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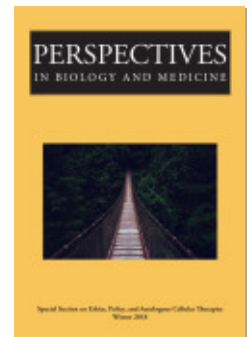
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THE FUTURIST AND HISTORIAN WILL SEE YOU NOW

SCOTT H. PODOLSKY

ABSTRACT Eric Topol's *The Patient Will See You Now: The Future of Medicine is in Your Hands* (2015) depicts a medical future in which the patient–doctor relationship is upended in the context of easily acquired and shared big data and the increasing computing power necessary to analyze such data. A chief obstacle to this future, in Topol's rendering, is the entrenched paternalism of the medical profession. But Topol's thought-provoking assessment misses other key potential obstacles to the rational and equitable implementation of this (or any) medical future and would benefit from a more nuanced telling of the history of attempts to empower patients in this country. Nancy Tomes's *Remaking the American Patient: How Madison Avenue and Modern Medicine Turned Patients into Consumers* (2016) traces the long history of patient consumerism in America. She points out that the history of attempts to inform and empower patients has often been characterized by the conflation of advertising with information, the inequitable distribution of access to information and care, and the prioritization of commercial over medical utility in the implementation of care. These remain critical obstacles to an ideal medical future, Topol's or otherwise.

LUKE FILDES'S ICONIC PAINTING *THE DOCTOR*, first exhibited in 1891, has long served as a symbol of the caring, priest-like physician, watching over a sick child as the child's parents place their faith in his ministrations, technologically

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meager as they may be. As physicians acquired more visible and potent interventions—x-rays, antibiotics, the complex infrastructure of the hospital itself—the 19th-century British scene depicted by Fildes of an individual doctor’s watchful waiting would be appropriated by the likes of the American Medical Association (AMA) in the 1940s to remind the American public of this idealized patient-doctor relationship, augmented by increasingly powerful curative tools at the disposal of the wise physician (Warner 2014). Over 125 years after the painting’s appearance, it serves as a very different touchstone. In the futuristic vision of Eric Topol, *The Doctor* can serve as a quaint reference point for a reimagining of personalized medicine “from the genome to the bedside,” in which the patient-doctor relationship is upended in the context of emerging technologies (Caring for the Patient 2012). According to Topol’s *The Patient Will See You Now* (2015), we are to replace the role of medical paternalism with a partnership enabled by easily acquired, freely shared data—lots of data. In the historical recounting of Nancy Tomes, the 1890s serve as a temporal starting point for a reinterpretation of the history of American patient-consumers themselves, rarely as passive in the past century as conventionally depicted. To evaluate any potential medical future, and any reimagining of the patient-doctor relationship, we need to appreciate the history, achievements, and limitations of prior efforts to seemingly empower patients. Reading Topol’s work through the lens provided by Tomes’s *Remaking the American Patient* (2016) offers the unique opportunity to consider the American patient’s past, present, and future alike.

Topol is a giant in his fields, a well-respected cardiologist and professor of genomics, and the Gary and Mary West Endowed Chair of Innovative Medicine at the Scripps Research Institute. In many ways, *The Patient Will See You Now* is a sequel to his 2012 book, *The Creative Destruction of Medicine*. As Topol reveals in his well-written and thought-provoking books, a related array of technological innovations—molecular sequencing, the rise of bioinformatics and big data, and remarkable advances in computing power to store and evaluate such data—have led to this transformative moment in medicine. The smartphone—capable of acquiring, storing, and transmitting enormous realms of data, from physiological to sociological—serves as the unforeseen embodiment of this new revolution in information acquisition and dissemination, potentially as momentous as the invention of movable type over five centuries earlier. And much as the printed book led to the democratization of knowledge, so, argues Topol, can big data and widely dispersed smartphones (or their future equivalents, one assumes) lead to the democratization of health care itself.

In Topol’s envisioned future, an informationally encoded “Panoromic” view of our lives will be continuously updated in real time, a multidimensional array of data consisting of at least 10 levels: the genome (sequenced for each of us and hence comparable to established norms), the epigenome (affecting the regulation of our genes), the transcriptome (what actually gets converted from DNA into

RNA), the proteome and metalabome (the biological expression of our bodies' proteins), the microbiome (the increasingly appreciated realm of microbes that live on and within us, comprising the majority of "our" cells and genes), the anatome and physiome (accessible through smartphone-enabled imaging and biosensing), the exposome (ranging from air pollution to radiation), and the phenome (our interconnected social relationships). Assuming the stability of such levels (and the sciences and social sciences underpinning them), Topol can envision a "prewomb to tomb" series of interventions to optimize health: genetic prescreening of would-be parents and embryos, newborn sensors and whole-genome sequencing, embedded sensors to detect chronic diseases like cancer and myocardial infarction before damage is inflicted, rapid microbial pathogen sequencing, pharmacogenomic data to guide rational drug prescribing, and (for those not saved to this point) molecular postmortems, especially for unforeseen deaths.

