



FROM CARELESS CONSUMPTIVES TO RECALCITRANT PATIENTS: THE HISTORICAL CONSTRUCTION OF NONCOMPLIANCE

BARRON H. LERNER

Columbia University, 650 West 168th Street, Room 101, New York, NY 10032, U.S.A.

Abstract—Thousands of articles on “noncompliance” have appeared since 1975. Yet the term has been criticized as paternalistic—as wrongly implying that patients should necessarily follow doctors’ orders. This paper, which reviews how noncompliance has been constructed historically, argues that the problem with noncompliance is more than just one of terminology. Changing social and cultural factors during the 20th century have influenced the way in which uncooperative patients have been described. For example, resentment of poor immigrants in the early 1900s led doctors to describe tuberculosis patients who did not follow advice as “ignorant” and “vicious.” Following World War II, patients who balked at taking new curative antibiotics for tuberculosis were called “recalcitrant.” The term “non-compliance,” popularized by Sackett and Haynes in the 1970s, reflected their early role in the field of research now termed “evidence-based medicine.” While Sackett and Haynes had hoped that the new term would eschew earlier value judgments, noncompliance, through its association with the positivistic ethos of evidence-based medicine, has been conceptualized as a “tragic” problem potentially solvable by clinical research. Hence, noncompliant patients are still seen as deviant. With the growth of managed care in the United States, there is increasing pressure to get patients to follow medical recommendations. History suggests that labels such as “noncompliant” are invariably judgmental. Rather than seeing the provider’s role as trying to get noncompliant patients to comply, we should emphasize the importance of negotiation and accommodation within the provider–patient relationship. © 1997 Elsevier Science Ltd

Key words—patient compliance, history of medicine, evidence-based medicine, tuberculosis, physician–patient relationship, managed care programs

A 47 year-old laborer had fibrocavitary tuberculosis in the upper lobes of both lungs... While undergoing treatment at the hospital, he...caused such a commotion on the ward that the police were called. He was arrested, charged with being drunk and disorderly, [and] put in jail.

[A] 30 year old man entered the hospital because of far-advanced pulmonary tuberculosis. He remained in the hospital 12 days, and then left without permission. Two weeks later he reported to an outpatient tuberculosis clinic. However, he failed to keep a return appointment and to complete a form for financial assistance.

The recent resurgence of tuberculosis in the United States has engendered a great deal of discussion about patients who are “noncompliant” with their medical treatment. Yet practitioners have long recognized that patients—with tuberculosis or other diseases—often do not adhere to therapeutic recommendations. For example, these case studies date not from the mid-1990s but from the early 1960s (Campagna and Greenberg, 1964).

The topic of patient noncompliance has generated a great deal of research over the past 20 years. Thousands of studies have sought to identify the causes of noncompliance and to design corrective interventions. At the same time, some commentators have criticized the term “noncompliance” as paternalistic, arguing that it wrongly implies that patients should necessarily follow doctors’ orders.

By explaining how we have come to refer to certain patients as noncompliant, history can help us to reframe this debate. Indeed, “noncompliant” is merely the latest adjective used by physicians to describe uncooperative patients, having achieved popularity in the 1970s after the publication of two books on the subject by David Sackett and Brian Haynes. In demonstrating the social construction of the term “noncompliance,” the historical record suggests that we may be overemphasizing the current strategy of identifying certain patient behaviors as deviant and then attempting to correct them.

Using 20th century tuberculosis control efforts in the United States as a case study, this paper first reviews the various terms that physicians have used historically to describe patients who disregard their advice. (While the discussion will focus on the role of the physician, the issues pertain to other practitioners as well.) Next, it looks more broadly at the concepts of compliance and noncompliance as developed by Sackett and Haynes in the 1970s. Despite Sackett and Haynes’ attempts to fashion a nonjudgmental term, noncompliance still retains earlier notions of deviance. The paper concludes with some thoughts regarding the issue of noncompliance in an era of managed care medicine.

A HISTORICAL PERSPECTIVE

It would be a mistake to assume that physicians only became preoccupied with patient "compliance" when they acquired definitive knowledge about the causes of diseases and developed specific therapeutic agents such as antibiotics. As far back as Hippocrates, medical writings show concern that patients follow physicians' advice (Haynes, 1979). Indeed, Jay Katz has argued that much of medical history has been characterized by efforts to get patients to "follow doctors' orders" (Katz, 1984, p. xiv). Prior to the availability of curative antibiotics for tuberculosis, certainly, physicians expected patients to adhere to their prescriptions regarding bed rest, fresh air, and exposure to specific climates.

Nevertheless, it was with the growing knowledge of the etiology of diseases such as tuberculosis that physicians' recommendations achieved greater authority. Tuberculosis raised special concerns. In a stunning series of experiments announced in 1882, Robert Koch had demonstrated that tuberculosis was a contagious infection. Koch's work led turn-of-the-century physicians and health officials to recommend that persons with the disease follow proper hygienic precautions in order to prevent its spread. These precautions included coughing into handkerchiefs, refraining from spitting, and, when necessary, agreeing to isolation (Teller, 1988, pp. 21-24).

