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Taking the cure:

Control and compliance in American medicine

by

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Taking the cure: Control and compliance in American medicine

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by

Melissa Susan Gosland

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I. Introduction

compliance (kom-pli'-ans) *n.* a quality of yielding to pressure or force without disruption
—*Dorland's Medical Dictionary,* 27th edition

drop-outs

drug defaulters

treatment failures

recalcitrant

nonconforming **terminators**

problem patients

nonadherence **disobedience**

noncompliance

misuse

discontinuation

attrition

defection

against medical advice

unwilling unable uncooperative unreliable unresponsive unmotivated unrealistic

uncontrollable...

These are the terms used by the medical profession to describe a phenomenon which dates back as far as written medical discourse.[1] The purpose of this study is to examine the context in which this phenomenon—presently referred to as "noncompliance"—takes place; to go beyond the individual and interpersonal to the social and historical in order to uncover the assumptions underlying the current explanations of this "problem;" and to explore how these assumptions legitimate the existing medical structure and limit recommendations for action. I will do this by examining the physician's perspective on noncompliance, rather than

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[1]See annotated bibliography in R. Brian Haynes, D. Wayne Taylor, and David L. Sackett, Compliance in health care (Baltimore: Johns Hopkins University Press, 1979) for examples of the ubiquitous nature of these (and other) terms.

looking at compliance from the perspective of the physician, as has been done at length in the past.[2]

As it is the most widely used term today, I will use *(non)compliance* to describe this phenomenon. This term is laden with meaning, not only for the reader who is familiar with its use in medicine, but for many others (e.g. lawmakers, public policy advisors) as well. The word itself imputes judgment on the behavior of another. Finding adequate terms to describe this phenomenon has been a struggle for researchers. A variety of descriptions were used previous to the 1970's (e.g. recalcitrant, uncontrollable, etc.). Once researchers began to consolidate their interest in the subject, they converged on a selected number of terms: first, "patient dropouts", and later, "noncompliance." More recently there has been an attempt to change the contractual implications of this term by using "adherence." However, this term has only served to further couch the underlying assumptions of the construct, rather than expose and examine these assumptions in a more critical light.

Obviously a new term is needed; however, changing words without altering their underlying meaning means little, as we will see. Therefore, I have opted to use the noncompliance-compliance axis to describe the extent to which the behavior of a "patient" and the desires of a medical professional are in consonance. This definition of compliance is similar to that used by Haynes and Sackett in their thorough literature review on the subject, where compliance is defined as "the extent to which a person's behavior coincides with medical or health advice."[3] I have altered their term concerning medical or health *advice* to the *desires* of the professional,

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[2]For examples consult Haynes, Taylor and Sackett's cumulative bibliography on the topic, which cites more than 850 of the studies done before 1979.

[3]Haynes, Taylor and Sackett, pp. 1-2.

and have placed the patient's behavior on equal footing with the desires of the health care provider, so that the patient is not placed in the position of coinciding (or not) with the provider; rather, the two parties are able to maneuver for mutual agreement. My reasons I hope will become clear as I go on.

The sequelae of noncompliance

Noncompliance has ramifications which extend into the realms of disease morbidity, mortality, and prevention; health policy and economics; clinical trials of pharmaceuticals; and also into the more intimate realm of the physician-patient relationship. If one believes that many of the treatments prescribed by physicians are efficacious in the management or cure of disease, it follows that noncompliance in the form of under-use of treatment might result in unnecessary morbidity and mortality from treatable diseases. Under-use of treatment—especially when response to therapy is assessed by physiologic effects—may cause the physician to prescribe greater and greater doses of a medication under the assumption that the patient's individual physiology requires above-average amounts. Such over-prescription can lead to toxic drug reactions and contribute to wasteful health care expenditures.[4] Another response of the physician may be to alter the diagnosis or treatment plan, assuming that the disease is "resistant" to a certain class of pharmaceuticals, or that nonresponse means missed diagnosis.[5] This reclassification may lead to a significantly increased number of physician visits, lab tests, and clinical procedures, all

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[4]William W. Neal, Reducing costs and improving compliance, American Journal of Cardiology **63**(4) (Jan 17 1989):18B.

[5]P.P. Joshi and S.K. Kate, Resistant hypertension or patient noncompliance? Journal of the Association of Physicians of India **38**(10) (1990):810-811.

of which contribute to the discomfort of the patient as well as to inflated health care costs.[6]

Noncompliance in clinical trials has recently been recognized as an important variable in evaluating the efficacy of a new drug.[7] "Hypo-compliance" may result in underestimates of the true efficacy of the agent being tested, while "hyper-compliance" (also considered noncompliance) can lead to excessive side effects as well as overestimates of therapeutic power. Thus, conclusions derived from studies which have not adequately assessed subject compliance may be inaccurate.[8]

Finally, within the physician-patient relationship, noncompliance may lead to increased feelings of hostility on the part of the physician, with important effects on the patient (whether or not that patient is actually noncompliant, for we shall see that physicians are notoriously inaccurate in such assessments). In dealing with a patient who is believed to be noncompliant, the physician may be frustrated, threatened and/or threatening, persuasive, or openly angry.[9] Most physicians view the patient as a person who is seeking advice, who by coming to the doctor has made an implicit agreement to follow that advice (a belief reflected in and

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[6]Marshall H. Becker, Patient adherence to prescribed therapies, Medical Care **23**(5) (May 1985):539.

[7]See D. Dickson and J. Hasford, 24-hour blood pressure measurement in antihypertensive drug trials: data requirements and methods of analysis. Statistics in Medicine **11**(16) (Dec 1992):2147-58; W.J. Loesche, N. Grossman and J. Giordano, Metronidazole in periodontitis: the effect of patient compliance on treatment parameters, Journal of Clinical Periodontology **20**(2) (Feb 1993):96-104; and P. Rudd, R.L. Pyyny, V. Zachary., *et al.*, The natural history of medication compliance in a drug trial: limitations of pill counts, Clinical Pharmacology and Therapeutics **46**(2) (Aug 1989):169-76. See also Alvan R. Feinstein, "Compliance bias" and the interpretation of therapeutic trials. In Compliance in health care (edited by Haynes R.B., Taylor D.W. and Sackett D.L.), pp. 309-322. (Baltimore: Johns Hopkins University Press, 1979).

[8]Felicia S. Hodge, Factors contributing to selective utilization of treatment regimens: diabetic perceptions and explanations PhD dissertation (Berkeley: University of California, 1987),4.

[9]Richard F. Gillum and Arthur J. Barsky, Diagnosis and management of patient noncompliance, Journal of the American Medical Association **228** (1974):1563.

institutionalized by Talcott Parsons' sick role theory).[10] The physician him- or herself has gone through years of training, and may view the noncompliant patient as ill-equipped to make certain health-care decisions. He or she speaks of patients "playing" with their medications—a term which implies childish, naïve behavior.[11] Others perceive noncompliant patients as lacking in intelligence, character, or self-control.[12] Moreover, those physicians who do not recognize noncompliance in their practices also risk the quality of their relationships with their patients, who may come to view their doctors as professionals dispensing advice which, at some level, is unwanted, intrusive, disruptive, and given in a presumptuous manner.[13]

These concerns are taken by some to mean that we must strive ever harder to quash noncompliance in order to have maximum economic and health effects. I hope in this paper not to promulgate this view, but mention these considerations because they are indeed of concern, and will continue to be until we have a better understanding of how the medical profession is limiting its own ability to cope with noncompliance.

Compliance as an area of study

Patient compliance seemed to burst onto the research scene in the mid-1970's, a growth marked by its entry into the official subject headings of *Index Medicus* (initially under the heading "Patient Dropouts" and later,

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[10]Talcott Parsons, The social system (Glencoe, IL: Free Press, 1951),437.

[11]James A. Trostle, Doctors' orders and patients' self-interest: two views of medication usage? Compliance in Epilepsy, Epilepsy Research, Supp. 1. (edited by Schmidt D. and Leppik I.E.), (Elsevier Science Publishers B.V., 1988.),64.

[12]Susan Hopper, Diabetes as a stigmatized condition: the case of low-income clinic patients in the United States, Social Science and Medicine **15B** (1981):15.

[13]Irving K. Zola, Structural constraints in the doctor-patient relationship: the case of non-compliance. In The relevance of social science for medicine (edited by Eisenberg L. and Kleinman A.), (Dordrecht: D. Reidel Publishing, 1981),242.

"Patient Compliance"). A *Compliance Newsletter* was started, and symposia on the topic sprang up across the country, sparking the interest of professionals and researchers from a range of disciplines.[14] During the 1960's, research articles on the subject began to appear sporadically in the literature, with less than 350 published before 1973. At that time, the number of articles skyrocketed, and as of mid-1993, there have been over 10,000 articles published which deal primarily with issues around patient compliance, including over 2500 since 1990 alone.[15]

Explanations for this flurry of interest vary. Many imply that compliance has become an issue now that "we have therapies that *really* work," and that previous to antibiotics, doctors "did not take noncompliance very seriously."[16] However, scientifically proven therapeutic efficacy does not always provide the foundation of physicians' beliefs and actions. Indeed, several researchers found that a complex combination of variables affects physician decision-making. These variables include the disease, the potential clinical benefits, risks and costs to the patient, economic benefit to the practitioner, the potential impact in terms of physician self-image, practice satisfaction, practitioner density, practitioner and patient characteristics, established routine in dealing with uncertainty, and status among colleagues and community members.[17] More specifically, Denig *et al.* found that knowledge of treatment outcomes determines drug choice only in part, and that in some cases the professional environment may be

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[14]Haynes, Taylor and Sackett, p. xv.
[15]Medline search and Haynes, Taylor and Sackett, p. 2.
[16]Haynes, Taylor and Sackett, p. 4.
[17]G.A. Maryniuk, Practice variation: learned and socio-economic factors, Adv. Dental Research 4 (Jun 1990):23.

the single most important factor in choice of drug.[18] Other studies supported these findings, also discovering that physicians' perceptions (however misguided) of patient compliance were important predictors of drug choice.[19] Given these various factors which affect therapeutic choice, then, the argument that interest in compliance has grown up around therapeutic effectiveness is questionable.

James Trostle suggests that the recent preoccupation with compliance is a consequence of the declining authority of the profession.[20] As in many professions, concerns about client compliance with rules or recommendations are at their peak when the profession (or the professional) is threatened. Paul Starr has reviewed the decline of professional sovereignty in medicine which began in the 1970's.[21] This "loss of legitimacy" occurred suddenly, and within the first five years of the decade, medicine had greatly lost the confidence of the public. Concerns were growing about the economic "crisis" in health care, patients' rights, and governmental regulation. These concerns coincide temporally with the sudden increase in compliance research—a correlation which points to reasons for the increased interest which occurred long after the onset and quite independent of the 20 year-old antibiotic era.

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[18]P. Denig, R.M. Haaijer-Ruskamp and D.H. Zijsling, How physicians chose drugs, Social Science and Medicine **27**(12) (1988):1386.

[19]K.T. Safavi and R.A. Haywar, Choosing between apples and apples: physicians' choices of prescription drugs that have similar side effects and efficacies, Journal of General Internal Medicine **7**(1) (Jan-Feb 1992):32-7.

[20]James A. Trostle, Medical compliance as an ideology, Social Science and Medicine **12** (1988):1299-1308.

[21]Paul Starr, The social transformation of American medicine (New York: Basic Books, 1982),381.

Patient-centered studies

Following the rush to study compliance, which was (and is) predominantly carried out by physicians and behavioral scientists, there was a "backlash" of sorts which came out of the fields of anthropology and sociology. Beginning with the work of Stimson and Hayes-Bautista in the '70's, and continued by Blumhagen, Leventhal, Trostle, Conrad, Huertin-Roberts, and Hunt in the '80's, and Donovan and Blake in the '90's, these researchers, noting that the mainstream research was limited in scope by "management bias," turned to patients to gain new insights into the realm of noncompliance. They found that patients' patterns of medication usage are often determined by their own "views of what's wrong," rather than the physicians'.[22] Not the passive recipients of care expected by the traditional medical model, these patients were found to be actively modifying their treatment regimens in order to more closely approximate *their* worldview and personal representation of illness. These studies are notable for their attempt to understand noncompliance within the context of the patients' worldview, an insight which has been missing from examinations rooted in the medical paradigm.