It is a world of endemic, ongoing self-surveillance, predicated on the easy, democratized acquisition of data (whether via improved micro-phlebotomy or imaging) and sophisticated algorithms to make sense of such data. Critically, it depends on patient ownership of the data itself, freely shared, whether for personal care or collaborative science. Research would be opened up through Massive Open Online Medicine (MOOM), reported in open-access journals. In the process, the very spaces of care and roles of the medical profession would be transformed. For a large percentage of cases, clinicians would become unnecessary to the obtaining of data (with the discarded stethoscope the symbol of outdated diagnostics), playing at best an ancillary role in data interpretation, with the remainder interpreted by smart patients assisted by their very smart phones. Surgical interventions aside, the hospital itself would become outdated for much of medical care, especially for those for whom the home can be set up to provide all the functions of monitoring that hospitals traditionally have provided. In some ways, the doctor would largely revert to the role in Fildes's painting, capable of empathy and the "healing touch" (280), but not much more. One doubts the AMA will make posters about this.

Topol recognizes that the vast majority of the science underlying his future has "yet to be validated" (256), and it is staggering for anyone who deals with diagnostic tests of varying sensitivities, specificities, and predictive values, who wrestles with the utility of screening tests, to consider just how difficult it will be to construct boundaries and balances between real findings and incidentalomas, disease and pre-disease, cost and benefit (Kohane, Masys, and Altman 2006; Manrai et.al. 2016). But that is to be the case for medical science in any event, and it is perhaps a question for another day. Multiple other concerns specific to Topol's envisioned future can be expressed. First, predictions regarding the utility of "Big Data" to transform care seem to have outrun actual accomplishments to date, though we admittedly remain in the early days of bioinformatics (Chen and

Asch 2017). Second, despite the multiple levels of data comprising the Panoromic Geographic Information System, most of Topol's key examples (especially regarding patient empowerment to self-diagnose) seem to revolve around genomic data, yielding an implicit genomic focus that runs throughout the book. Third, and fundamentally, despite a chapter on how such envisioned changes can "flatten the earth" and enable global health efforts, there is little attention in the book to the social determinants of health (are they part of the exposome? the phenome?) or the structures of daily living that have seemed to shape the uptake of nearly every medical technology to date. Ensuring that Topol's hoped-for future is more equitable than the present will require more than the broad distribution of smartphones and internet access.

Rather, Topol seems to have two chief concerns. The first is technical: namely, ensuring the security of the vast amounts of data to be obtained. The second concern—and the book's primary bugbear—is the entrenched paternalism of the medical profession. Topol depicts a wagon-circling profession that has been hoarding information and power from the time of Hippocrates (and especially in America from the founding of the AMA in 1847), concerned to protect its hard-earned prerogatives to screen, diagnose, treat, and charge patients, with little accountability (until now). But this assessment of the present and future misses a far more nuanced—and instructive—telling of the history of the patient-doctor relationship in American medicine, with important implications for any envisioned future. Let us turn from the futurist to the historian.

Nancy Tomes, a giant in her own field, is a Distinguished Professor in the Department of History at Stony Brook University. Historians like Martin Pernick (1982), Barron Lerner (2004), and Christopher Crenner (2005), in fascinating case studies, have complicated our prior narrative of docile patients, but Tomes is the first to longitudinally examine patient consumerism—and the capacity of laypeople to stand back, examine, and critique medical care—from the 19th century to the present day.

In Tomes's telling, any hearkening back to Hippocrates (or even to Fildes) misses the "free trade in doctoring" that characterized much of 19th-century American medical care, as patients chose from practitioners of varying medical sects, when not self-treating with widely advertised proprietary medications. By the end of the 19th century, however, a determined cohort of reformers (some, but not all, physicians) chose to upgrade medical professional standards through improvements in medical education and licensing (epitomized by the Flexner Report), and to improve the medical marketplace through the 1906 Pure Food and Drugs Act (eliminating the unlabeled use of such toxins as alcohol and narcotics). This was, in essence, a form of restriction of public choice; but as medicine, pharmaceutical development and display, and advertising co-evolved in the post-World War I era, plenty of opportunities existed for would-be consumers to cast evaluative judgments.