Monitoring how well patients followed such advice was quite difficult. Not only was tuberculosis ubiquitous in many American cities in the early 1900s, but the number of sanatorium beds available for treating and isolating infectious patients remained woefully inadequate. Although there was great difficulty in controlling the disease in the population in general, one group of tuberculous patients generated particular scrutiny: transient men, often alcoholics, who resided in the rundown sections of many cities. Because these men were often unwilling to remain hospitalized and follow precautions, officials believed they were highly likely to spread tuberculosis throughout the community.

Transient tuberculous alcoholics were routinely excoriated in the medical literature. One author, for example, still employing the old term of "consumption" for tuberculosis, called in 1905 for "Detention Institutions for Ignorant and Vicious Consumptives" (Foster, 1905). Even as he developed a sophisticated program to control tuberculosis in New York City, local public health officer Hermann Biggs used similar language to describe certain persons with the disease. In 1904 he advocated the detention of "[h]omeless, friendless, dependent, dissipated and vicious consumptives... likely to be most dangerous to the community" (Biggs, 1904). Backed by state laws permitting the quarantine of patients who were health hazards,

Biggs quickly established a program of forcible isolation.

Why did medical authors employ such derisive terminology to describe these men, particularly at a time when there were inadequate facilities to hospitalize them anyway? In order to answer this question, it is necessary to examine the social circumstances that influenced this interaction between medical official and patient (Fox, 1989; Feudtner, 1994). The rise of urbanization and industrialization in early 20th century American cities had been accompanied by the growth of slums, in which large numbers of the poor lived in crowded conditions. Progressive Era reformers enacted numerous interventions to improve the lives of the so-called "worthy" poor. Yet there was much less sympathy for the "unworthy" poor, such as transients and alcoholics, who were regarded as responsible for their condition (Katz, 1986). At the same time, eugenicists and others with nativist leanings specifically directed their obloquy at recent immigrants from Eastern Europe, who offered competition for jobs and threatened the nation's supposed racial purity. This resentment culminated in the passage of the 1924 Immigrant Restriction Act (Kevles, 1985, pp. 96, 97).

In this setting, the problem of the transient with tuberculosis came to embody the larger societal problems of poverty and immigration. While it may have been true that poor or immigrants were less likely to follow medical recommendations, the language used to describe such individuals was less a reflection of medical or public health concerns than a value judgment about the patients themselves. Thus, one physician wrote that the "careless," "incorrigible" and "irresponsible" consumptive was most likely to be found "among our ignorant and foreign population" (Lloyd, 1918). So, too, the "[h]omeless, friendless, dependent, dissipated and vicious consumptives" forcibly detained by Biggs at New York's Riverside Hospital consisted almost exclusively of "the vagrant, the poor, and the immigrant." In this manner, Sheila Rothman has argued, Riverside became as much a "dumping ground" for societal outcasts as a public health facility for tuberculous persons who did not follow the advice of medical authorities (Rothman, 1994, pp. 192-194).

Despite the great concern about tuberculosis patients whose behavior endangered the community, relatively little was done about the problem throughout the first half of the 20th century. Detention programs, such as that initiated by Biggs, were expensive and difficult to operate; given the paucity of sanatorium beds, health officials preferred to fill them with patients willing to undergo prolonged hospitalization (Lerner, 1993). The next surge of interest in the subject of cooperation of tuberculosis patients did not come until the mid-1940s. Once again, an examination of social factors

helps to explain both why this issue arose anew, and how it was characterized.

The driving force behind discussions of unfinished tuberculosis therapy at this time was World War II. Authors have noted how antituberculosis efforts in the United States were regularly characterized as a "fight" or "crusade" against the disease (Sontag, 1978); World War II made such military analogies even more explicit. As the *Bulletin of the National Tuberculosis Association* noted in 1943:

The armed forces have done their duty in keeping tuberculosis out of the service; it is now up to the civilian population to shoulder the responsibility for keeping it out of our communities (Anon, 1943).

Interestingly, however, when it came to discussions of patients who did not follow treatment recommendations, it was the tuberculous World War II veteran that raised the most concern. In the years following World War I, veterans hospitalized in sanatoria had displayed considerable "restlessness," with rates of discharge against medical advice that often exceeded 50%. Although the incidence of tuberculosis had declined considerably in the United States between the 1910s and the 1940s, screening x-rays for World War II had still led to the disqualification of one of out every 100 soldiers (Newcomb, 1944; Dublin, 1946). In addition, thousands of soldiers diagnosed with tuberculosis while on active duty had been sent to Veterans Administration Hospitals.

While no one termed the tuberculous veterans "ignorant" or "vicious," those who left hospitals against medical advice did represent a "menace to the general public welfare." If veterans did not remain in public hospitals, argued Louis I. Dublin of the Metropolitan Life Insurance Company, "local health authorities must be promptly notified and encouraged to exercise the control over these men which the public health laws give them" (Dublin, 1946). The attention paid to the so-called "irregular" discharges among veterans quickly spread to the civilian population. Large numbers of articles with titles such as "Why They Leave Against Advice" and "How We Can Reduce 'Sign Outs'" appeared in medical journals (Bobrowitz, 1946; Drolet and Porter, 1949; Sheen, 1950). The topic also engendered considerable discussion at meetings of the National Tuberculosis Association.