Assessing noncompliance

In recent decades, investigators have developed a wide range of methods to measure compliance. Pill counts, urine assays, plasma drug levels, glycosylated hemoglobin, chemical tags on medications (e.g. riboflavin on isoniazid), breath tests, pharmacy refill records, chart reviews, physiologic responses, pharmaceutical "compliance tests," patient interviews and questionnaires have all been utilized to uncover the "true"

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[22]Linda M. Hunt, Brigitte Jordan and Susan Irwin, Views of what's wrong: diagnosis and patients' concepts of illness, Social Science and Medicine **9** (1989):945-956.

rates of noncompliance.[23] One Northern California company has even developed a microprocessor which fits into the pill bottle cap, recording each bottle opening, or "medication event."[24] Despite these multiple, often high-tech maneuvers, several studies demonstrate the equal and sometimes superior efficacy of simply asking patients about their patterns of medication usage.[25] For example, Hershey *et al.* found that asking outpatients whether they took their medications "always, most of the time, some of the time, or never" yielded results which were generally consistent with the measurable decrease in these patients' blood pressures.[26] Furthermore, Haynes *et al.* developed an interview instrument which yielded results which were more consistent with pill counts than qualitative measures of serum or urine levels of drug metabolites.[27] Despite these results, physicians and researchers continue to search for and experiment with new tools for compliance assessment—tools which may serve to reinforce unequal power relations between physicians and patients in their attempts to improve patient care.

Physicians' accuracy in assessment

Physicians, who are generally confident in their abilities to diagnose and treat, are similarly confident in their abilities to assess patient

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[23]Joshi and Kate, p. 810; and Haynes, Taylor and Sackett, p. 23-45.

[24]J.A. Cramer, R.H. Mattson, M.L. Prevey, *et al.*, How often is medication taken as prescribed? JAMA **261** (1989):373-7.

[25]Lawrence E. Klein, Compliance and blood pressure control, Hypertension **11**(3 pt. 2) (Mar 1988):II-62.

[26]J.C. Hershey, B.G. Morton, J.B. Davis and M.J. Reichgott, Patient compliance with antihypertensive medication, American Journal of Public Health **70** (1980):1081-1089.

[27]Structured interviews yielded 75% accuracy, vs. 66-67% for serum levels of metabolites and 52-64% accuracy for hydrochlorothiazide urine tests. R.B. Haynes, D.W. Taylor, D.L. Sackett, E.S. Gibson, D.C. Bernholz and J. Mukherjee, Can simple clinical measurements detect patient noncompliance? Hypertension **2** (1980):760-762.

compliance. Few, however, utilize the methods of assessment outlined above. Based on subjective criteria which are deeply rooted in professional beliefs, physicians feel that they are able to accurately assess the medication-taking behavior of their patients.[28] Physicians are wrong. The few studies in this area show that physicians overwhelmingly are unable to differentiate the compliers from the noncompliers.[29] In a 1966 study, Milton S. Davis asked physicians to estimate the percentage of their patients who adhered to the medical advice given. His results showed that overestimations were the rule, with 82% of fourth-year medical students and 93% of senior physicians believing that at least three-fourths of their patients were compliant.[30] By more objective standards, the investigators found mean patient compliance rates to be 63%.[31]

Two more recent studies again showed that most physicians overestimate the rates of adherence in their practice, based on comparisons between physician estimates and careful observation of inpatient consumption of medications. Median compliance rates by physician assessment were 70%, while median rates by direct observation were 46%.[32] Even more importantly, Mushlin and Appel demonstrated that physicians

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[28]A 1984 study of nurses found that social-psychological factors accounted for more of the variance in predicting whether a patient was labeled as compliant than did biochemical evidence. Alexis M. Nehemkis, The eye of the beholder: staff perceptions of noncompliance. In Compliance: the dilemma of the chronically ill (edited by Nehemkis A.M.), pp. 158-181. (New York: Springer Pub. Co., 1986),171.

[29]G. Sahm, A. Bartsch and E. Witt, Reliability of patient reports on compliance, European Journal of Orthodontics **12**(4) (Nov 1990):438-46.

[30]Milton S. Davis, Variations in patients' compliance with doctors' orders: analysis of congruence between survey responses and results of empirical investigations, Journal of Medical Education **41** (1966):1039.

[31]Milton S. Davis, Variations in patients' compliance with doctors' advice: an empirical analysis of patterns of communication, American Journal of Public Health **58**(2) (Feb 1968):278.

[32]Herbert S. Caron and Harold P. Roth, Patients' cooperation with a medical regimen: difficulties in identifying the noncooperator, JAMA **203** (1968):121.

not only overestimate the compliance of their patients, but they also are unable to correctly identify "good" vs. "poor" cooperators. Even when limited to those patients whose compliance status they felt very confident of, physicians were no more accurate than would have been predicted by chance alone.[33] Furthermore, as Davis[34] demonstrated earlier, these researchers found that physicians were more likely to get worse, rather than better, in their assessments as their careers progressed.[35]

Many providers believe that they can identify patients prone to noncompliance based on intellectual, motivational, and emotional characteristics of the patient, thus attempting to describe an "epidemiology" of noncompliance. For example, Davis found that over 60% of physicians interviewed felt that noncompliance could be attributed to the patient's "uncooperative personality," and over 40% attributed noncompliance to the patient's "inability to understand recommendations."[36] Numerous studies have been done in an attempt to ascertain the demographics of noncompliance, with mixed results. While the articles selected for this study mentioned several factors associated with poor blood pressure control, including black race, male sex, single marital status, and young age, it is not clear if this is due to noncompliance. Literature reviews have shown that studies reporting no relation between patient compliance and social class, age, sex, education, occupation, and marital status outnumbered those that did report some relation by almost

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[33]Alvin I. Mushlin and Francis A. Appel, Diagnosing potential noncompliance: physicians' ability in a behavioral dimension of medical care, Archives of Internal Medicine **137** (1977):318-321.
[34]Davis(1966), p. 1039.
[35]Caron & Roth, p. 124.
[36]Davis(1966). p.1043.

three to one.[37] Finally, a "noncompliant personality" has never been demonstrated, and attempts to predict noncompliance on the basis of various personality tests routinely fail.[38] Nevertheless, researchers continue to pursue reliable patient predictors of noncompliance in order to selectively apply those "treatment" measures discussed above.

The prevalence and causes of noncompliance

Noncompliance is commonly identified today as a major cause of therapeutic ineffectiveness and thus is considered an indirect cause of "preventable" morbidity and mortality. Studies have shown rates of compliance in clinical medicine which vary from 10% to 94%, depending on various study parameters.[39] Clinical setting, therapeutic goals, patient population, definition of compliance, and measurement of compliance all differ from study to study. The picture grows confusing. Clinical settings range from in-patient hospitals to one-time out-patient visits; therapeutic goals include screening, prevention, management, and cure; patient populations range from healthy young adults to children on welfare to Tanzanian lepers to neurotic Americans. Definitions of compliance vary as well, from simply "showing up" for appointments to taking >95% of prescribed medications. The result of this research, then, is at best an "unsystematic multiplicity of findings which are often not predictive of compliance or are mutually contradictory."[40] The findings are spun into a multifactorial "web of causation" filled with descriptive detail but lacking in

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[37]Haynes, Taylor and Sackett, pp. 68, 460-61.

[38]A.M.W. Porter, Drug defaulting in a general practice, British Medical Journal 1 (1969)218.

[39]Haynes, Taylor and Sackett, pp. 15-20.

[40]Marshall H. Becker, Understanding patient compliance: the contribution of attitudes and other psychosocial factors. In New directions in patient compliance (edited by Cohen S.J.), (Lexington, MA., 1979),11.

any unifying theoretical orientation or specific recommendations for action which go beyond the personal to the social and the political[41]

The need for social and historical context

Results of these studies are rich in descriptive detail, but lacking in any theoretical guidance, without which results are difficult to integrate across levels of analysis, or to generalize across places and times.[42] Also, without theory, it is difficult to know just how and why certain methods of study were chosen and others ignored. The result is that we now have over 10,000 published articles on the topic of compliance, written mostly since 1973, which provide us with no clear directions for change.

Additionally, these studies are uniformly ahistorical. Without an understanding of the social context and historical emergence of present-day notions of noncompliance, it seems that any attempts to "solve" the "problem" of noncompliance are at best only band-aids, for in ignoring the context of noncompliance, we are ignoring the root of our problems. At the currently popular level of analysis which ignores the social, the political, and the historical context of our practices, the problems become focused at the level of the individual, and by ignoring the larger processes at work, we legitimate them.[43] In the medical profession, power is hidden in the structure of our language, our knowledge, our assumptions, and our practices. It is that power, as it manifests itself in the ideology of patient compliance, which I have chosen to examine in this thesis.

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[41]Sylvia Noble Tesh, Hidden arguments: political ideology and disease prevention policy (New Brunswick: Rutgers University Press, 1990),70; and Howard Leventhal, The role of theory in the study of adherence to treatment and doctor-patient interactions, Medical Care 23(5) (May 1985):557.

[42]*Ibid.*

[43]Eugenia M. Porto, Social context and historical emergence: the underlying dimensions of medical ethics. Theoretical Medicine 11 (1990):161.

Shifting paradigms

We have seen that compliance is a variable and unpredictable part of medical practice, and that interest in the topic has grown up rapidly in the last twenty years, but studies utilized flawed methodology and obtained inconsistent results. The need for an historical and social context for these studies, as well as a theoretical framework, points to several questions:

- Can compliance be better understood as an "ideology" or world view which is a product of the history and social experiences of the medical profession, and comes complete with its own underlying assumptions?

- How have these assumptions have been guiding (and limiting) the questions asked by compliance researchers and the actions proposed?

- Finally, by investigating the physician's perspective, is it possible to uncover the nature of these assumptions, and their implications for action?

I will be exploring these questions by examining what physicians are saying to other physicians, via books, journal articles, and personal letters, about noncompliance in clinical medicine. As these are primarily published opinions, they yield insights into the dominant medical worldview—insights which are telling, not only in what they contain, but also in what they omit.

Chapter two examines the issue as understood by physicians in turn-of-the-century America, giving an historical perspective which informs our current understanding of the problem by demonstrating that objective knowledge of success is not necessarily what undergirds physicians' preoccupations with control of patients. Tuberculosis treatment from 1890-1917 is used as a case study because of the many changes which were occurring in the scientific understanding and medical treatment of tuberculosis, as well as the changes which were occurring among

physicians as a profession. Specifically, in 1890 Koch announced a cure for tuberculosis, which though it later proved false, spurred hope among physicians that they could indeed control the ravages of consumption. In 1917, the United States entered the World War and thus public attention was drawn away from the tuberculosis campaigns; shortly thereafter, physician attention was caught up with the 1918 influenza epidemic, thus ending a period of intense public and professional devotion to tuberculosis. Sources of information for this chapter include a variety of books and journal articles written by physicians practicing among the tuberculous at that time, as well as a recently published review of the contents of a private collection of letters kept by Lawrence Flick, one of the preeminent tuberculosis physicians and policy advocates at that time.

Chapter three examines the contemporary understanding of patient noncompliance using hypertension as a model. In 1988, noncompliance with therapy was identified as the primary reason for poor blood pressure control by the Joint National Committee on High Blood Pressure.[44] Many researchers have examined noncompliance in hypertensive patients, and as a result there is a wealth of information reflecting the biomedical perspective on the subject.[45] Four review articles were selected from the recent medical literature for examination, and several other were referred to for supplementary information. The primary articles come from four professional journals, each with slightly different target populations: *American Family Practice, Archives of Internal Medicine*, *Hypertension*, and *The American Journal of Cardiology,*[46] These articles were selected

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[44]The 1988 report of the Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure, Archives of Internal Medicine 148(5) (May 1988):1023.

[45]Haynes, Taylor and Sackett, p. 138.

[46]Michael A. Moore, Improving compliance with antihypertensive therapy, American Family Practice 37(1) (Jan 1988): 142-148; Richard N. Winickoff and Paul K. Murphy,

because they review and reflect the prevailing views about hypertension and compliance in clinical medicine today. Individual authors were not considered in selection, yet it is worthwhile noting that each of the articles is written by one or more male physicians based in a teaching and research institution (two from Veterans' Administration Medical Centers, and two from U.S. medical schools). This chapter explores, based on these review articles, what physicians are saying to other physicians about their clientele, keeping in mind that these notions are influencing both today's research projects and the attitudes of the next generation of physicians.

Chapter four reviews several powerful studies which show that there is indeed an alternative way of viewing noncompliance—that is, from the perspective of the patient. These studies show that noncompliance may not be an irrational act, but rather is a rational event when seen in the context of the patient's illness representation and desire for self-regulation.

Finally, with the historical and contemporary context provided herein, as well as the review of noncompliance from the perspective of the patient, chapter five discusses policy implications which encourage physicians to reevaluate the assumptions which underlie current expectations for patient behavior and helps them negotiate new ways of "managing noncompliance."

