priorities; analyses of health care spending would justify others. An ideal, sophisticated health policy would integrate all measures to form a holistic map of the burden of disease, but in practice competing interests use different representations of disease burden to recommend particular policies.

Accounting for the Burden of Disease



Regardless of the metric chosen, any map of the burden of disease exposes disparities within and among populations. Two aspects of the burden of disease have remained particularly vexing: changes over time in the prevailing diseases and the persistence of health inequalities.

By examining the many new diseases that have appeared over the past two centuries, historians have categorized the ways in which diseases emerge. New causes (e.g., severe acute respiratory syndrome, motor vehicle accidents, radiation poisoning), new behaviors (cigarette smoking, intravenous drug use), and even the consequences of new therapies (insulin transforming the course and manifestations of diabetes) can produce new diseases. Changing environmental and social conditions can increase the prevalence of once-obscure ailments (myocardial infarction, lung cancer, kuru, and “mad cow” disease). New diagnostic technologies and therapeutic capacity can unmask previously unrecognized conditions (hypertension). New diagnostic criteria can expand a disease's boundaries (hypercholesterolemia, depression). Changing social mores can redefine what is or is not a disease (homosexuality, alcoholism, masturbation). New diseases can emerge as the result of conscious advocacy by interested parties (chronic fatigue syndrome, sick building syndrome). HIV–AIDS alone demonstrates many of these modes of emergence. The emergence, recognition, and impact of disease are never just a bioscientific process; the advent of a new disease always involves social, economic, and political processes that shape its epidemiology and influence our understanding and response.

The interaction between the biologic and the social is equally apparent in the decline of a disease. Cannonball injuries, a frequent cause of concern in 1812, disappeared from the *Journal*, only to be replaced by a new and more terrible litany of war-related injuries. Neurasthenia, a widespread phenomenon of depleted nervous energy in the late 19th century, has disappeared, but traces of it have remained recognizable in other diagnoses throughout the past century. In some cases, a disease's decline clearly resulted from medical action. Immunizations eradicated smallpox and may someday eradicate polio. Genetic screening has led to dramatic reductions in Tay–Sachs disease, thalassemia, and familial dysautonomia (2009). But often the potential for eradication has been incompletely realized — witness the continued prevalence of AIDS and tuberculosis in low-income countries and of atherosclerotic heart disease globally.

Even as prevailing diseases have changed, health disparities have endured. Inequalities in health status have always existed, regardless of how health has been measured or populations defined. When Europeans arrived in the Americas, they witnessed stark disparities in the fates of European, American, and African populations. During the ravages of 19th-century industrialization, physicians grew familiar with health disparities between rich and poor. Health inequalities remain ubiquitous, not just among races and ethnic groups but also according to geography, sex, educational level, occupation, income, and other gradients of wealth and power.⁵

The persistence of health inequalities challenges our scientific knowledge and political will. Can we explain them and alleviate them? Genetic variations don't explain why mortality rates double as you cross Boston Harbor from Back Bay to Charlestown or walk up Fifth Avenue from midtown Manhattan into Harlem. Nor do they explain why Asian-American women in Bergen County, New Jersey, live 50% longer than Native American men in South Dakota.⁶ Although we know something about the relationships among poverty, stress, allostatic load, and the hypothalamic–pituitary–adrenal axis, doctors and epidemiologists need more precise models that sketch in the steps between social exposure, disease, and death.

Accounting for the history of disease also requires us to examine why some disparities in disease are seen as proof of a natural order while others are considered evidence of injustice. The 4.3-year life-expectancy gap between blacks and whites in the United States provokes outrage, but the 4.9-year gap between men and women does not. It is tempting to assume that differences between the sexes are natural and those between races are not. But a 19th-century *Journal* reader might be skeptical of this explanation: men then lived at least as long as women. The survival advantage of women that appeared in the 20th century owed as much to changes in childbearing, improvements in obstetrical practice, and a new epidemic of heart disease disproportionately affecting men as to differences between the X and Y chromosomes. Disparities in health and disease are outcomes that are contingent on the ways society structures the lives and risks of individuals.