THE IMPACT OF ANTIBIOTICS

The impetus to prevent discharges against medical advice took on even greater urgency with the introduction of the first antibiotic agents to treat tuberculosis in the late 1940s. Within a few years, it appeared likely that the vast majority of tuberculosis cases could be cured by combining an initial period of hospitalization with an extended course of

antibiotics after discharge. Patients who left sanatoria prematurely or took their outpatient antibiotics inappropriately threatened to squander the outstanding opportunity that the new drugs provided.

Not surprisingly, physicians grew extremely frustrated with patients who disregarded their instructions regarding hospitalization and antibiotic therapy. Almost all persons who left a sanatorium against advice, noted one doctor, "show poor judgment that is as reckless and may be as fatal as the judgment of a careless driver who tries to beat a train to a crossing" (Davies, 1952). As they had earlier in the century, physicians and health officials began to use quite distinctive terminology to describe such patients, who once again were most likely to be transient, "Skid Row" alcoholics. Yet there was one major difference. Whereas earlier negative language had equated uncooperative behavior with patients' social status and ethnicity, the term most commonly employed in the 1950s and 1960s emphasized the act of disobedience itself. Articles during these two decades (Bridge, 1949; Northrop *et al.*, 1952; Davies, 1954) regularly termed such patients "recalcitrant," which *Webster's Dictionary* defines as "obstinately defiant of authority or restraint" (Webster's, 1981, p. 1893). This emphasis on defiant behavior is not surprising. The new antibiotic agents greatly enhanced the authority of physicians treating tuberculosis. Patients who disregarded therapeutic recommendations posed a direct challenge to this authority.

If language revealed a great deal about the social setting in which physicians and tuberculosis patients interacted, it also influenced that interaction. It was too quickly assumed, noted Ruth B. Taylor of the United States Public Health Service in 1956, that an "uncooperative," "recalcitrant" patient was apt to be an "unattached, transient, male alcoholic" (Taylor, 1956). Seattle sociologist Joan K. Jackson agreed, stating in 1960 that in regards to the treatment of tuberculosis, "'alcoholic' and 'recalcitrant' have come to be used as synonyms" (Jackson, 1960). In turn, this assumption helped to validate the overuse of coercive measures to ensure that Skid Row alcoholics followed treatment recommendations. Throughout the country, health officials forcibly isolated tuberculous Skid Row alcoholics—even those with inactive tuberculosis—for months or years; patients from other social classes who did not adhere to prescribed therapy received much less harsh treatment (Roth, 1969; Lerner, 1996).

As Sackett and Haynes have noted, the introduction of antibiotics influenced discussions about "compliance" for diseases other than tuberculosis. For instance, a series of articles in the 1950s and 1960s documented that as many as 80% of children with streptococcal pharyngitis (strep throat) were unlikely to complete the requisite treatment, which was three or four penicillin tablets daily for ten

days (Bergman and Werner, 1963). This situation not only lowered cure rates, but also increased the likelihood that children would develop a serious sequela of strep throat, rheumatic fever. Investigators also documented poor cooperation among children with past histories of rheumatic fever who were supposed to take oral penicillin prophylactically to prevent a recurrence of the disease.

Once again, social factors determined how this issue was characterized in the medical literature. Physicians had referred to tuberculous alcoholics—persons with two stigmatizing conditions—as “recalcitrant.” In contrast, even though they noted that it was of “paramount importance” (Mohler *et al.*, 1955) that patients completed their penicillin therapy, authors did not use derogatory terms to describe the children (or their parents) who did not follow recommendations. Instead, one representative study looked at “patient reliability”; another examined the “fidelity of prophylaxis” (Mohler *et al.*, 1956; Feinstein *et al.*, 1959). Presumably, it was much more difficult to criticize children than alcoholics. In addition, research demonstrated that irregular consumption of penicillin extended to all social classes (Charney *et al.*, 1967). As always, the manner in which treatment default was characterized reflected the value judgments of those involved.

This use of relatively uncritical language may have influenced the type of penicillin therapy that physicians ultimately employed. In the case of tuberculosis, as we have seen, condemnatory language contributed to the aggressive use of coercive measures. Yet quite a different situation ensued in the treatment of strep throat and the prophylaxis of rheumatic fever. In 1952, physicians had introduced benzathine penicillin, a long-acting antibiotic that cured strep throat with one intramuscular injection. Subsequent studies demonstrated that benzathine penicillin, because it eliminated the problem of missed pills, was far superior to oral therapy both for treating strep throat and for preventing rheumatic fever (Feinstein *et al.*, 1968; Hellmuth, 1973). Yet despite these data and reports of a few physicians who routinely used benzathine penicillin (Markowitz, 1985), oral therapy remained in widespread use. Thus, less judgmental language may have encouraged less aggressive therapy with respect to ensuring patient cooperation.

Many investigators in the 1950s were well aware of how social factors influenced the degree to which patients followed physicians' advice. Among the notable work performed during this period was that of the sociologist Talcott Parsons, who proposed the concept of the “sick role.” Parsons had suggested a type of quid pro quo: those persons whose illnesses excused them from their usual societal responsibilities were expected to cooperate fully with medical recommendations (Parsons, 1951). By the 1960s, sociologists, anthropologists and others had significantly problematized the sick

role, noting that patients from different cultures had different “clinical realities.” Moreover, even physicians and patients with similar cultural backgrounds experienced sickness differently. Given the wide variety of “illness behaviors” that patients manifested, these commentators argued that the expectation that patients would always follow recommendations was unreasonable (Freidson, 1961; Mechanic, 1962; Kleinman, 1978; Zola, 1981).