The roots of compliance

Although I am starting my study with an exploration of treatments of tuberculosis from 1890-1917, this era does not mark the first time concerns arose about compliance and patient control. The medicine of the Greeks and Romans in fifth century B.C. provides a point of departure for

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The persistent problem of poor blood pressure control, Archives of Internal Medicine 147(8) (Aug 1987):1393-6; Klein; and Neal.

this discussion. The notion that patients have a responsibility to obey physicians' orders can be traced back to this "ancient" medicine. For example, Aristotle in his Ethics likens a bad moral state to a sick man whose illness "is voluntary, being the result of incontinent living and disobeying his doctors."[47] Hippocratic physicians criticize those who "put all the blame upon those who practised the art of medicine. . ..It is much more likely that the sick [man] cannot follow out the orders, . . . and not following them, he meets with his death."[48] The notion that class and education play a role in compliance is also present in ancient writings, as Plato's Dialogues show. Plato states that working-class patients expect their physicians to cure them with "an emetic, purging, cautery, or the knife, [because] if anyone prescribes for him a long course of treatment. . . he hastily says that he has no leisure to be sick." The freeman, however, is considered to be capable of giving information and receiving instruction from the physician, who "will not prescribe for him until he has at first convinced him".[49] Finally, physicians are urged to "consider the character, habits, and powers of the person; for some more readily than others conform to directions."[50]

The context of compliance for the medical practitioners of that time differed from today, however. Hippocratic physicians were secular craftsmen in Greek society, and shared a relationship with their patients which was based in social equality—a markedly different position from that

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[47]Aristotle, Nicomachean ethics. In The basic works of Aristotle (edited by McKeon R.), (New York: Random House, 1941),973.

[48]Hippocrates. The art. In Hippocrates (edited by Capps E., Page T.E. and Rouse W.H.D.), (New York: G.P. Putnam's Sons, 1923),203.

[49]Plato, Laws. In Plato's dialogues (edited by Hamilton E. and Cairns H.) (Princeton: University Press, 1969),720 C-E.

[50]Hippocrates, Prorrhetikon II. In The writings of Hippocrates and Galen (edited by Coxe J.R.), (Philadelphia: Lindsay and Blakiston, 1846),127.

of their priest-magician ancestors, or their modern-day descendants.[51] Disease was ascribed to "fate" (e.g. accidents or heredity), and the individual was freed from responsibility for its occurrence. However, the sick individual was still responsible for getting well, and physicians struggled to be the mediators of this healing. Lacking religious sanction, they relied on their abilities to prognosticate to attract and keep patients (and therefore fees), "being well assured that, by just predictions, they will be esteemed. . .by every intelligent person."[52]

Compliance was important to the Greek physician because it had an impact on his abilities to prognosticate. An accurate prognosis could be waylaid by a patient who did not obey, and this in turn reflected poorly upon the physician. In his essay *On Decorum*, Hippocrates warns his fellow practitioners to:

> Keep a watch also on the faults of the patients, which often make them lie about the taking of things prescribed. . . .What they have done never results in a confession, but the blame is thrown upon the physician. [53]

Physicians were encouraged to develop their "ability to tell the patient to his face whether he is following orders or not," to create an impression of special powers of divination.[54] Hippocrates' second book of predictions (*Prorrhetikon II*) contains detailed instructions in this skill.[55] Skill in identifying noncompliers was important, for it allowed the physician to escape some of the responsibility for harm caused by disobeying his orders.

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[51]Guenter B. Risse, Patients and their healers: historical studies in health care. In Who decides: conflicts of rights in health care (edited by Bell N.K.), (Clifton: Humana Press, 1982),31.

[52]Hippocrates, Prorrhetikon II, p. 126.

[53]Hippocrates, On decorum. In Hippocrates (edited by Capps E., Page T.E. and Rouse W.H.D.), (New York: G.P. Putnam's Sons, 1923), 297.

[54]Owskei Temkin and C.Lillian Temkin, eds., Ancient medicine: selected papers of Ludwig Edelstein (Baltimore: Johns Hopkins Press, 1967),81.

[55]Temkin p. 81; and Hippocrates, Prorrhetikon II.

Concerns about the control and persuasion of patients prevailed throughout the following centuries, as Jay Katz touches on in his examination of the physician-patient relationship.[56] Medieval physicians emphasized the importance of faith and obedience in therapeutic effectiveness, while Renaissance physicians utilized deception with their "unenlightened" patients, who could not be expected to voluntarily submit to their authority. It was not until the eighteenth century, however, that medicine began to consolidate its power over the corporeal body. Michel Foucault's insights are helpful here. A combination of changes in medical practice regulation, public health, the role of doctors, and preventive medicine meant that "the practice of medicine on the one hand became more elitist, protected, and regulated (from within), and, on the other hand, permeated more deeply into the social fabric, into the homes and daily practices of individuals."[57]

With rising social power, the physician came to view the patient differently—no longer as a complex individual, but now as a body which was faulty in some way, and which needed to be controlled. Foucault refers to a relation of docility-utility which might be called 'disciplines.' "In the course of the seventeenth and eighteenth centuries, the disciplines became general formulas of domination."[58] Medical supervision of disease was guided by this docility-utility relation of discipline. "A body is docile that may be subjected, used, transformed, and improved. . . .[It is]. . .a body manipulated by authority, rather than imbued with animal spirits . . .The technicians of discipline were elaborating procedures for the individual and

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[56]Jay Katz, The silent world of doctor and patient (New York: Free Press, 1984), chapter one.

[57]Porto, p. 153.

[58]Michel Foucault, Discipline and punish (New York: Vintage Books, 1979),137.

collective coercion of bodies."[59] As I will show, these "procedures" were manifested and reified by physicians in America at the turn of the century, and continue to be so today.

[59]Foucault (1979), pp. 136, 155. & 169.

II. Control and submission: Tuberculosis, 1890-1917

All must admit that out of every ten patients who leave Mont Alto at least eight are making a mistake, a fatal mistake, going home too soon, wasting the time they did spend and wasting the state's money. This is the reason Mont Alto cannot point to more cures; the patients won't stick. A stranger listening to the reasons the patients give for going home would never imagine that a life was at stake; that these men were voluntarily giving up their only chance of life.

-Elmer E. McKee, 1916, in *Spunk*, the patients' magazine at Mont Alto sanatorium

Now that we have been introduced to noncompliance as it exists today as well as the place it has held in the evolution of western medicine, I now turn to the pre-antibiotic era of tuberculosis treatment in America, specifically examining the years from 1890-1917. I will first consider the various macro- and micro-level changes which were occurring in the medical understanding of tuberculosis and in medicine's place in society. I will show how these changes contributed to an ideology of control and submission which characterized the medical treatment of tuberculosis. I will then go on to examine the various components of treatment to demonstrate the ways in which this manner of thinking was manifested in practice.

Introduction to tuberculosis

In the early 1900's, doctors considered TB the number one killer of Americans, and also pointed to the great costs in terms of disability and years of life lost.[1] A 1906 Census showed that 11.5% of all deaths in the U.S. that year were due to tuberculosis "of all kinds," with TB of the lung ("phthisis") making up over 90% of those cases. The death-rate per 100,000 was 164, and when stratified by age, TB of the lungs was shown to be responsible for over one-third of all deaths of persons aged 15-30, and over one-fourth of deaths in the 30-40 age group.[2] The disease was known to be widespread, affecting and infecting men, women and children across racial and class lines; however, higher rates of disease were observed among the poor and the underclass (e.g. Negroes, Chinese, Irish, and Indians).[3] Explanations for these rates varied,

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[1]Irving Fisher, The cost of tuberculosis in the United States and its reduction. In Transactions of the Sixth International Congress on Tuberculosis, Volume 3 (Philadelphia: William F. Fell Co., 1908):9.

[2]*Ibid.*, pp. 7, 33.

[3]See various papers in Transactions; Barbara Bates, Bargaining for life: a social history of tuberculosis, 1876-1938 (Philadelphia: University of Pennsylvania Press, 1992), 326 ; and

with some arguing that these races were inherently predisposed to the disease, others pointing to environmental causes such as crowding and poverty, and still others promulgating the theory that the personal habits of these groups led to or formed a tuberculous "diathesis" (predisposition or tendency to a certain disease or group of diseases).[4]

The period 1890-1917 represents a time of great interest and change in the scientific understanding of tuberculosis as well as a time of declining death rates from the disease. In 1882, Koch announced his identification of the tubercle bacillus, a discovery culminating 20 years of research which had begun with Pasteur's development of the germ theory of disease in 1862, and the subsequent demonstration by several investigators (Villemin, Chauveau, Gerlach, Armanni, Klebs) that TB was infectious. By the last decade of the nineteenth century, the understanding of tuberculosis was slowly changing from a diathetical to an infectious one. However, the disease developed quite slowly when compared to other known infectious diseases of the day (e.g. smallpox), infection did not always lead to disease, and diagnosis was difficult. For these reasons, the classification of tuberculosis continued (and continues) to be a source of confusion among medical authorities and laypersons alike. Despite the works of Koch and his predecessors, TB continued to be listed in *Index Medicus* as a "diathetic disease" along with cancer, diabetes, gout, and leprosy until 1903, when it was first listed among infectious diseases.[5]

This period also represents a time of greater awareness of a *decrease* in the death rate from tuberculosis. Physicians, recognizing the change in

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Richard M. Burke, An historical chronology of tuberculosis (Springfield: Charles C. Thomas, 1955),60.

[4]Bates, p. 292.

[5]see Index Medicus, 1903 and prior.

mortality trends, attributed the decline in death rates to medical methods of prevention and treatment.[6] Retrospectively, however, it is clear that the declining death rate from tuberculosis in the United States began in the 1870's (even earlier in England) and accelerated after the first World War.[7] These changes in mortality appear to have been rather unaffected by changing methods of treatment during that time period, and are more likely to be due to social and economic changes such as decreased crowding, better ventilation, improved diet, and rising per capita income.[8]

Partly because of the identification of the bacillus, and partly because of the decline in death rates from tuberculosis, physicians during the last decade of the nineteenth century and into the early twentieth century experienced an increased feeling of control over the disease. Such a feeling had been absent from the consciousness of most physicians in the previous few decades, for they had seen most of their patients "consumed" by the disease despite their attempts at treating symptoms and strengthening the individual.[9] With the discovery of the tubercle bacillus, and Koch's subsequent announcement of a "cure" (tuberculin—quickly found not to be curative, but useful to test for infection), physicians began to believe that a cure had indeed arrived, or at least was on the way.[10] Despite the fact that tuberculin was quickly found not to be a "magic bullet," physicians continued to talk of the medical capability to cure. As time went on, physicians became less concerned with defining the content of this cure, and more concerned

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[6]Bates, p. 313.

[7]Bates, p. 319; and Joseph G. Ellis, Plague (tuberculosis) and plaque (atherosclerosis), New England Journal of Medicine **296**(12) (Mar 24 1977):695.

[8]Rene and Jean Dubos, The white plague: tuberculosis, man and society (Boston: Little, Brown and Company, 1952),217; and Bates, pp. 321-323.

[9]Bates, p. 328.

[10]Burke, p. 49.

with ensuring that the cure was "taken" by the patient. Taking the cure became synonymous with cure itself, and simply by submitting oneself to treatment of any medically sanctioned sort, one could expect to recover. At the fifty-fifth annual session of the AMA (1904), Dr. A. Mansfield Holmes of Denver exhorted his audience, "It is an undeniable fact that many curable patients die. A failure to recover may be ascribed to two causes—a lack of effort or an irrational effort."[11] If a patient failed to recover, it no longer signified divine visitation or an unfortunate, uncontrollable event—rather, the fault was now placed squarely on the patient.

The newfound optimism and confidence of the medical establishment permeated all areas of society, from the very public to the very private. An example of the former in the United States is the growth of the "tuberculosis movement," which sought to involve the public directly in the fight against the disease. In 1889, Hermann M. Biggs and his associates formulated the American plan for tuberculosis control and made a direct appeal to the public to participate in the fight; in 1892, Lawrence F. Flick founded the first tuberculosis association in the U.S. (the Pennsylvania Society for the Prevention of Tuberculosis); and in 1904 the National Association for the Study and Prevention of Tuberculosis was organized.[12] The public responded with enthusiasm and energy, as evidenced by the success of the annual Christmas Seal campaign, which was initiated in 1907 by the Pennsylvania Society.[13]

In the more private realm with which I am concerned here—that of the individual patient's life, and the ways in which physicians attempted to have

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[11]A. Mansfield Holmes, Problems for the tuberculous convalescent, JAMA **43** (Oct 22 1904):1200.
[12]Burke, p. 48-50, 56.
[13]Bates, p. 252.

an impact on that life—physicians gradually displaced family, friends, and clergy as caretakers of those with tuberculosis.[14] They introduced discipline and strict medical supervision into the "case management" of tuberculosis in ways that will be examined below.