Recognition of the contingency of health inequalities should make them a target for intervention, yet the opposite has frequently happened: the ill health of impoverished or marginalized groups has been used against them — as evidence of their inferiority or as an argument that they're unworthy of assistance. In the late 19th and early 20th centuries such sentiments produced government policies with tragic outcomes for blacks and Native Americans. They may underlie current policies that would limit health care access for mentally ill, impoverished, and immigrant populations.

The Roles of Medicine



Medical practice and health policy rely on the assumption that the solution to the problem of disease is to be found in physicians and their therapies. Physicians tend to credit biomedical science with 20th-century improvements in health and longevity. The history, however, is complex and contested.

For example, after Robert Koch's 1882 discovery of *Mycobacterium tuberculosis* and the advent of antibiotics in the 1940s, physicians claimed responsibility for the decline of tuberculosis in Europe and North America. But closer examination revealed that this decline had begun before Koch's discovery and had substantially run its course before effective antibiotics became available. Medicine's critics instead credited improvements in the standard of living, especially diet. A similar debate has emerged about coronary artery disease. Heart disease, like tuberculosis, followed a century-long epidemic wave, peaking in the United States in the 1960s before beginning 50 years of decline. Researchers have struggled to determine how much credit should be given to health care providers and how much to risk-factor reduction (2007). This debate has now been complicated by recent increases in coronary disease elsewhere, notably Russia and China, and by signs of a plateau and possible reversal of decline in the United States, Australia, and Western Europe (2005). The stakes of this debate are substantial, with implications for the allocation of contested health care resources.

Is there a best health policy? Our goal should be an integrated policy under which health care and public health programs together fully address the disease burden. But the details depend on how we conceptualize and measure disease. And disease is never static. Just as organisms evolve to keep up with changing environmental conditions (the “Red Queen Effect”), medicine struggles to keep up with the changing burden of disease. Since therapeutic innovation takes time, the burden shifts even as solutions appear. By the time antibiotics and vaccines began combating infectious diseases, mortality had shifted toward heart disease, cancer, and stroke. Great progress has been made to meet these challenges, but the burden of disease will surely shift again. We already face an increasing burden of neuropsychiatric disease for which satisfying treatments do not yet exist.

In many respects, our medical systems are best suited to diseases of the past, not those of the present or future. We must continue to adapt health systems and health policy as the burden of disease evolves. But we must also do more. Diseases can never be reduced to molecular pathways, mere technical problems requiring treatments or cures. Disease is a complex domain of human experience, involving explanation, expectation, and meaning. Doctors must acknowledge this complexity and formulate theories, practices, and systems that fully address the breadth and subtlety of disease.

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[Disclosure forms](#) provided by the authors are available with the full text of this article at NEJM.org.

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Supplementary Material



Disclosure Forms	PDF	98KB
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Comments (3)

ELENA SNCHEZ, MD PHD 
Jul 23, 2012

AVOIDABLE DEATHS: EVOLVING CONCEPT. PERSPECTIVE

From a different point of view, There is an even more striking problem: the forgotten and uncompleted studies about Avoidable and Amenable Deaths, concepts which evolve in time as well, with therapies' improvement. At the same time we are fighting against high mortality rates caused by different diseases and other causes, we are not aware of epidemiology in preventable deaths with timely and effective healthcare: premature deaths

CHARLES JESSEE 
Jul 06, 2012

Facts and Fancy

The Brady Campaign is going to be furious that Firearms Homicides and Firearms Accidents are not culled out in the graphics. But I suppose there would need to be some magnifier tool to see them if detailed...

JAMES JOSEPH RYBACKI ▾
Jun 21, 2012

Non-adherence, the most prevalent undiagnosed disease-a 6th vital sign?

Our health care system must clearly adapt to changing faces of disease within a social world, yet we have yet to develop a system to address a major problem which by some estimates happens in one out of two patients over time-NON-ADHERENCE.