One set of critics, a group of social psychologists at the United States Public Health Service, developed a complicated explanation of patients' behaviors known as the “Health Belief Model” (Becker *et al.*, 1979). By looking at how patients understood diseases, perceived their personal susceptibility, and considered treatment options, this model specifically examined those factors that might interfere with patient cooperation. Researchers eventually used these insights to design studies to modify patients' behaviors (Pomerleau *et al.*, 1975; Zifferblatt, 1975).

Of course, this decision to focus on the patient's belief system (as opposed to other potential social factors) was itself historically contingent. Psychological theories of behavior, which drew heavily on the teachings of Sigmund Freud, enjoyed a great deal of popularity in the post-World War II era (Grob, 1991, pp. 134–139). Hence, it should come as little surprise that efforts to improve cooperation centered on understanding how individual patients reacted to and interpreted their diseases. Physicians even invoked such psychological concerns when dealing with “recalcitrant” tuberculosis patients (Tollen, 1950).

COMPLIANCE IS “DISCOVERED”

Investigators actually began using the terms “compliance” and “noncompliance” in the 1960s. For example, a sociologist named Milton Davis published a number of studies that attempted to correlate noncompliance with demographic variables, such as age, sex and income (Davis and Eichhorn, 1963; Davis, 1966). But it was not until the 1970s that Sackett and Haynes created a professional discourse around this topic. Building on symposia they had organized at McMaster University in Canada beginning in 1974, they published books on compliance in 1976 and 1979. While occasional authors had referred to “compliance” (and its corollary “noncompliance”) in the past, Sackett and Haynes used the term to retroactively include all studies of patient cooperation performed since the 1940s. Their success in legitimizing both the area of inquiry and the term “compliance” was confirmed, Haynes noted, when Index Medicus added “Patient Dropouts” and “Patient Compliance” to its index of topics (Haynes, 1979). Studies have consistently found that 38 to 75% of patients do not adhere to prescribed treatments (DiMatteo, 1994). In response,

authors have subsequently published thousands of studies and commentaries investigating various aspects of compliance.

Sackett and Haynes' efforts were considerably more sophisticated than earlier work. First, they proposed a definition of compliance as: "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (Haynes, 1979). Second, they developed a classification system for improving patient compliance, categorizing interventions into those that educated the patient, changed the patient's behavior, or altered the organizational setting in which the physician-patient encounter occurred (Dunbar *et al.*, 1979). Finally, they listed three criteria that had to be satisfied prior to any attempts to change patient behavior: (1) the diagnosis had to be correct; (2) the proposed therapy had to do more good than harm; and (3) the patient had to be an "informed, willing partner" (Sackett, 1976a). This latter requirement reflected the growing role of patient autonomy in medical decision-making in the 1970s.

At first glance, Sackett and Haynes' rigorous approach to compliance might appear to have eliminated many of the earlier judgmental methods by which physicians assessed patient cooperation. After all, the authors had built in numerous safeguards to ensure that efforts to improve compliance were both justifiable and appropriately implemented. Yet Sackett and Haynes' work, too, arose within a particular social context. Specifically, these two men were not only physicians concerned with their own patients, but also epidemiologists performing clinical research (Preface, 1976). Moreover, Sackett and Haynes' primary research focus was in an area that would ultimately be termed "evidence-based medicine." This type of research, which has revolutionized the field of clinical epidemiology, stresses the need to base clinical decision-making on the results of rigorously designed studies that assess among various treatment options (Evidence-Based Medicine Working Group, 1992; Rosenberg and Donald, 1995). Evidence-based medicine well exemplifies the McMaster emphasis on problem-based learning (Davidoff *et al.*, 1995): identification of a clinical problem; evaluation of the problem through appropriate scientific research; and implementation of the therapeutic intervention determined to be the best.

Having been popularized by physician-researchers, it should come as no surprise that noncompliance since the 1970s has been characterized not only as a vexing clinical concern, but also as a scientific problem that researchers could study and correct. Moreover, the issue of noncompliance fit quite nicely into the self-proclaimed "new paradigm" (Evidence-Based Medicine Working Group, 1992) that McMaster's evidence-based medicine represented. That is, noncompliance became one of

many clinical problems that could be identified and studied with the goal of discovering and implementing so-called "authoritative" (Davidoff *et al.*, 1995) solutions. The identification of "authoritative" solutions to noncompliance, in turn, could not but help legitimate the notion that such solutions should be followed—in other words, that patients should comply.

This inherently positivistic approach to noncompliance becomes apparent in the following quote by Brian Haynes and his colleagues:

If true tragedy lies in the failure to achieve that which can be achieved, then true non-compliance is a tragic flaw in our efforts to reap the benefits of treatments that work when they are taken (Haynes *et al.*, 1987).

Not surprisingly, therefore, the literature of compliance since 1976 is replete with various interventions—such as the use of long-acting medications, pill-dispensing systems, educational outreach, and behavior modification strategies—that begin with the assumption that noncompliance is both a definable and potentially "fixable" problem (DiMatteo, 1994; Stephenson *et al.*, 1993; Roter and Hall, 1994) (While Sackett and Haynes did express some doubts about the ultimate success of measuring compliance, these reservations reflected only methodological limitations) (Haynes, 1987).