Diagnosis, treatment, and prevention

In turn-of-the-century America, a diagnosis of "phthisis," or tuberculosis, was made based on the story the patient told, the family history, and a physical examination performed by the physician. The tuberculous patient's story of illness was expected to include a history of one or more of the following: cough with sputum (possibly bloody), pain, shortness of breath, lassitude and diminished appetite. A family history of tuberculosis indicated the possibility of either an inherent "tuberculous diathesis" or exposure to infectious droplets, depending on the beliefs of the assessor about etiology. Physical exam was often deferred, but when conducted included assessment of appearance (gaunt, withered, wasted), pulse (quickened), and pulmonary function (by auscultation and percussion). The X-ray was developed by Röntgen in 1895, but was not widely used in America until the 1920's.[15] Presence of bacilli in the sputum aided diagnosis and was used by some to monitor the effects of treatment, but its absence did not serve to rule out consumption.[16]

Aside from the brief flurry of interest in Koch's tuberculin (1890-92), treatments for tuberculosis were not generally considered "specifics" by the medical profession. Popular remedies during this time consisted of

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[14]Bates, p. 329.

[15]Burke, p. 51; Bates, p. 320; and Edward Shorter, Doctors and their patients (New Brunswick: Transaction Publishers, 1990),88-89.

[16]Bates, p. 265.

overfeeding with eggs and milk (1865-1905), artificial collapse of the lung (pneumothorax) (first recommended in 1822, popularized in the U.S. in the 1920's and 30's), hydrotherapy (waning in popularity during this time), a variety of drugs, both medically accepted and patent (trademarked formulas with secret ingredients) (e.g. iodine, creosote, strychnine, arsenic, and others), and counter-irritant remedies such as fly-blisters, plasters, and dry cupping. The mainstays of treatment, however, were diet, rest, exercise, and fresh air.[17] Together, these form what came to be known as "the cure."

The process of treatment, or "taking the cure" underwent significant changes between 1890 and 1917. Throughout most of the nineteenth century, tuberculous patients were advised to seek rest and fresh air at one of the various health resorts around the world. Sea voyages, mountain air, and dry deserts were all promulgated as useful, and those with the financial means would embark upon journeys to resorts and lodgings found in these ideal environments.[18] These resorts were not supervised by physicians, did not cater specifically to the needs of the tuberculous, and their benefit was believed to be drawn from the combination of a change of environment, fresh air, rest, and mental happiness. The ethos of such resorts is reflected in the motto of a Davos hotel *"Hilares mox sani"* ("The merry are soon well").[19]

In 1884, noting the considerable efflux of American tuberculous patients to European health resorts, physicians formed the American Climatological Association. The aim of the Association was to revive and further the knowledge of climatology, especially among health professionals,

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[17]Bates, pp. 29-30, 37; Dubos, pp. 104-6, 259; and Burke, pp. 29, 57, 64.

[18]Dubos, p. 176.

[19]Bates, p. 41. Davos, in the Swiss Alps, had become a popular place for the treatment of tuberculosis during the mid-nineteenth century, and is the setting for Thomas Mann's novel, *The Magic Mountain.*

and in doing so to encourage patients to seek treatment within the U.S.[20] In 1885, American physician Edward L. Trudeau, himself a consumptive, founded the first U.S. sanatorium for tuberculous patients at Saranac Lake. His institution was based on principles provided by German models such as Hermann Brehmer's, whose motto was "Die Patienten kommen nicht um sich zu amusiren sondern um geheilt zu werden" ("Patients do not come here to amuse themselves, but to be cured").[21] Others began establishing similar sanatoria in various areas throughout the East, such as Karl von Ruck's in Asheville, North Carolina. These sanatoria differed from the European health resorts in that they provided, in addition to a healthful climate, closer medical supervision and a more disciplined life.[22]

As the sanatorium movement gained popularity in the United States during the 1890's, health workers and others began to note that, much like the health resort era before it, the sanatorium movement excluded the poor and those of lower social classes. Late in the decade, and into the early 1900's, attempts to correct this discrepancy were undertaken, for there were rising anxieties about the contagiousness of tuberculosis.[23] Methods for treating the tuberculous poor involved either including them in the sanatorium movement by developing state-funded sanatoria (first in Massachusetts, 1898), or developing a separate program of home treatment, usually combined with dispensary care and classes.

Along with new hopes for a cure came increased public interest in the prevention of the spread of disease. During the 1890's, in the U.S. and abroad, tuberculosis associations were formed which aimed to educate the

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[20]Bates, pp. 27-28.
[21]Bates, p. 41.
[22]Bates, p. 38.
[23]Bates, p. 54.

public, fundraise, advocate laws, and, in some cases, provide care for tuberculous poor or children at risk.[24] These associations provided the driving force to the anti-tuberculosis campaigns which targeted for education or institutionalization those who were considered threats to the public health, i.e. the poor, the unsupervised, and the "vicious" (who refused to follow appropriate plans for treatment and prevention).[25] The increase in public attention made it possible for legislators to pass laws concerning the spread of tuberculosis. In 1897 New York state adopted mandatory notification of pulmonary tuberculosis, with other states subsequently following this example.[26] Mandatory notification during this time period was not backed up with compulsory segregation, and most often it was the physician who enforced the legislation by acting as "the intermediary:"

> He will use his influence with the patient to have all necessary precautions observed for the protection of the public, and having the confidence, good-will, often even the affection of the patient, he will be able to procure a willing and careful compliance with the official regulations. In this relation the patient . . . need not so much as know that there is a government.[27]

The physician had thus become an arm of the government, and was able to enforce laws by extracting obeyance from patients.

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[24]Dubos, pp. 210-211.

[25]Bates, pp. 257; and Sherman Grant Bonney, Pulmonary tuberculosis and its complications, with special reference to diagnosis and treatment for general practitioners and students (Philadelphia: W.B. Saunders Company, 1910),577.

[26]In 1911, New Jersey passed a law requiring segregation of the "careless consumptive" (Burke, p. 62). However, widespread laws about incarceration of "negligent" patients were not passed until much later in this century, e.g. in North Carolina, Iceland, and Minnesota (Dubos, pp. 172 and 260).

[27]Samuel G. Dixon, The government control of tuberculous patients in Pennsylvania, In Transactions of the Sixth International Congress on Tuberculosis, Volume 4:1, (Philadelphia: William F. Fell Co., 1908),233.

Doctors and patients

The decades around the turn of the century also encompass a time of great change in the way physicians saw themselves as a profession and in how they related to their patients. It was a time of increasing power and authority for the physician in America. Medical schools became more "scientific" and were subject to greater scrutiny and licensure laws, challengers to medical authority diminished in number and fervor, and the physician underwent changes in his[28] self-image while at the crossroads between the traditional physician as embodied by English physician Thomas Percival and the new physician coming out of Germany. Together, these changes provided physicians with an ever more powerful bid for control over patients' lives, and left patients with fewer means of challenging the authority of the medical profession.

The consolidation of medical authority took place on several fronts. In 1893, Johns Hopkins medical school was opened. Johns Hopkins represented all that was new in medical training: more stringent academic requirements, and a new focus on the sciences of the day—pathology, bacteriology, and experimental medicine.[29] Regulations handed down from state Boards of Health resulted in closure of many proprietary medical schools, and those that were left started limiting their numbers, ultimately making doctors a more scarce commodity.[30] At the same time, quacks and medical sects were becoming less formidable competition to medicine, as they were either

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[28]Women entered medicine in increasing numbers in the second half of the nineteenth century, only to be progressively shut out in the early years of the twentieth as medical school openings began to be limited. By 1909, the total number of women medical students had dropped to 921 from 1,419 fifteen years earlier. See Paul Starr, The social transformation of American medicine (New York: Basic Books, 1982),124 .

[29]Shorter, p. 80.

[30]Shorter, pp. 81, 102; and Starr, p. 118.

mainstreamed or ostracized.[31] Physicians, now increasing in their authority, began a fight against patent medicines, and eventually gained control over pharmaceutical distribution.[32] The result of these trends was to solidify the authority of the physician in America, culminating the rise in medicine's social power that had begun at the end of the eighteenth century.[33]

Concomitant with these changes which were occurring in medicine as a profession, there were changes taking place at the level of the individual physician and his interactions with patients. The AMA's first Code of Medical Ethics, drafted in 1847, remained as a guide for many physicians in their clinical encounters. The code was based in large part on English physician Thomas Percival's Medical Ethics, written in 1803.[34] Percival, and later the AMA, urged physicians to "unite tenderness with firmness, and condescension with authority, [so] as to inspire the minds of their patients with gratitude, respect, and confidence."[35] Doctors had "a right to expect and require that their patients should entertain a just sense of the duties which they owe to their medical attendants."[36] These duties included

> prompt and implicit. . .obedience of a patient to the prescriptions of his physician. . .[The patient] should never permit his own crude opinions as to [the prescriptions'] fitness to influence his attention to them. A failure in even one particular may render an otherwise judicious treatment dangerous, and even fatal.[37]

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[31]Starr, pp. 100-102.

[32]Starr, p. 129; and James A. Trostle, Medical compliance as an ideology, Social Science and Medicine **12** (1988):1299-1308.

[33]Michel Foucault, The birth of the clinic: an archaeology of medical perception (New York: Vintage Books, 1973).

[34]Guenter B. Risse, Patients and their healers: historical studies in health care. In Who decides: conflicts of rights in health care (edited by Bell N.K.), (Clifton: Humana Press, 1982),37.

[35]From the opening Articles of the 1847 AMA Code of Ethics, in Jay Katz, The silent world of doctor and patient (New York: Free Press, 1984),21.

[36]Katz, p. 21.

[37]From the AMA Code of Ethics, 1847, Chapter 1, Article II in Katz, p. 232. This resonates with Boussanelle's description of the "disciplined soldier", who "begins to obey whatever he is ordered to do; his obedience is prompt and blind; an appearance of indociltiy, the least

This statement was removed from the AMA's *Code* in 1903, but was not revised or replaced, thus leaving the beliefs it embodies concerning patients' obligations to physicians largely intact.

In a similar way, Maryland physician Daniel W. Cathell's Book on the Physician Himself and Things That Concern His Reputation and Success, first published in 1881, was a "testimony to the status anxieties" of the young profession.[38] Cathell urged his readers to "endeavor to acquire and maintain a proper professional influence over all your patients" and to do all that is possible to secure the cooperation of nurses and attendants.[39] Finally, Cathell reminds his reader that:

> When a sick person puts himself under your care he gives you a responsible duty to perform, and no one has any right to ask your advice without a sincere intention of following it, for if he neglects or refuses to use your remedies, or obeys your instructions in a half-way or imperfect manner, he ties your hands and frustrates your efforts for his relief, and cannot hold you to full responsibility in the case.[40]

The physician's responsibility is paramount, and patients have a duty to maintain the authority of the physician through their obedience. Cathell's book, and the beliefs it contained, remained popular well into the twentieth century.[41]

As concerned as physicians were about impression management, the influence of Germany in the late 1800's was strong, and was shaping the development of a new type of physician. Germany at that time was widely acknowledged as the world leader in medicine.[42] The scientific and technical

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delay would be a crime'." (Boussanelle, in Michel Foucault, Discipline and punish (New York: Vintage Books, 1979),166).

[38]Starr, p. 85.

[39]D.W. and W.T. Cathell, Book on the physician himself (Philadelphia: F.A. Davis, 1911),178, 210.

[40]Cathell, p. 211.

[41]Final edition in 1922. Shorter, p. 131.

[42]Risse, p. 38.

achievements of the Progressive era had worked their way into the physician-patient encounter, with the result being a marked cooling and considerable detachment in the relationship. Physicians were less concerned with the subjective experience of the patient, and philosophers and laypersons were increasingly critical and skeptical of the contemporary state of medicine.[43] Physicians responded to the criticism by retreating into their newfound world of objectivity and science. This world provided the tools to gain the confidence and cooperation of patients without having to bow to their desires. Less often did physicians need to remind one another of their "right" to patient cooperation—they were coming to expect it, for they bore the mantle of science, diagnosis, and prognosis which implicitly assured obedience.[44]

Patients themselves were somewhat complicit in this change due to the widespread public enthusiasm for scientific knowledge which characterized the Progressive era. The Progressive era ushered in a public who "believed that science provided the means of moral as well as political reform and who saw in the professions a new and more advanced basis of order."[45] People's beliefs about their own abilities to understand and deal with their personal and physician problems were changing, and the public became more willing to defer to professionals in matters of health. Such changes in attitude led medicine to consolidate its authority both as a response to deferential treatment and as a reaction to criticisms mentioned above.[46]

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[43]Risse, p. 41.

[44]cf. emergence of instrumentation, microbiology, autopsy, anti-toxins, and use of percussion, palpation, and auscultation. See Shorter, pp. 83-4, 131; and Starr pp. 136-7.

[45]Starr, p. 19.

[46]Shorter, p. 107.