With medicine increasingly attached to science and technology, and with specialization becoming an appealing alternative to general practice and physicians setting up well-appointed offices in desirable spots in town, Fildes's model was already fading in the (increasingly prevalent) rear-view mirrors of patients and doctors alike. And in an era before the advent of health insurance, some patients took notice. Some of the earliest consumerist patients, increasingly trained to evaluate an expanding general marketplace, began to question the cost and value of medical care as well. It was in this context, tellingly, that the Committee on the Costs of Medical Care critiqued the distribution and financing of medical care in the late 1920s and early 1930s.

At the same time, as drugstores and manufacturers of proprietary drugs practiced an aggressive commercialism—with supposedly scientific physicians offering little resistance to such marketing—consumer reformers could train their sites on the evaluative judgments and therapeutic practices of physicians as well. As Tomes relates, former nurse Katharine Kellock would state in a 1935 article entitled “Shopping for Medical Care” that “There is a growing irritation and objection among consumers with the tendency of medical men to arrogate to themselves the prerogatives of the deity and to treat their patients as persons who should gratefully pay the high charges for medical services, and question those services and their value as little as possible” (105). Indeed, Kellock advised her readers that “a person suffering from a condition that defies diagnosis or treatment, or who is being given drugs and treatments of which he is doubtful, can go to the nearest medical library, and with the aid of the *Index Medicus*, check up on the points that trouble him” (121). Kellock's article was part of a new wave of consumer protectionism, perhaps best exemplified by Arthur Kallet's and F. J. Schlink's 1933 classic, *100,000,000 Guinea Pigs*, that was “intended not only to report dangerous and largely unsuspected conditions affecting the health and safety of all consumers of foods, drugs, and cosmetics, but also, so far as possible, to give the consumer some broad measure of defense against such conditions” (111). With respect to seemingly dangerous drugs (like the sulfa drugs, introduced in the mid-1930s), reform took shape with the passage of the 1938 Food, Drug, and Cosmetic Act, mandating proof of drug safety (though not efficacy) prior to drug approval. With respect to the image of the medical profession, while a still-powerful AMA remained strong enough to ward off most criticism, progressive reformers both within and beyond the profession called for the increased scrutiny of the financing and practice of medicine by the late 1930s.

The decade and a half following World War II in many ways represented the “golden age” of American medicine, with antibiotics, anti-psychotics, steroids, minor tranquilizers, and anti-hypertensives all newly appearing on the market, produced by an increasingly research-intensive pharmaceutical industry and wielded by an increasingly self-confident medical profession. Private health insurance, introduced on a small scale in the interwar era, had expanded dra-

matically during and after the war, covering the majority of Americans (at least among working families). Medicine epitomized the virtues of American free enterprise, with public critique especially muted during the early 1950s red scare. But this would be a brief respite. With respect to pharmaceuticals, the 1951 Durham-Humphrey amendments formally separated drugs into over-the-counter versus prescription-only remedies (themselves only marketed to physicians), thereby supporting—but simultaneously increasing the scrutiny of—physician prescribing authority. As the marketing, prescribing, and cost of prescription drugs escalated dramatically throughout the 1950s, the same critiques leveled at the advertising of proprietary drugs to consumers in the first half of the century were now leveled at the marketing of prescription drugs and at the seemingly gullible doctors who prescribed them. The passage of the Kefauver-Harris amendments in 1962, mandating proof of drug efficacy prior to drug approval (and setting the foundation for much of drug approval as we know it today), thus can be seen as part of President John F. Kennedy's larger agenda for consumer protection (even if the bill nearly fell off the table prior to being salvaged by the thalidomide scandal).

At the same time, as more physicians specialized and fewer made house calls (one in 10 by the early 1960s), medicine appeared to have become like any other service industry, with customer service concerns to follow. A 1961 *Journal of the American Medical Association* article, in which nearly 90% of clinicians preferred to not to reveal cancer diagnoses to their patients, is often cited (including by Topol) as evidence of the paternalism that persisted at the time (Oken 1961). But during that same time, psychiatrist Ernst Dichter was conducting focus group research on perceptions of physicians, reporting: "Patients, being part of the world we live in, have changed with this world. They no longer simply accept the authority of the doctor" (Tomes 2016, 190). Dichter advised that the physician needed "to regard himself as more a business man and less a saint [and to] accept the fact that today's patient has grown up and can read current medical articles" (191). Patients could indeed read articles and critique medicine. Tomes notes that in 1960 *Harper's Magazine* was the first to describe a looming "crisis" in American medicine, pointing to its lack of coordination, both at the system level and at that of the individual patient (196).

This would set the stage for a decade of activism starting in the mid-1960s—and of course reflecting larger trends in American politics and culture, including the passage of Medicare and Medicaid in 1965—that offered "medical power to the people." Clinics run by the Black Panthers, the publication by the Boston Women's Health Collective of *Our Bodies, Our Selves*, and the Naderite activities of the Health Research Group all represented direct challenges to the medical status quo, itself first termed the "medical industrial complex" in 1970. This would be an optimistic era noteworthy for increasing attention to informed consent, patient information leaflets for selected drugs, and the launch of the

(hospital-based) Patient Bill of Rights. “Shopper’s Guides” to hospitals began to appear, accompanying and increasing attention to outcomes measurement within medicine itself, and prompting iterative calls for better and more transparent data collection.