Perhaps half of the patients prescribed a statin may stop taking it within 5 years, numerous authors (Avorn and others) have dutifully researched and published, yet a national systems approach is yet to be developed. I myself have documented this failure to take medicines in chronic diseases and conditions in many of my books, yet have failed to advance an approach to stop an immensely expensive problem which no doubt is a key to uncounted therapeutic failures and progression of disease.

Perrone and Nelson proposed using medication reconciliation as a controlled substance monitoring tool in this edition of the Journal--a laudable approach. What I propose today is that we make adherence the 6th vital sign-integrated in Med Rec. This could be checked on every office visit, hospital admission, discharge & clinic visit and with every pharmacy refill. Time for a national metric on adherence and for us to learn true outcomes from powerful medicines.

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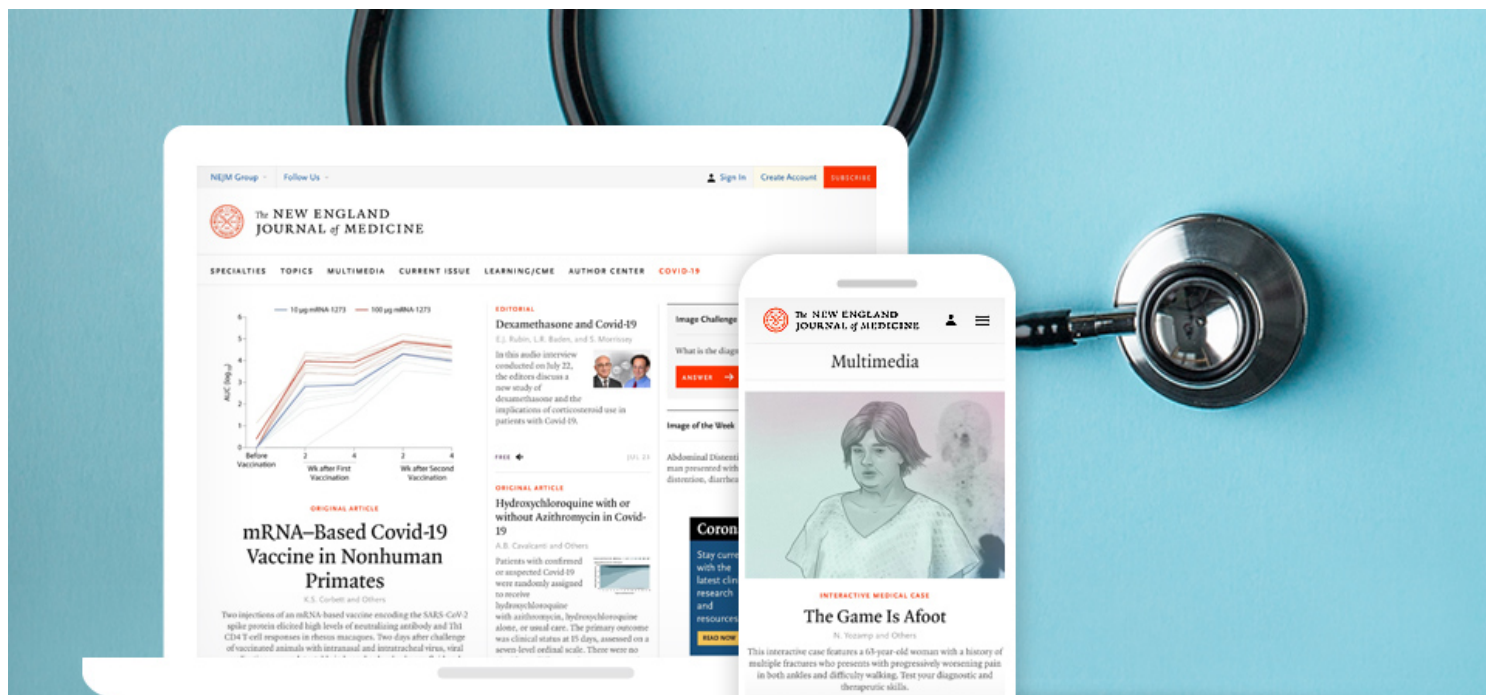
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