Control and submission

From 1890-1917, the changes in medicine described above fostered a medical practice centered around control and submission. While physicians who worked with tuberculous or phthisical patients may not have always agreed on which treatments were appropriate, or how to properly diagnose and categorize the disease, it seems that physicians did agree on one thing: control of the patient meant control of the disease, and submission to treatment on the part of the patient was critical, indeed prerequisite, to cure. The language of control and submission became both overt and ubiquitous in medical journals, conferences, and in doctor's correspondence to and about patients.

In 1896, Charles L. Greene, M.D., an instructor at the University of Minnesota Medical Department, stated simply that "Absolute control and ardent hopeful cooperation form the *sine qua non* of successful treatment." Lawrence Flick, a tuberculous Pennsylvania physician who devoted his life to the control and eradication of tuberculosis, echoed Greene's sentiments in his numerous guides for physicians of tuberculous patients, stating that: "The treatment of tuberculosis is not a matter of giving drugs so much as regulating the patient's life. Every action of the patient must be brought under control."[47] Furthermore, Flick reminded his colleagues that "[p]erfect discipline and strict compliance with the rules laid down by the physician are essential for success in the treatment of tuberculosis. . .."[48] Flick's letters to his patients also demonstrate this attitude, as he wrote to Mrs. Mary A. South,

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[47]Lawrence F. Flick, Consumption a curable and preventable disease: what a layman should know about it (Philadelphia: David McKay, 1903):212.

[48]Lawrence F. Flick, Tuberculosis as it concerns the physician, Interstate Medical Journal **18** (Feb 1911):204.

> I am sorry to hear that you have done so poorly since you have gone home and yet I am not greatly surprised. It is a great pity that you did not follow my advice and content yourself at the Sanatorium until such time as in my judgment it would have been well for you to return home. It is the old story of people trying to form judgments in matters which they do not understand.[49]

Concerns about control and cooperation were linked to truth-telling in clinical practice. In his two-volume treatise on Clinical Tuberculosis, published in 1917, Dr. Francis Pottenger stated: "The patient consulting the physician should be in a frame of mind to receive the truth and obey instructions and carry out his part of the therapeutic plan."[50] The benefits of truth-telling were argued at the time, with the proponents of honesty advocating it as a means to gaining the full cooperation of the patient, for "the absolute control of the patient. . .cannot be secured in any other way."[51] Unless the case was an "exceptional" one, stated C.P. Ambler at the fifty-fourth annual session of the AMA, in which there was someone else "who can control him," the patient must be told the truth.[52]

Rules for recovery

As concerns about control grew, physicians published various sets of "rules for recovery," targeting tuberculous patients and their families. These lists of rules were provided to patients directly, in clinics or sanatorium newsletters, and were also disseminated throughout the medical community via medical journals and books. The rules were detailed, leaving little open to

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[49]Bates, p. 261.

[50]Francis Marion Pottenger, Clinical tuberculosis (St. Louis: C.V. Mosby Company, 1917),211, 645.

[51]Charles L. Greene, The need of greater frankness in our dealings with phthisical patients. Northwestern Lancet **16** (1896):28.

[52]C.P. Ambler, Should the tuberculous patient know the truth regarding his condition? JAMA **41** (1903):657. Also Maurice Fishberg, Pulmonary tuberculosis (Philadelphia: Lea & Febiger, 1916),299-300.

interpretation by the patient and covering every aspect of the tuberculous patient's life, from disposition ("hopeful and cheerful") to care of sputum (never swallow) to underwear ("according to the season") to bathing and bowel habits.[53] The rules also explicitly described the behavior which was expected from patients in regard to their physician's advice.

In 1903, M.L. Stevens from Asheville, NC published a list of "things every tuberculous patient should know." These include notes on "Cooperation" such as:

> Make a business of getting well. No one with tuberculosis, however slight, has any foundation for the hope of recovery, unless he is willing to devote his whole energy and determination to that end. His every act should be guided by the one purpose. Cooperation with his physicians must be full, honest, and complete.[54]

In 1906, the New York Department of Health published "Advice for Patients," a leaflet designed for distribution to tuberculous clinic patients. It admonishes patients to "carefully obey your physician's instructions," and warns against carelessness. The circular concludes with the statement: "Your cure depends on obeying all instructions faithfully."[55]

In the Journal of the Outdoor Life, a patients' magazine from the sanatorium at Saranac Lake, Charles L. Minor, M.D. published various "Hints and Helps" which include the following:

> The relation of the patient and the doctor in this trouble is of extreme importance, and if the results of the treatment are to be

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[53]New York Department of Health, First report of the clinic for the treatment of communicable pulmonary diseases (New York, 1906),20-23.

[54]M.L. Stevens, Things every tuberculous patient should know, New York Medical Journal (Dec 19 1903):1183.

[55]New York, p. 23.

> satisfactory, a complete co-operation and confidence between them is *essential* (emphasis Minor's).[56]

Following this was a story meant to illustrate this "hint." The vignette described a steamboat owner who had reluctantly hired a pilot to get him through an area of "rapids and hidden rocks." The pilot instructed the owner to "stoke the fires carefully," and "run the engines according to my ideas and not yours, for if you don't I can't possibly get you through." Furthermore, the owner was instructed not to "come into the pilothouse and bother me, for I will have all I can do to get your boat safely through."[57]

Physicians were obviously concerned with patients' behavior, and sought their cooperation by establishing "rules" such as these. Patients were encouraged to abandon their own plans, and "run the engines" according to the ideas of the physician. Citing overarching concern for the management of the corporeal body, physicians were able to excuse themselves from negotiating treatment plans with patients, and often discussions were limited to persuasion, which was an important skill for any physician, as will be discussed below.

Sanatorium: For maximum security

While many sanatoria advertised climate as their primary advantage over home treatment, physicians were open with one another and with their patients about what they perceived to be the real benefits of the sanatorium: ultimate control, both in terms of public health and individual cure. The public health concerns had grown as knowledge of the infectious nature of the

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[56]Charles L. Minor, Hints and helps. In John Bromham Hawes, Consumption, what it is and what to do about it (Boston: Small, Maynard and company, 1915),103. (Originally appeared in Journal of the Outdoor Life, a patients' magazine published at Saranac Lake).
[57]Minor, pp. 103-4.

tubercle bacillus became a part of medical consciousness. Physicians and others in the tuberculosis movement advocated sanatoria as the only way of effectively isolating and stopping the spread of the disease. Of more concern to me here, however, is how physicians perceived sanatoria as a place of treatment and cure for the individual tuberculous patient.

Emphasizing medical control of patients' lives, physicians were advocating sanatoria long before the advent of the germ theory, with Dr. George Bodington opening up a house near his own in England in 1839, and Dr. Hermann Brehmer in Goerbersdorf, Germany in 1859.[58] Brehmer's former patient, Dr. Peter Dettweiler, at Falkenstein near Frankfurt, Germany, provided an influential voice to the growing sanatorium movement in the United States in the late 1800's. The climate at Falkenstein was never alleged to have any "specific influence on the diseased organ;" rather, it was "Dettweiler's method" which gained popularity in the States. Dettweiler considered treatment within institutions as being of the greatest importance, for only institutions could provide the constant personal supervision which he considered necessary for cure.[59] When Dr. Paul Kretzchmar made his appeal for the establishment of a sanatorium in New York, he outlined Dettweiler's requirements for a successful physician-manager of a sanatorium:

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[58]Paul H. Kretzschmar, Dr. Dettweiler's method of treating pulmonary consumption, New York Medical Journal **47** (Feb 18 1888):175; and Frederick I. Knight, What shall we do with patients having pulmonary tuberculosis? Boston Medical and Surgical Journal **151** (Sep 1 1904):257.

[59]The question arises, however, to what extent did physicians' insistence on the superiority of sanatorium treatment stem from financial incentives, as physicians themselves often owned the sanatoria which they "prescribed". While no studies have been done on this, Bates (p. 166) points out that "necessary treatment" such as work requirements varied with ability to pay, and the ideologies supporting these treatments faded when the economic justification for them disappeared. Furthermore, physicians had little objective data to support their recommendations. Indeed, many physicians based their treatments on what they had found to be useful in the treatment of their own phthisis (cf. Flick's recommended diet of milk and eggs, and Trudeau's locale in the Adirondacks).

> The smallest details of the patient's life are controlled by the supervising physician, and nothing of any importance is left to his or her judgment. . .. The physician. . .must himself be a good man, the possessor of a big heart and much patience, and he must be supplied with all the instincts of a "shepherd's dog." The relation of teacher and pupil, in the fullest sense of the word, must exist between the physician and his patients, and, without entering into the field of popular medical lectures, the patients should be taught to understand the physiological and hygienic laws which it is so essential for them to follow if they desire to come out victorious in the battle with the bacillus tuberculosis. The physician's office should be the patient's confessional chamber, and every possible effort should be made to foster implicit confidence in, and strict obedience to, the physician among the patients.[60]

Dr. Lawrason Brown from Saranac Lake summarized these sentiments by stating that the patient-physician relationship should be "comparable to that which exists between penitent and priest. . .The physician must be [the patient's] confidant."[61]

By the end of the nineteenth century, then, the enthusiasm for climatic treatment was waning, and concerns about control and supervision had supervened.[62] For either reason, however, the sanatorium was considered to be superior to the alternative, home care. When climate therapy was in vogue, home treatment was considered inferior because of the urban environment, yet this could be managed somewhat by open-air living on rooftops or balconies. With the emphasis now on control, however, the discrepancy between sanatorium and home treatment became more pronounced.

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[60]Kretzschmar, p. 178.

[61]Lawrason Brown, Rules for recovery from pulmonary tuberculosis: a layman's handbook of treatment (Philadelphia: Lea & Febiger, 1923),130-2. (This is a compilation of articles, many of which first appeared in Saranac Lake's Journal of the Outdoor Life, during the previous two decades).

[62]G.K. Sabine, Home treatment of phthisis, Boston Medical and Surgical Journal **3** (1894):61.

Home Treatment: The threat of friends and family

Physicians generally considered home treatment of tuberculosis to be less efficacious than sanatorium treatment due to the inability to control the patient to the same degree. At home were the differing opinions of friends and family to contend with, as well as the competing priorities of working and/or keeping house.[63] Physicians feared that these factors could and would prevent the full cooperation with treatment which was necessary for patients to achieve a cure. Family members were believed to "ignore the ironclad rules laid down for the patient by the well-intentioned physician. . ., and not only miscarry the instructions but unwillingly harm their charge." Patients were considered to be "capricious, irritable, and selfish in their relations towards the immediate family."[64] Here again, it was not a change in climate, but "unenforced sanatorium rules" (upon return to the home) which did the most harm. [65] Physicians perceived patients to be at extreme risk of falling into "the old habits," and "ignoring all rules and precautions," for "too often the rigid discipline is lacking in the home."[66]

In the New York clinic circular, "Advice for Patients," patients were admonished not to talk to anyone about their disease (except the physician or nurse), and not to "listen to tales of other patients, or follow their suggestions or those of others concerning the treatment of your disease.[67] Similarly, Stevens wrote that "one of the greatest obstacles" to getting well "is the well meaning advice of friends."[68] And Dr. Minor, in his Hints and Helps to

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[63]*Ibid.*

[64]Henry Levien, Home treatment of the tuberculous "is just as good"--but it is not, Medical News 84 (Apr 2 1904):647.

[65]*Ibid.*

[66]*Ibid.* p. 648 and Holmes, p. 1202.

[67]New York, p. 20.

[68]Stevens, p. 1183.

patients at Saranac Lake placed the following as *rule #1* under "Mental Attitude": "Never talk of your case or symptoms with anyone save the doctor, and allow no one to talk of theirs to you."[69] Pottenger warned that the patient who "does not have a physician to whom he may take [his cares]. . .will tell his troubles to the neighbors and the result is misdirection and meddlesome advice."[70]

However, the family members, it was recognized, could also be enlisted as assistants to the physician:

> The head of the family should learn in detail exactly what the physician has advised about these tuberculous cases and should see that such directions are carried out carefully. . ..The family should be sure that their advice conforms to that of the physician. His word should be law.[71]

Some physicians saw home treatment as superior to sanatorium treatment, for the opportunity it afforded to educate the family as well as the patient "so that they are more willing for a continuance of his mode of living."[72]

Dispensaries / class method of teaching

The class method of treatment for tuberculosis was made popular by Joseph H. Pratt, a Boston physician who organized his first Tuberculosis Class through the Emmanuel Church in Boston in 1905. Class meetings were held weekly, and patients were also visited at home by the class nurse. Instructions and rules formed the backbone of the method. Supervision, both at the dispensary and at the home (through periodic visitation, usually by specially trained nurses as per Osler) was considered essential to

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[69]Minor, p. 104.

[70]Pottenger, p.225.

[71]C.P. Ambler, Points to be observed by the family of a tuberculous patient, Medical Record **64** (Dec 19 1903):976.

[72]Henry Marion Neale, Sanatorium treatment of pulmonary tuberculosis, The Pennsylvania Medical Journal 11 (Jan 1908):284.

compliance.[73] At meetings, patients were instructed with lectures and demonstrations in the proper conduct of all aspects of their lives.