On the one hand, such efforts epitomized ongoing attempts at patient empowerment, further evidenced by such best-selling titles as Donald Vickery and James Fries’s 1976 volume, *Take Care of Yourself: A Consumer’s Guide to Medical Care*. Organized medicine was not blind to such critique, and it is no coincidence that this era witnessed the advent of bioethics (and, it should be noted, a resurgence of interest in the “medical humanities”), as well as increasing attention to the “whole patient,” the “activated patient,” and patient engagement in medical care and decision-making itself.

On the other hand, by the late 1970s and especially the 1980s, organized medicine and the AMA were no longer the powerful bugbears they had been, and patient consumerism would be co-opted by a new set of forces. The AMA’s ban on physician advertising—long a manifestation of the dignified calling of the profession, but equally a manifestation of the profession’s monopoly over information—was overturned by the Federal Trade Commission in the name of information provision, but this simply led to increasing commercial advertising in medicine. And by the 1980s, with the advent of for-profit health maintenance organizations and hospital systems, while advertising and the promotion of the “new and improved” would increasingly shape patient expectations, such seemingly newly empowered and informed patients would become restricted in their choices of which physicians and hospitals they could actually access and which medications they could take. “Consumerism” thus had its obvious limitations, and even its paradoxes. And the process by which “information” and the “education” of patients actually took the form of advertising would perhaps find its apotheosis in the direct-to-consumer advertising of pharmaceuticals from the mid-1990s onward, which increased 11-fold (to \$4.2 billion per year in advertising costs) between 1995 and 2005.

This brings us to the present. For Tomes, the glass half-full view is that, à la Topol, “armed with cellphones and wireless communication, American patient-consumers seem ready and able to take charge of their medical care” (388–9). Patients are better-educated and more engaged with their care than in the past, and physicians, for the most part, are willing to engage with them. For all the continuities of patient consumerism over the past 125 years, there has clearly been change over time. As Tomes notes, “It would be virtually impossible to find an opinion leader in the medical field today who would disagree with what counted as a radical principle in 1938—Hugh Cabot’s insistence that the ‘patient, now known as the consumer’ has the ‘right to a very large word in what is done and in how it is done’ in the world of medicine” (398). But there is a powerful glass half-empty viewpoint as well. As Tomes eloquently summarizes:

“The overblown promise of the ‘new and improved,’ the misleading conflation of advertising and information, the entrenched barriers to coordination of care, the limited political clout of consumer groups, and the toxic effects of income inequality continue to pose formidable obstacles to the goal of improving patient care” (399). It is no accident that organized medicine, the pharmaceutical and drugstore industries, and advertising have all grown in tandem in the 20th and 21st centuries, and that the sources of medical “information” for the public and clinicians alike bear the imprint of particular interests and biases. Beyond this, those patient consumers most able to access both medical information and optimal medical care have consistently been wealthier and better-educated. And when optimal patient care and the commercial aspects of care have come into conflict, the profit motive of those representing the medical industrial complex have generally taken precedence (for the speculative financial aspects of “do-it-yourself” medicine, see Greene 2016).

Which brings us to the future, Topol’s or otherwise. Futures themselves are performative, generative, helping to mobilize attention and resources to bringing about the very visions they signify (Podolsky and Lie 2016). Hospitals are already following some of the ideas in Topol’s projected future. At Massachusetts General Hospital, where I practice primary care, I am no longer to be paid via fee-for-service, but through a capitated model, incentivized to communicate with my patients securely via an online portal, and, soon, through virtual online visits where they can report data that they have assembled, such as blood pressure, blood sugars, and mood status. This is a small component of Topol’s decentralized future, to be sure. But as Tomes’s historical analysis has revealed, the paternalism of the medical profession is hardly the unchanging monolithic force Topol has described. If history is a guide, then the chief dangers to the rational implementation of the patient-empowering future that Topol envisions will be the conflation of advertising with information, the inequitable distribution of access to information and care alike, the prioritization of commercial over medical utility, and the propensity to blame seemingly empowered patients/consumers for their inability to adhere to whatever ideal pattern of care is envisioned, no matter what structural hindrances to such adherence are in place. While Fildes’s lone doctor is unlikely to reemerge in any projected future of American medicine, who, exactly, will be shaping the care of the future patient remains an unanswered question. One hopes they will be thinking as hard, and in as patient-oriented fashion, as Fildes’s doctor at least appears to be doing.

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