Sackett and Haynes' notions of compliance and noncompliance have received a great deal of criticism. Commentators have argued that these terms mask an inherent ideological message: that any patient who does not comply with the advice of physicians is by definition behaving in an irrational manner (Stimson, 1974; Trostle, 1988; Donovan and Blake, 1992). Persons writing about compliance, James Trostle has stated, incorrectly presuppose that doctors' recommendations should invariably be followed. He offered the following quote by Milton Davis as an example:

When the doctor performs a service, the patient is obligated to reciprocate: first, by cooperating with the doctor in their interaction; and second, by complying with the medical recommendations once he leaves the doctor's office (Trostle, 1988).

Thus, Gerry Stimson concludes, the ideology of compliance reinforces a model of physician control in which "the patient should obey or comply with what the doctor says" (Stimson, 1974).

How valid are these criticisms of compliance? In certain instances, they are somewhat overblown. After all, as physicians are highly trained professionals who have earned the cultural authority to treat illness, there is good reason why they might expect that patients would choose to follow their recommendations. Moreover, in the case of certain contagious diseases, a societal consensus exists that noncompliance cannot be tolerated. Here it is instructive to return to the case of tuberculosis. Since the 1960s, growing attention to civil liberties

in the United States has discouraged the use of forcible detention of noncompliant tuberculosis patients except as a last resort (Lerner, 1996). Nevertheless, with the recent resurgence of tuberculosis and the emergence of multidrug-resistant strains, health officials have come to rely on another restrictive intervention, directly observed therapy (DOT). In DOT, patients are required to take their antibiotics under the direct supervision of a health worker—either in a clinic, at the patient's home, or on the street. Indeed, DOT has become the method of choice for promoting compliance among the millions of predominantly poor persons with the disease worldwide (Bayer and Wilkinson, 1995).

Overwhelmingly, however, issues of noncompliance arise in the treatment of noncontagious chronic diseases, where a clear public health mandate does not exist. For these conditions, such as hypertension, heart disease and asthma, our current notion of compliance may indeed imply unfair presuppositions about proper patient behavior. Is a patient with mild hypertension noncompliant if he chooses not to take daily medications that cause him fatigue and impotence? What about a man with a mildly elevated prostatic specific antigen (PSA) level who declines a biopsy that would reveal if he has early prostate cancer? By reflexively terming such behavior "noncompliant" or even "nonadherent," a negative value judgment is being made about what may be a legitimate patient choice.

Interestingly, Sackett and Haynes had predicted that the use of the term "compliance" was likely to generate criticism. Noting how the concept of compliance might seem "troublesome" in an era of increasing patient autonomy, they intended the term to be "nonjudgmental" (Sackett, 1976a; Haynes, 1979). With the advantage of historical hindsight, however, we now can understand how the notion of compliance was in fact intrinsically tied in to the powerful model of evidence-based medicine that physicians would use to reassert the authority of both medicine and science during the 1980s and 1990s.

CONCLUSION

In describing tuberculous and other patients who did not follow medical recommendations, physicians during the 20th century have used numerous judgmental terms. In many cases, to paraphrase the historian JoAnne Brown, the language itself "succeeded" (Brown, 1986). That is, calling patients "recalcitrant" and "noncompliant" reinforced the widely held cultural belief that patients who did not follow physicians' advice were both deviant and deserving of aggressive remedial interventions. In this sense, the recent criticisms of compliance make an important point about how use of the term may serve to legitimate physician control.

Yet at the same time, focusing too closely on the negative repercussions of terminology may limit our inclination to address the larger issues at stake. This paper has argued that the language used to describe patient noncompliance has been historically contingent, reflecting the particular social circumstances of both physicians and patients in different historical eras. Thus, rather than simply replacing compliance with less pejorative terms, such as "adherence," "fidelity," "drug-taking behavior" or "medication consumption" (Trostle, 1988; Feinstein, 1990; Scofield, 1995), we need to ask why the issue of compliance has so regularly been framed in terms of the need for patients to slavishly follow physicians' orders.

The answer to this question has to do with the limitations of informed consent as a guiding principle for medical decision-making (Cross and Churchill, 1982). Despite the growth of patient autonomy over the last quarter-century, clinicians have been reluctant to cede decision-making authority to their patients. At one extreme are physicians such as the late Franz Ingelfinger, who wrote that "a certain amount of authoritarianism, paternalism, and domination are the essence of the physician's effectiveness" (Ingelfinger, 1980). While many clinicians would be uncomfortable with this statement, it is clear that large numbers of (if not all) doctors continue to believe that some degree of persuasion and "mind bending" is necessary if one is to be an effective physician (Sackett, 1976b; Eraker *et al.*, 1984; Tomlinson, 1986). Indeed, in one recent study, 29% of physicians admitted to having actually manipulated patients into accepting or rejecting a procedure or test (Green *et al.*, 1996). And, of course, some patients prefer that their physicians make decisions for them, a process that Alan Cross and Larry Churchill have termed "paternalism with permission" (Cross and Churchill, 1982; Ende *et al.*, 1989).