Patients were selected based on diagnosis and stage of illness, but no one was taken into the class "from whom we cannot exact full obedience to the rules."[74] Those who refused either were not admitted, or, once found out, were dismissed from treatment.[75] When Pratt's associate Dr. N.K. Wood established a new class at Arlington Street, the fundamentals which he brought with him from Pratt's class included strict supervision, insistence on rest out of doors, and on absolute obedience.[76] The results, according to Pratt, were "equally good."[77]

Nurses

Nurses, both at home and in the sanatorium, were considered essential for the maintenance of proper control and discipline of the patient. Nurses were responsible for carrying out doctor's orders, and protecting their charge from the threats posed by surrounding family and friends. They often trained in sanatorium schools, where students were drawn from recovering patients, thereby providing "an ever-present object-lesson"[78] of the benefits of cooperation. Upon graduation, they usually accepted placements in private

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[73]Bates, p. 201; Burke, p. 55; and Joseph H. Pratt, The class method in the home treatment of tuberculosis, and what it has accomplished, Transactions of the American Clinical and Climatological Association **27** (1911):93-4.

[74]*Ibid.*, p. 109.

[75]*Ibid.*, p. 91; and Joseph H. Pratt, Results obtained by the class method of home treatment in pulmonary tuberculosis during a period of ten years, Boston Medical and Surgical Journal **176** (Jan 4 1917):13.

[76]Pratt (1911), pp. 93-94.

[77]*Ibid.*

[78]Charles J. Hatfield, Training for professional nursing in institutions for tuberculous patients: a report of the training schools at the Henry Phipps Institute and the White Haven Sanatorium. In Transactions of the Sixth International Congress on Tuberculosis, Volume 3, (Philadelphia: William F. Fell Co., 1908),409.

homes. Pennsylvania physician Henry Neale outlined the "immediate duty of the attendant":

> . . .to begin work in dispelling doubt, correcting false impressions, and at the same time to giving the patient a firm understanding as to the course of treatment to which he must now submit and what is expected of him. . ..[79]

The nurse was especially valuable if the patient was "unaccustomed to discipline, or a child."[80] Yet Flick reminds us that "the physician must not be content with merely telling the attendant what to do, but should show her how to do it and should continually watch whether she does it right."[81] Thus, along with the patient and his or her family and friends, even the nurses must be kept "under control."

Disobedience, sequelae, and physician response

As we have seen, obedience was considered crucial to effective treatment of tuberculosis. Physicians perceived several consequences of disobedience: dismissal from treatment, danger to others, and, of course, death. Disobedience could take many forms, given all the rules for wholesome living that were promulgated at the time. Speaking with friends about one's illness, taking too much (or too little) exercise, rest, or food, leaving the sanatorium prematurely ("against medical advice"), or disrupting "institutional harmony" are some of the many ways which led to a patient being labeled "disobedient," "uncontrollable," "intractable," or "vicious."[82]

Physicians generally held preconceived notions about who was most likely to disobey. The "day-laborer, the shop-girl, [and] the drunken negro"

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[79]Neale, p. 283.
[80]Edward O. Otis, Tuberculosis: its cause, cure, and prevention (New York: Thomas Y. Crowell, 1914),119.
[81]Flick (1911), p. 201.
[82]Bonney, p. 578.

were among those who belonged to "a class that, by reason of the very conditions that constitute it as a class, is unable to make use of what it learns."[83] They were considered "unteachable" by some, while others worked to demonstrate that, with special provisions, these unfortunate souls could be made "tractable," and hence cured.[84] These provisions included close supervision, live demonstrations in addition to written instructions, repeated reminders, and sometimes threats. In the case of women, the physician was reminded to deal "severely with frivolity."[85] While this class of people was ostensibly "unable" to carry out doctor's orders, the behavioral methods developed to make them "tractable" imply that educators considered them to be at some level *unwilling*, rather than truly "unable" to carry out treatment.

Physicians believed that temperament and character also affected cooperation. Flick placed these as two of the several factors which played a role in prognosis in tuberculosis, along with such things as the dose and virulence of the bacillus, the resistance of the host, and the environment.[86] The patient of strong character was considered capable of living up to all the conditions laid down by his physician, while the patient of "weak mercurial character" might "do hard things for awhile and live the life which is necessary. . .under the spur of fear," but soon "breaks loose from his anchorage."[87] Likewise, "[p]atients who are sanguine and hopeful usually do better than patients of a lymphatic, despondent temperament."[88]

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[83]Ellen N. La Motte, The unteachable consumptive. In Transactions of the Sixth International Congress on Tuberculosis, Volume 3, (Philadelphia: William F. Fell Co., 1908),257.
[84]e.g. La Motte, Pratt, and others.
[85]Flick (1911), p. 200.
[86]Lawrence F. Flick, Prognosis in tuberculosis, American Medicine 11 (Jan 6 1906):13.
[87]*Ibid.*, p. 15.
[88]*Ibid.*

Finally, Pottenger and Fishberg warned physicians about those "well-informed patients" whose "preconceived notions" may prevent their full and unquestioning cooperation with the regimen prescribed by the physician.[89] This group makes "bad patients after consuming some of the popular books on what tuberculosis is and how to combat it."[90] These physicians recommended persuasion as the method of choice in dealing with these patients, using "patience and tact" to "displace wrong ideas by right ones."[91]

The response of physicians to patient disobedience was both general and specific to each case. To deal with the general threat of noncompliance, the physician "must be a masterful man, dominating the situation."[92] The physician must be willing to "direct the patient intelligently," and "be able to keep his patient at doing hard things."[93] The need for physicians to understand the disease was considered important, not for patient care directly, but rather "to merit the cooperation of the patient."[94] When faced with a disobedient or uncontrollable patient, the responses ranged from instruction (esp. for the intelligent class), compulsion and threats (for the less intelligent), to dismissal from treatment.[95]

These responses indicate that physicians considered disobedience to be the result of relatively fixed characteristics of certain classes of patients which might be circumvented by behavioral modification techniques. Rarely did physicians pause to address questions of barriers encountered by patients, or even whether the treatment was valid—questions which surely

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[89]Pottenger, pp. 220, 222; and Fishberg, p. 302.
[90]*Ibid.*
[91]Pottenger, p. 222.
[92]John Bressner Huber, Consumption, its relation to man and his civilization, its prevention and cure (Philadelphia: J.B. Lippincott Company, 1906),197.
[93]Flick (1911), pp. 200, 202.
[94]Pottenger, p. 219.
[95]Flick, in Bates, p. 113.

plagued their patients as they lay at night in open-air tents, kept awake by the sounds of coughing.

III. The etiology of noncompliance: The case of hypertension

"If the only tool you have is a hammer, you tend to treat everything as if it were a nail."
—Abraham Maslow, 1969

In this chapter, I move to the 1990's to explore current medical theories about noncompliance. Hypertension is used as a case study, as it is a prevalent condition, noncompliance with therapy is of concern to physicians, and it shares many other similarities with the earlier medical understanding of tuberculosis.

Hypertension in America

Hypertension, or high blood pressure, is a condition which is estimated to affect nearly 60 million Americans, and thus represents one of the most common problems in clinical medicine today.[1] The literature on the topic is vast and continues to grow, reflecting both the heightened awareness and the confusion which surrounds hypertension as a disease process. A measurement of blood pressure which is increased over certain levels (usually 140/90 mm Hg) may indicate any one of several things (the "differential diagnosis"). The cuff may not be fitted or placed correctly, the observer may be inattentive, the increase may be transient or positional, or the patient may indeed have a sustained increase in blood pressure which is observable on several occasions.[2] In this case, the physician then moves to excluding all of the rather rare causes of secondary, or "remediable" hypertension, such as kidney disease, hormonal dysregulation, or aortic coarctation.[3] Approximately 5-10% of patients with high blood pressure are found to have one of these conditions. If none are found, the patient joins the ranks of the millions of Americans with "primary" or "essential" hypertension, currently viewed as "a

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[1]Luther T. Clark, Improving compliance and increasing control of hypertension: needs of special hypertensive populations, American Heart Journal **121**(2, Pt. 2) (Feb 1991):664.
[2]Amy W. Larson and Cameron G. Strong, Initial assessment of the patient with hypertension, Mayo Clinic Proceedings **64** (1989):1533-1542.
[3]Andreoli, *et al.*, p. 206.

heterogeneous syndrome in which multiple factors [including obesity, diet, social/environmental causes, physiologic changes, and inherent, or "essential" differences] contribute to the elevated blood pressure."[4]

In the U.S., epidemiologists show that hypertension and its sequelae disproportionately affect blacks, in whom it occurs at a younger age and with higher prevalence and greater severity than in whites, and for whom the discrepancy becomes more pronounced with age.[5] Puerto Rican and Cuban-Americans are also at higher risk, as are older people in general, and people living in certain regions of the country (e.g. the Southeast).[6] These populations, as well as women, are often referred to as "special" hypertensive populations, and are held in contrast to the generic hypertensives (assumed to be white, middle-aged males).

Sequelae of long-standing hypertension include significant morbidity and mortality due to atherosclerotic complications such as stroke and myocardial infarction as well as complications (such as intracerebral hemorrhage, congestive heart failure, and nephrosclerosis) which arise from chronically elevated arterial pressures.[7] Physicians today believe that if blood pressures can be reduced to and kept at "normal" levels, many of

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[4]Andreoli, *et al.*, p. 205.

[5]Clark, p. 667; The Fifth Report of the Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure (JNC V), Archives of Internal Medicine **153** (Jan 25 1993):174; and Elijah Saunders, Tailoring treatment to minority patients, American Journal of Medicine **88**(supp. 3B) (Mar 12 1990):21S-22S.

[6]The 1988 report of the Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure, Archives of Internal Medicine **148**(5) (May 1988):1024, 1034; Charles K. Francis, Making a difference: managing hypertension in minority patients, American Journal of Medicine **88**(suppl. 3B) (Mar 12 1990):3B-1S; Saunders, p. 21S; and Clark, pp. 667-668. Paradoxically, rates among Mexican-Americans are lower than or equal to comparable groups of non-Hispanic whites. See Michael P. Stern, Cardiovascular and other chronic diseases among Mexican Americans: the emerging picture, Ethnicity & Disease **3** (Winter 1993):9; and Nancy Krieger, Influence of social class, race and gender on the etiology of hypertension among women in the United States. Submitted for publication.

[7]Andreoli, *et al.*, p. 205.

these sequelae are preventable.[8] Indeed, the death rate from complications of atherosclerosis has been declining in the United States since the late 1960's.[9] While some physicians point to the better identification and treatment of hypertension and claim responsibility for the decline, others point out that, like tuberculosis before it, death rates from atherosclerosis may be regressing independent of new treatments.[10]

The recommended therapy for essential hypertension involves a "stepped" approach to reducing blood pressure to lower levels, with a goal level lower than 140/90 mm Hg.[11] This approach starts with non-pharmacologic recommendations such as restriction of sodium and alcohol, exercise, and weight control.[12] However, most physicians will concomitantly start the hypertensive patient on pharmacologic therapy such as diuretics, beta-blockers, calcium antagonists, or ACE inhibitors, using nonpharmacologic therapy as an adjunct.[13] If these drugs are not efficacious, physicians may add a second drug of a different class, increase the dosage of the first drug, or substitute another drug. So it goes, up the "steps" of treatment, until blood pressures are reduced, or the patient on three to four drugs remains hypertensive, at which point he or she may be evaluated further ("worked-up") for an underlying cause or referred for treatment elsewhere.[14]

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[8]*Ibid.*, p. 205.

[9]*Ibid.*, p. 63.

[10]Joseph G. Ellis, Plague (tuberculosis) and plaque (atherosclerosis), New England Journal of Medicine **296**(12) (Mar 24 1977):695.

[11]The 1988 Joint National Committee, p. 1025.

[12]When American blood pressure experts announced in 1984 a new policy reversing an earlier recommendation for drug treatment of even mild hypertension, they urged that non-drug therapies be "pursued aggressively." See Lynn Payer, Medicine and Culture (New York: Holt, 1988).

[13]Andreoli, *et al.*, pp. 207-8.

[14]1988 Joint National Committee, p. 1028.

Treatment for hypertension is expected to be lifelong, as it is considered "manageable" but not curable by the medical profession. Thus, the previously asymptomatic individual, upon discovery[15] of an increased blood pressure is now "committed" to a lifetime of visiting doctors, paying for, and regularly consuming one or more medications up to several times each day.[16] These medications often have various effects in addition to decreasing blood pressure—these effects ("side effects") may include fatigue, fluid retention, insomnia, and sexual dysfunction, among many others.[17]

With this description, it is perhaps not surprising that many hypertensive patients (40-75%) do not follow prescribed therapeutic regimens.[18] In 1988, the Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure named noncompliance with anti-hypertensive therapy as "the major reason for inadequate control of high blood pressure."[19] This proclamation fanned the flames of compliance research, whose advocates had already been focusing much of their energies on hypertension as a disease model. [20] Now their claims were legitimated, their work made all the more vital, for the only thing

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[15]A discovery made possible by the creation and popularization of the sphygmomanometer in the early part of this century. See Edward Shorter, Doctors and their patients (New Brunswick: Transaction Publishers, 1990),90.

[16]Michael A. Moore, Improving compliance with antihypertensive therapy, American Family Practice **37**(1) (Jan 1988):144-5; and Richard N. Winickoff and Paul K. Murphy, The persistent problem of poor blood pressure control, Archives of Internal Medicine **147**(8) (Aug 1987):1395.

[17]Andreoli, *et al.*, p. 207.

[18]Lawrence E. Klein, Compliance and blood pressure control, Hypertension **11**(3 pt. 2) (Mar 1988):II-61; and Kathleen G. Andreoli, Self-concept and health beliefs in compliant and noncompliant hypertensive patients, Nursing Research **30**(6) (Nov-Dec 1981):323.

[19]The 1988 Joint National Committee, p. 1032.

[20]R. Brian Haynes, D. Wayne Taylor and David L. Sackett, Compliance in health care (Baltimore: Johns Hopkins University Press, 1979),138.

standing between the doctor and the normalization of blood pressure was the patient.

Control of physiologic phenomena

Locus of control is an important issue in medicine today, arising commonly in descriptions of treatment strategies for hypertension, where blood pressures are monitored regularly and compared with "target" ranges. Most physicians consider "tight control" to be crucial to the management of this disease, although, at least in the case of mild hypertension, this goal is currently being questioned.[21] Patients are encouraged to monitor their blood pressure levels at home to assess the efficacy of their "regimen." Although it may appear that by doing so, patients are managing their disease, physicians tend to view themselves as the one in charge.

Such a view is reinforced by advertisements for prescription drugs in medical journals which target and strengthen physicians' views of themselves as experts and of their patients as passive, dependent, and somewhat childlike. For example, for several weeks in 1991 the *New England Journal of Medicine* ran an ad for Veralan (verapamil) touting it as the antihypertensive which can give a physician ". . .the control you want, the protection they need."[22] Physicians aim to control the disease, and in doing so, believe that they are protecting the patient from unstated dangers.

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[21]Edward D. Fries, Rationale against the drug treatment of marginal diastolic systemic hypertension, American Journal of Cardiology **66** (Aug 1 1990):368-371.

[22]Lederle Laboratories, "In hypertension, once-a-day Veralan®" (advertisement), NEJM **325**(19) (Nov 7 1991): advertisement section. This advertisement pictures the interior of a sports car, and opening text instructs the reader (a physician) to "Shift to Veralan." The implied driver is the physician, who in turn "drives" the patient's body like a finely tuned automobile.

In his discussion of methods of improving outcomes of "special" hypertensive populations, Luther T. Clark, M.D. recommends having the physician "convey interest in and commitment to controlling the patient's blood pressure" as a means of improving physician-patient interactions.[23] Winickoff and Murphy, in their discussion on the "persistent problem of poor blood pressure control," outline further areas for research in hopes that soon, "we should be able to. . .complete *our* victory over hypertension"(emphasis mine).[24] It is the physician, not the patient, who wins.

Unfortunately, physicians have not been satisfied with only controlling disease (perhaps because they have not been entirely successful). All too often, mention of the disease is dropped from dialogue, and the physician is described as controlling not the hypertension, but the hypertensive. As a result, the hypertensive with "uncontrollable" and "unresponsive" blood pressure becomes the "out-of-control" and "unresponsive" patient.[25] This rhetoric implies that it is now the patient, not only the disease, that is in need of physician "management." In contrast to the touted need to "care for the whole patient", the forms this management takes are generally presented in ways which are controlling rather than caring, as shall be demonstrated below.

The forms of "management" are based in beliefs about the cause, or "etiology" of noncompliance. The authors of the articles under review generally explain noncompliance by pointing to the interaction of three agents: drug regimens, environmental factors, and the physician-patient

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[23]Clark, p. 666.

[24]Winickoff & Murphy, p. 1395.

[25]Susan Hopper, Diabetes as a stigmatized condition: the case of low-income clinic patients in the United States, Social Science and Medicine **15B** (1981):15.

relationship. Psychosocial factors are selectively invoked when physicians consider patient populations which are not part of the implicit "norm" (middle-aged, white males). Physician-researchers then develop "strategies for improving compliance" which are "applied to" problem patients.[26] Each of the "agents" of noncompliance is discussed below, along with its proffered method(s) of "treatment".

Drug Regimens Upon diagnosis of essential hypertension, most patients are started on one or more medications—their drug "regimen" (from the Latin, *regere*, "to rule"). Pharmacologic therapy for hypertension has the drawbacks of complexity and negative side effects. Control of hypertension often requires two or more medications each day, each with its own dosage requirement. Side effects of these medications are many, as was mentioned in chapter one. The compliance literature urges physicians to reduce the number of pills prescribed by utilizing combination drugs and slow-release preparations, make maximum use of non-pharmacologic therapies (such as low-salt diets), and provide patients with a written "aide-memoire" and color-coded pill containers to assist with the therapeutic regimen.[27] In regards to negative side effects, which seem to be ubiquitous among anti-hypertensive medications, some authors imply that these effects are psychological, or can be resolved psychologically; however, these authors suggest that clinicians change the prescribed regimen anyhow, not because the patient is experiencing discomfort or distress, but because "it is unlikely that the patient will continue taking that medication."[28]

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[26]William W. Neal, Reducing costs and improving compliance, American Journal of Cardiology **63**(4) (Jan 17 1989):19B.

[27]*Ibid.*, p. 19B; Winickoff & Murphy; Moore, p. 143; and Thomas F. Lüscher and Wilhelm Vetter, Adherence to medication, Journal of Human Hypertension **4**(Suppl 1) (Feb 1990):45.

[28]Moore, p. 146; and Lüscher, p. 45.

Such recommendations make sense in terms of making therapy the least intrusive for the patient, despite other motivations physicians may or may not have. However, whether or not such measures actually improve compliance has been disputed.[29] No studies have shown that alteration of therapeutic regimen alone will transform the majority of noncompliers into compliers.

Environmental factors Cost of therapy is generally mentioned by authors as a determining factor in compliance. Since hypertension most often requires lifelong treatment, costs (including initial medical evaluation, medications, follow-ups, and laboratory studies) can run high, with drug costs comprising 70-80% of total expenditures.[30] Time constraints and access to care are also mentioned as possible factors affecting compliance. Authors recommend that clinicians prescribe the less expensive medications[31] when possible, and "consider" such factors as the patient's schedule and ease of access.[32] Even when considering the needs of minority populations which have higher rates of prevalence of both hypertension and noncompliance, authors fail to go farther then simply mentioning that issues of cost and access to care "may well be implicated in the disproportionate cardiovascular morbidity and mortality rates of black and Hispanic patients."[33]

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[29]Klein, p. II63-64.

[30]Moore; and The Fifth Report, p. 161.

[31]According the JVC V, newer classes of antihypertensive drugs are up to 30 times more expensive than generic diuretics and ß-blockers. The Fifth Report, p. 161. In 1988, Moore (p. 145) reported that costs range from 5-80 cents/day.

[32]Neal, p. 19B; and Moore, pp. 142-3.

[33]Charles K. Francis, Making a difference: managing hypertension in minority patients, American Journal of Medicine 88(suppl. 3B) (Mar 12 1990):1S.

Physician-patient interaction Aspects of the patient-physician encounter have received an increasing amount of interest in the past two decades, and have subsequently become incorporated into compliance research. Of the four articles reviewed here, the earliest one (1987) makes no mention of the physician-patient relationship, while subsequent articles devote varying amounts of attention to the subject, generally focusing on communication via patient education.[34] The message to physicians is to increase patient understanding by "overcoming" barriers to effective communication and by providing educational materials.

Semantics here, as in the concept of compliance itself, are important. Physician-patient communication is generally assumed to be unidirectional, from doctor *to* patient. The physician's role is portrayed as "controlling," "overcoming," "conveying," "responsible," and "influencing".[35] Patients, on the other hand, are conceptualized as "rejecting," "misunderstanding," "lacking," "dropping-out," and "failing."[36] Except in the case of "special" hypertensive populations (see below), psychosocial factors are rarely considered. Rather, patient misunderstanding and lack of information are determined to be the problem for "the general hypertensive population," and proper education in the biomedical model of hypertension is considered by most authors to be the answer.

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[34]Klein; Winickoff; Neal; Moore. See also Davis' study in which 40% of physicians blame the patient's "inability to understand recommendations." Milton S. Davis, Variations in patients' compliance with doctors' orders, Journal of Medical Education 41 (Nov 1966):1043.

[35]Klein; Winickoff; Neal; Moore; and M. Robin DiMatteo and D. Dante Nicola, Achieving patient compliance (New York: Pergamon, 1982).

[36]Clark, p. 665; Klein; Winickoff; Neal; Moore; and Dimatteo.

Increasing patient knowledge through educational strategies has not been shown to improve rates of compliance as expected.[37] Pamphlets, brochures, reminder calendars, memory aides, and telephone monitoring may increase patient awareness, but have little effect on compliance.[38] These studies demonstrate that, while knowledge of the regimen may be a prerequisite for compliance, it in no way guarantees it. Those few researchers who do quote studies which seem to show that patient education improves compliance often overlook the fact that in these studies, it was the *physicians*, not the patients, who received the intervention.[39]

Biopsychosocial models In the four articles specifically selected for analysis in this paper, no mention is made of psychological, social, or cultural influences on compliance. This is worth noting, because there is also no discussion of patient demographics, thereby implying either that the methods proffered are universally applicable, or that providers deal only with the "general" hypertensive population—that is, white, middle-aged males. It is doubtful that the latter is true, given that hypertension occurs with greater prevalence and severity in blacks and some Hispanic populations than in whites, and has greater prevalence in elderly vs. younger adults. If it can be assumed that all physicians are not dealing

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[37]See Marshall H. Becker, Patient adherence to prescribed therapies, Medical Care **23**(5) (May 1985):539-55; Lawrence E. Klein, P.S. German, S.J. McPhee, C.R. Smith and D.M. Levine, Aging and its relationship to health knowledge and medication compliance, Gerontologist **22** (1982):384-387; D.L. Sackett, R. Brian Haynes and E.S. Gibson, *et al.*, Randomized clinical trial of strategies for improving medication compliance in primary hypertension, Lancet **1** (1975):1205-1207; and D.M. Levine, L.R. Bone, D.M. Steinwachs, R.E. Parry, D.M. Morisky, and J. Sadler, The physician's role in improving patient outcome in high blood pressure control, Maryland State Medical Journal **32** (1983):291-293.

[38]Haynes, Taylor and Sackett, pp. 128-9; and Martha N. Hill, Strategies for patient education, Clinical and Experimental Hypertension--Theory and Practice **A11**(5 & 6) (1989):1194.

[39]*Ibid.*, p. 1192.

exclusively with the "general" hypertensive population, is it true that the methods suggested by compliance authors are universally applicable?

Arthur Kleinman and others analyze physician-patient interactions and demonstrate that they are not.[40] In one example, Kleinman examines the interaction between a 39 year-old black woman with hypertension and her white male physician. He uncovers that the physician misses important information about his patient's understandings of her disease and its treatment which could help him understand what he labels noncompliance on the part of his patient. Kleinman suggests that the reasons for the physician's negligence are twofold: one, because his is a rigidly biomedical approach which cannot accommodate other types of information, and two, because the replication of societal class relations within the medical encounter leads to frustration and discomfort.[41]

In attempts to find a solution to these problems, some writers have studied hypertension and noncompliance in what are commonly referred to as "special" populations—blacks, Latinos, the aged, the young, and women.[42] To understand noncompliance in these populations, biopsychosocial models are often invoked. The biopsychosocial model differs from more traditional models in that it is constructed to take into account the missing dimensions of the biomedical model[43]—dimensions such as health beliefs and cultural influences. Based in systems theory,

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[40]Alexandra D. Todd, Intimate adversaries: cultural conflict between doctors and women patients (Philadelphia: University press, 1989); Arthur Kleinman, The illness narratives: suffering, healing, and the human condition (New York: Basic Books, 1988); and Howard Waitzkin, The politics of medical encounters (New Haven: Yale University Press, 1991),9.

[41]Kleinman, pp. 134-6.

[42]Francis; Clark; Kleinman; Dan Blumhagen, Hyper-tension: a folk illness with a medical name, Culture, Medicine, and Psychiatry **4** (1980):197-227; and Suzanne Heurtin-Roberts, Health beliefs, compliance--hypertension, JAMA **264**(22) (Dec 12 1990):2864.