Acknowledging the limitations of clinical decision-making based either entirely on paternalism or patient autonomy, commentators have long proposed alternative models. Early suggestions came from anthropologists, who, emphasizing the different cultural expectations of the clinical encounter, encouraged negotiation between physicians and patients (Good and Delvecchio Good, 1981; Katon and Kleinman, 1981). More recently, ethicists have made similar arguments, conceptualizing the physician-patient relationship as one of accommodation or mutual persuasion (Siegler, 1982; Thomasma, 1983; Smith and Pettigrew, 1986). The findings of this paper support the use of these types of strategies. Rather than replacing the paternalistic word "compliance" with a more benign term respectful of patient autonomy, we need to integrate the issue of compliance into a model that accepts both a degree of physician control and patient resistance. In such a system, we might replace the question "How can

we make a noncompliant patient compliant?" with a different question: "To what extent (and in what ways) should a physician encourage a given patient who is resisting his or her advice?" One helpful strategy for approaching this latter question might include the use of narrative knowledge, in which the physician examines clinical dilemmas "within the framework of a patient's culture and biography" (Charon *et al.*, 1995).

The possibility of adopting this type of model, however, now faces a new barrier, especially in the United States. Managed care organizations (MCOs), which attempt to provide quality care as inexpensively as possible, have a particular interest in the issue of noncompliance. Patients who do not take their medications as prescribed may be at a higher risk of bad health outcomes, which may increase costs. Such concerns pertain not only to pills but to behaviors. Thus, in the managed care setting, consumption of junk food, inadequate exercise, or even overwork may be defined as noncompliance with one's "appropriate" medical regimen. Financial or other penalties might then ensue, especially for persons who lack consistent access to health insurance through stable employment (Morreim, 1995).

One notable intervention being pursued by MCOs, often in conjunction with pharmaceutical companies, is "disease management." Such programs employ strategies such as reminders, incentives, home visits, and even electronic "home-monitoring" technologies to ensure that patients "adhere to a rational care program" (Marwick, 1995; Freudenheim, 1997). These efforts may also include the use of financial pressures to induce physicians and employers to get patients to change their behaviors (Morreim, 1995; Goldsmith, 1995; MacKinnon *et al.*, 1996). Yet—like "compliance" and "noncompliance"—an ostensibly scientific phrase such as "disease management" will also require scrutiny. By examining the historical construction of language, we remind ourselves how a social agenda may be concealed within scientific terminology.

Acknowledgements—The author is Arnold P. Gold Foundation Assistant Professor of Medicine at Columbia University and a Robert Wood Johnson Foundation Generalist Faculty Scholar. The views expressed here do not necessarily reflect those of either foundation. Helpful suggestions regarding this paper were made by Ellen S. More, E. Haavi Morreim, David J. Rothman and Cathy Seibel.

REFERENCES

Anon (1943) A wartime obligation. *Bulletin of the National Tuberculosis Association* 29, 1, 26.
 Bayer, R. and Wilkinson, D. (1995) Directly observed therapy for tuberculosis: history of an idea. *Lancet* 345, 1545–1548.

Becker, M. H. *et al.* (1979) Patient perceptions and compliance: recent studies of the health belief model. In *Compliance in Health Care*, eds R. B. Haynes *et al.*, pp. 78–109. Johns Hopkins University Press, Baltimore.
 Bergman, A. B. and Werner, R. J. (1963) Failure of children to receive penicillin by mouth. *New England Journal of Medicine* 268, 1334–1338.
 Biggs, H. M. (1904) The administrative control of tuberculosis. *Medical News* 84, 337–345.
 Bobrowitz, I. D. (1946) Why they leave against advice. *Bulletin of the National Tuberculosis Association* 32, 151–152.
 Bridge, E. (1949) The recalcitrant patient. *Bulletin of the National Tuberculosis Association* 35, 119–120.
 Brown, J. (1986) Professional language: words that succeed. *Radical History Review* 34, 33–51.
 Campagna, M. and Greenberg, H. B. (1964) Recalcitrant patients with pulmonary tuberculosis. *Journal of the Louisiana State Medical Society* 116, 262–267.
 Charney, E. *et al.* (1967) How well do patients take oral penicillin? A collaborative study in private practice. *Pediatrics* 40, 188–195.
 Charon, R. *et al.* (1995) Literature and medicine: contributions to clinical practice. *Annals of Internal Medicine* 122, 599–606.
 Cross, A. W. and Churchill, L. R. (1982) Ethical and cultural dimensions of informed consent. A case study and analysis. *Annals of Internal Medicine* 96, 110–113.
 Davidoff, F. *et al.* (1995) Evidence based medicine. A new journal to help doctors identify the information they need. *British Medical Journal* 310, 1085–1086.
 Davies, R. (1952) Why people die of tuberculosis. *Health Pilot of the Washington Tuberculosis Association* 35(1), 4–5.
 Davies, R. (1954) Isolating the recalcitrants. *Bulletin of the National Tuberculosis Association* 40, 121–122.
 Davis, M. S. (1966) Variations in patients' compliance with doctors' orders: analysis of congruence between survey responses and results of empirical investigations. *Journal of Medical Education* 41, 1037–1048.
 Davis, M. S. and Eichhorn, R. L. (1963) Compliance with medical regimens: a panel study. *Journal of Health and Human Behavior* 4, 240–249.
 DiMatteo, M. R. (1994) Enhancing patient adherence to medical recommendations. *Journal of the American Medical Association* 271, 79–83.
 Donovan, J. L. and Blake, D. R. (1992) Patient non-compliance: deviance or reasoned decision-making. *Social Science & Medicine* 34, 507–513.
 Drolet, G. J. and Porter, D. E. (1949) *A Study of "Why Do Patients in Tuberculosis Hospitals Leave Against Medical Advice."* New York Tuberculosis and Health Association, New York.
 Dublin, L. I. (1946) The problem of the tuberculous veteran. *Transactions of the National Tuberculosis Association* 40, 151–154.
 Dunbar, J. M. *et al.* (1979) Behavioral strategies for improving compliance. In *Compliance in Health Care*, eds R. B. Haynes *et al.*, pp. 174–190. Johns Hopkins University Press, Baltimore.
 Ende, J. *et al.* (1989) Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine* 4, 23–30.
 Eraker, S. A. *et al.* (1984) Understanding and improving patient compliance. *Annals of Internal Medicine* 100, 258–268.
 Evidence-Based Medicine Working Group (1992) Evidence-based medicine. A new approach to teaching the practice of medicine. *Journal of the American Medical Association* 268, 2420–2425.

- Feinstein, A. R. (1990) On white-coat effects and the electric monitoring of compliance [editorial]. *Archives of Internal Medicine* **150**, 1377-1378.
- Feinstein, A. R. et al. (1959) A controlled trial of three methods of prophylaxis against streptococcal infection in a population of rheumatic children. II. Results of the first three years of the study, including methods for evaluating the maintenance of oral prophylaxis. *New England Journal of Medicine* **260**, 697-702.
- Feinstein, A. R. et al. (1968) Prophylaxis of recurrent rheumatic fever. Therapeutic-continuous oral penicillin vs monthly injections. *Journal of the American Medical Association* **206**, 565-568.
- Feudtner, C. (1994) To live a normal life: history and health behavior. *Journal of the American Medical Association* **271**, 82-83.
- Foster, J. P. C. (1905) Detention institutes for ignorant and vicious consumptives. *Transactions of the National Association for the Study and Prevention of Tuberculosis* **1**, 333-338.
- Fox, R. C. (1989) The social and cultural significance of health and illness. In *The Sociology of Medicine: A Participant Observer's View*, ed. R. C. Fox, pp. 1-37. Prentice-Hall, Englewood Cliffs.
- Freidson, E. (1961) *Patients' Views of Medical Practice*. Sage, New York.
- Freudenheim, M. (1997) In the H.M.O. era, the house call is by telephone. *New York Times* February 24, D1, D10.
- Goldsmith, J. C. (1995) Managed care comes of age. *Healthcare Forum Journal* **38**(5), 14-22, 24.
- Good, B. and Delvecchio Good, M. (1981) The meaning of symptoms: a cultural hermeneutic model for clinical practice. In *The Relevance of Social Science for Medicine*, eds L. Eisenberg and A. Kleinman, pp. 165-196. Reidel, Dordrecht.
- Green, M. J. et al. (1996) Do actions reported by physicians in training conflict with consensus guidelines on ethics? *Archives of Internal Medicine* **156**, 298-304.
- Grob, G. N. (1991) *From Asylum to Community. Mental Health Policy in Modern America*. Princeton University Press, Princeton.
- Haynes, R. B. (1979) Introduction. In *Compliance in Health Care*, eds R. B. Haynes et al., pp. 1-6. Johns Hopkins University Press, Baltimore.
- Haynes, R. B. (1987) Patient compliance then and now [editorial]. *Patient Education and Counseling* **10**, 103-105.
- Haynes, R. B. et al. (1987) A critical review of interventions to improve compliance with prescribed medications. *Patient Education and Counseling* **10**, 155-166.
- Hellmuth, G. A. (1973) Preventing rheumatic fever and rheumatic heart disease. *American Family Physician* **7**, 129-132.
- Ingelfinger, F. J. (1980) Arrogance. *New England Journal of Medicine* **303**, 1507-1511.
- Jackson, J. K. (1960) Alcoholism and tuberculosis. Unpublished manuscript.
- Katon, W. and Kleinman, A. (1981) Doctor-patient negotiation and other social science strategies in patient care. In *The Relevance of Social Science for Medicine*, eds L. Eisenberg and A. Kleinman, pp. 253-279. Reidel, Dordrecht.
- Katz, J. (1984) *The Silent World of Doctor and Patient*. Free Press, New York.
- Katz, M. B. (1986) *In the Shadow of the Poorhouse: A Social History of Welfare in America*. Basic Books, New York.
- Kevles, D. J. (1985) *In the Name of Eugenics*. Knopf, New York.
- Kleinman, A. (1978) Clinical relevance of anthropological and cross-cultural research: concepts and strategies. *American Journal of Psychiatry* **135**, 427-431.
- Lerner, B. H. (1993) New York City's tuberculosis control efforts: the historical limitations of the "war on consumption". *American Journal of Public Health* **83**, 758-766.
- Lerner, B. H. (1996) Temporarily detained: tuberculous alcoholics in Seattle, 1949 through 1960. *American Journal of Public Health* **86**, 257-265.
- Lloyd, J. J. (1918) The necessity for caring for the careless consumptive. *Transactions of the National Tuberculosis Association* **14**, 163-165.
- MacKinnon, N. J. et al. (1996) Disease management program for asthma: baseline assessment of resource use. *American Journal of Health-System Pharmacy* **53**, 535-541.
- Markowitz, M. (1985) Long-acting penicillins: historical perspectives. *Pediatric Infectious Disease* **4**, 570-573.
- Marwick, C. (1995) Another health care idea: disease management. *Journal of the American Medical Association* **274**, 1416-1417.
- Mechanic, D. (1962) The concept of illness behavior. *Journal of Chronic Diseases* **15**, 189-194.
- Mohler, D. N. et al. (1955) Studies in the home treatment of streptococcal disease. I. Failure of patients to take penicillin by mouth as prescribed. *New England Journal of Medicine* **252**, 1116-1118.
- Mohler, D. N. et al. (1956) Studies in the home treatment of streptococcal disease. II. A comparison of the efficacy of oral administration of penicillin and intramuscular injection of benzathine penicillin in the treatment of streptococcal pharyngitis. *New England Journal of Medicine* **254**, 45-50.
- Morreim, E. H. (1995) Lifestyles of the risky and infamous. From managed care to managed lives. *Hastings Center Report* **25**(6), 5-12.
- Newcomb, C. (1944) All out offensive. *Bulletin of the National Tuberculosis Association* **30**, 334.
- Northrop, C. et al. (1952) The practical management of the recalcitrant tuberculous patient. *Public Health Reports* **67**, 894-898.
- Parsons, T. (1951) *The Social System*. Free Press, Glencoe, IL.
- Pomerleau, O. et al. (1975) Role of behavior modification in preventive medicine. *New England Journal of Medicine* **292**, 1277-1282.
- Preface (1976) in *Compliance with Therapeutic Regimens*, eds D. L. Sackett and R. B. Haynes, pp. xi-xiv. Johns Hopkins University Press, Baltimore.
- Rosenberg, W. and Donald, A. (1995) Evidence based medicine: an approach to clinical problem solving. *British Medical Journal* **310**, 1122-1126.
- Roter, D. L. and Hall, J. A. (1994) Strategies for enhancing patient adherence to medical recommendations. *Journal of the American Medical Association* **271**, 80.
- Roth, J. A. (1969) The treatment of the sick. In *Poverty and Health. A Sociological Analysis*, eds J. Kosa et al., pp. 215-243. Harvard University Press, Cambridge.
- Rothman, S. M. (1994) *Living in the Shadow of Death. Tuberculosis and the Social Experience of Illness in American History*. Basic Books, New York.
- Sackett, D. L. (1976a) Introduction. In *Compliance with Therapeutic Regimens*, eds D. L. Sackett and R. B. Haynes, pp. 1-6. Johns Hopkins University Press, Baltimore.
- Sackett, D. L. (1976b) Priorities and methods for future research. In *Compliance with Therapeutic Regimens*, eds D. L. Sackett and R. B. Haynes, pp. 169-189. Johns Hopkins University Press, Baltimore.
- Scoufield, G. R. (1995) The problem of (non-)compliance: is it patients or patience? *H E C Forum* **7**, 150-165.
- Sheen, T. N. (1950) How we can reduce "sign outs". *Bulletin of the National Tuberculosis Association* **36**, 131-132.

- Siegler, M. (1982) The physician-patient accommodation: a central event in clinical medicine. *Archives of Internal Medicine* **142**, 1899-1902.
- Smith, D. H. and Pettigrew, L. S. (1986) Mutual persuasion as a model for doctor-patient communication. *Theoretical Medicine* **7**, 127-146.
- Sontag, S. (1978) *Illness as Metaphor*. Farrar, Straus and Giroux, New York.
- Stephenson, B. J. *et al.* (1993) Is this patient taking the treatment as prescribed?. *Journal of the American Medical Association* **269**, 2779-2781.
- Stimson, G. V. (1974) Obeying doctor's orders: a view from the other side. *Social Science & Medicine* **8**, 97-104.
- Taylor, R. B. (1956) Patients who disregard medical recommendations. *Public Health Reports* **71**, 904-907.
- Teller, M. E. (1988) *The Tuberculosis Movement. A Public Health Campaign in the Progressive Era*. Greenwood Press, New York.
- Thomasma, D. C. (1983) Beyond medical paternalism and patient autonomy: a model of physician conscience for the physician-patient relationship. *Annals of Internal Medicine* **98**, 243-248.
- Tollen, W. B. (1950) Why do patients go AWOL? *Bulletin of the National Tuberculosis Association* **36**, 101-102.
- Tomlinson, T. (1986) The physician's influence on patients' choices. *Theoretical Medicine* **7**, 105-121.
- Trostle, J. A. (1988) Medical compliance as an ideology. *Social Science & Medicine* **27**, 1299-1308.
- Webster's Third New International Dictionary of the English Language Unabridged* (1981) Merriam-Webster, Springfield, MA.
- Zifferblatt, S. M. (1975) Increasing patient compliance through the applied analysis of behavior. *Preventive Medicine* **4**, 173-182.
- Zola, I. K. (1981) Structural constraints in the doctor-patient relationship: the case of non-compliance. In *The Relevance of Social Science for Medicine*, eds L. Eisenberg and A. Kleinman, pp. 241-252. D. Reidel, Dordrecht.