[43]George L. Engel, The need for a new medical model: a challenge for biomedicine, Science **196**(4286) (Apr 8 1977):132.

the model takes into account the patient as well as the disease. Though inclusive in theory, the biopsychosocial model in practice is applied selectively and paternalistically to non-dominant groups, and thus fails to challenge the physicians' worldview. Indeed, most writers unfortunately advance their biopsychosocial theories as a tool to aid physicians in "clarifying the patient's misconceptions".[44] While the biopsychosocial model may be a positive expansion of the biomedical model, it leaves intact the existing structure of the physician-patient interaction, which carries with it the expectation of passive obedience on the part of the patient. It is compliance literature at its most coercive, teaching physicians how to manipulate their patients' behavior without questioning their own beliefs.[45]

The disease of noncompliance

From the above, it seems that the dominant view of "compliance" differs little from the more physiological mechanisms of pulmonary and aortic compliance—a metaphor which suggests a view of the physician-patient relationship in which the patient is a passive element acted on by and resisting the influences of external forces. Theories of noncompliance, then, are grounded in these views. *The problem lies with the patient; the physician offers solutions.*

Titles such as Achieving Patient Compliance and "Diagnosis and management of patient noncompliance"[46] further illustrate how physicians are most comfortable viewing noncompliance—as a specific

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[44]Workshop participants, Summary statements on selected aspects of educating hypertensive patients, Journal of Human Hypertension 4(supp. 1) (1990):102.
[45]James A. Trostle, Medical compliance as an ideology, Social Science and Medicine **12** (1988):1305.
[46]Richard F. Gillum and Arthur J. Barsky, Diagnosis and management of patient noncompliance, Journal of the American Medical Association **228** (1974):1563-67; and Dimatteo.

disease entity in need of medical management. As we have seen, this outlook leads physician/researchers on a search for patient-centered "etiologic agents" and physician-centered strategies for intervention—an outlook which is reinforced by the messages both implicit and explicit in pharmaceutical advertising. As in tuberculosis treatment in turn-of-the century America, physicians view themselves as being in control, not only of the patient's disease, but of the patient him- or herself, while at the same time remaining relatively unconcerned with the patients' understanding of and response to disease.

It is now possible to imagine how the modern ideology of compliance came to dominate American medical thought. The historical power of physicians was institutionalized and reinforced by various political, social, and economic factors until professional authority and control became so integral to the physicians' identity that it rarely is called into question. Thus patients came to be seen as "the core of the problem—they are unsophisticated about medical treatments, or they are too headstrong to follow instructions."[47] Physicians, as medicine's gatekeepers, are unwilling to relinquish control over patients' behavior, and so continue to claim ultimate responsibility for achieving patient compliance.

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[47]Todd, p. 22.

IV. Toward new theories of noncompliance

"Something kept telling me I didn't have to take [medication] anymore, a feeling or somethin'. It took me quite a while to work up the nerve to stop takin' the pills. And one day I said, 'One way to find out. . . .'"

—man who had been taking medication three times a day for 16 years
(from Peter Conrad, "The meaning of medications: another look at compliance.")

We have seen that the topic of compliance has been excessively determined by the attitudes and beliefs of physicians. This perspective is problematic in two ways. First, it views patient behavior as a passive response to preceding events, whether they be physiologic or situational, and thus denies the integrity and validity of the person who is labeled noncompliant. Second, the model fails to allow for ways in which the experts themselves may be contributing to the noncompliance they are attempting to resolve ("iatrogenic noncompliance?"). These problems arise from the fundamental orientation which is aligned with a physician's (rather than a patient's) perspective. The lack of consistent results stemming from this orientation indicates the pressing need for a new focus among researchers and practitioners.

Recent research has focused on medication usage as understandable only when both physicians' *and* patients' worldviews are taken into account.[1] A shift to the perspective of the patient yields new ways of exploring compliance. David Hayes-Bautista has commented on the social construction of illness:

> . . .it is not likely that the average patient explains her behavior to herself in terms of age, sex, education, marital status, social class, norms, values, or other variables often used by social scientists in their descriptions of her world. Instead, the patient will often have her own set of explanations for non-compliance.[2]

His comments and others' point to the benefits of examining patients' worlds from their own perspectives—only then can we understand the ways in which their coping strategies make sense. When viewing the

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[1]James A. Trostle, Doctors' orders and patients' self-interest: two views of medication usage? In Compliance in epilepsy (Epilepsy res. suppl 1) (edited by Schmidt D. and Leppik I.E.), (Elsevier Science Publishers, 1988),58.

[2]David E. Hayes-Bautista, Modifying the treatment: patient compliance, patient control and medical care, Social Science & Medicine **10** (1976):233.

illness experience as the patient does, we come to understand and respect him or her as a decision-making individual who lives "in a culture from which he or she is receiving information about health and illness."[3]

Two helpful theoretical approaches have been used by the handful of researchers who have examined noncompliance from the perspective of the patient. One approach views patient behavior in the context of his or her "illness representation." The second examines patient behavior as a form of self-regulation. These approaches yield valuable results which are not contradictory; rather, they help to begin constructing a new view of the patient as an active participant in the processes of health and illness. Furthermore, these approaches allow us to see, from the perspective of the patient, how physicians are complicit in noncompliance.

"Illness representation" indicates a personal construct of illness which a patient develops based upon abstract notions such as disease labeling and concrete features such as symptoms.[4] Both abstract and concrete features are shaped by previous personal experience as well as influences from the person's surroundings (opinions and experiences of family members, friends, and health care providers; cultural norms; and media images). The development of representations is a dynamic process, in which new information is constantly being taken in, compared with current constructs, and incorporated (perhaps in an altered form) or discarded. As the experience of symptoms and treatments unfolds, the

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[3]Gerry V. Stimson, Obeying doctor's orders: a view from the other side, Social Science & Medicine **8** (1974):103.

[4]Howard Leventhal, Emerging perspectives. In Handbook of health, health care, and the health professions (edited by Mechanic D.), (New York: Free Press, 1983),718.

representation is reworked and modified so that it remains useful to the patient in everyday life.[5]

Representations of illness are utilized by the patient in several ways. They allow the integration of a variety of information into a form which makes sense in terms of the patient's experience. They also direct planning and action strategies, and provide methods for appraising outcomes.[6] Expectations are developed for the outcomes of various behaviors, whether they be consulting a physician, following a medical regimen, or any other coping mechanism. Outcomes are then compared to expectations, and behavior is modified accordingly.[7]

Several anthropological studies have confirmed that symptoms play a major role in the continuing development and appraisal of illness representations.[8] The patient's experience and labeling of physiological symptoms form the basis of the representation, with external variables such as culture, demographics, emotional states, and interaction with others modifying the ways in which symptoms are interpreted. How, then, do hypertensive patients construct a representation of a condition which ostensibly has no symptoms?

This question has been asked by several researchers in recent years as they examine prevalent illness representations of hypertension. Their findings indicate that even for a purportedly asymptomatic condition such as hypertension, symptoms play a major role in the personal construct of

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[5]Linda M. Hunt, Brigitte Jordan, and Susan Irwin, Views of what's wrong: diagnosis and patients' concepts of illness, Social Science and Medicine **9** (1989):945-956.
[6]Howard Leventhal, R. Zimmerman, Mary Gutmann, Compliance: a self-regulation perspective. In Handbook of Behavioral Medicine (edited by Gentry W.D.), (New York: Guilford Press, 1984).
[7]*Ibid.*
[8]Hunt, *et al.*;.Hayes-Bautista; and James A. Trostle, W. Allen Hauser, and Ida S. Susser, The logic of noncompliance: management of epilepsy from the patient's point of view, Culture, Medicine, and Psychiatry **7** (1983):35-56.

the condition. For example, Blumhagen found that nearly 75% of individuals interviewed who had biomedically defined hypertension held a symptomatic view of "hyper-tension"—manifested by tiredness, dizziness, headache, flushing, altered psychological states, and a changed social status.[9] Other representations elucidated by this study and Heurtin-Roberts' include such disorders as "high blood" and "high-pertension", both of which describe symptom constellations which patients use to monitor their "pressure".[10] Meyer, Leventhal, and Gutmann found that, while 80% of hypertensive patients may agree that "most people" cannot tell when their blood pressure is elevated, they believe that they are exceptions.[11]

These researchers go on to explore how illness representations influence compliance. For example, Meyer, *et al* . found that hypertensives who believed that medications helped their symptoms were more likely to be compliant, with 70% of these patients taking their medications as directed, compared to only 31% of those who did *not* believe that treatment helped their symptoms.[12] Furthermore, those in the first group who were not considered compliant but believed treatment was helpful for symptoms were found to be treating their blood pressure as an acute illness, taking medications only when symptoms were present. These results demonstrate the important role of symptoms in the medication-taking behavior of patients.

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[9]Dan Blumhagen, Hyper-tension: a folk illness with a medical name, Culture, Medicine, and Psychiatry 4 (1980):197-227.
[10]Suzanne Heurtin-Roberts, My blood boils: folk models of hypertension (UCSF dissertation, 1988),211.
[11]Daniel Meyer, Howard Leventhal, and Mary Gutmann, Common-sense models of illness: the example of hypertension, Health Psychology 4(2) (1985):122.
[12]*Ibid.*, p. 125.

Heurtin-Roberts demonstrated the effects of abstract labeling as well as the importance of symptoms to maintenance of representations in her study of hypertensive African-American women in New Orleans.[13] She divided the study population into three groups based on their dominant illness representation, and found that those with symptomatic illness representations were significantly more likely to apply treatments in a cyclical or acute fashion which would be deemed noncompliance by the medical profession. Furthermore, she found that women who shared a biomedical view of hypertension were more likely to be compliant than those women who labeled their condition by other, "folk" terms. The symptomatic view of hypertension clearly has complex effects on compliance. On one hand, patients are more likely to take their medications if they believe that treatment helps symptoms, but they are also more likely to take medications in a way which is inconsistent with the wishes of the physician.

Assuming the viewpoint of the patient enables one to see that a physician's actions may fail to promote and at times actually hinder medicine-taking by the patient. Physicians must realize that just as they expect patients to comply with their recommendations, so to do patients have expectations of physicians. Expectations for the encounter are based upon a patient's representation of his or her illness, and may pertain to the quality of the interaction, its duration, the diagnosis, and/or the therapy advised.[14] Physicians who fail to elicit and respond to these expectations have patients who are frustrated, dissatisfied, and less compliant.[15]

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[13]Heurtin-Roberts.

[14]Stimson, p. 102.

[15]*Ibid.*; and D. Roter, Patient participation in patient-provider interactions: the effects of patient question-asking on the quality of interactions, satisfaction, and compliance, Health Education Monographs **5** (1977):281.

In terms of the symptomatic view of hypertension described above, many physicians unknowingly reinforce this through persistent patterns of poor communication. For example, physicians often inquire about symptoms during follow-up exams for hypertension without identifying these symptoms to the patient as manifestations of drug side effects or end-organ damage.[16] These symptoms may be identical to those which the patient has included in his or her illness representation as attributes of increased blood pressure—e.g. palpitations, dizziness, and weakness. Thus, the symptomatic view of hypertension is reinforced with each visit by the physician, who seldom, if ever, tells the patient why questions about symptoms are being asked. Indeed, Meyer, *et al.* found that self-identification of hypertensive symptoms increased from 71% in newly treated patients to over 90% in continuing patients.[17] When patients infer that the practitioner accepts their diagnostic indicators, they are more likely to continue to use these indicators in making treatment decisions.

Physicians also develop their own representations of illness which are continually being modified by interactions with patients.[18] Thus, a physician who ostensibly ascribes to the biomedical view of hypertension as an asymptomatic disorder may nevertheless find him- or herself believing that some patients (perhaps doctors themselves) can indeed sense when their blood pressure is elevated. Steele and Leventhal observed physician-patient interactions and found that patients may ultimately persuade their providers that hypertension causes symptoms.[19] Providers then become involved with the patient in the symptomatic representation of

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[16]Leventhal(1983), p. 719.
[17]Meyer, Leventhal, and Gutmann.
[18]Leventhal(1983), p. 719.
[19]Meyer, Leventhal, and Gutmann, p. 130.

hypertension, yet continue to label ensuing variations in medication-taking as irrational acts of noncompliance.

In addition to illness representation theory, a self-regulation perspective is also illuminating areas of patient and physician behavior which were previously ignored. Self-regulation emphasizes the fact that it is the patients who have ultimate control over consuming their medications.[20] David Hayes-Bautista carried out an exploration from this perspective in 1976 with patients from the San Francisco Bay Area.[21] He found through interviews that patient noncompliance is often based in an attempt to exert control over an unsatisfactory treatment regimen, and was able to describe the measures taken by patients to regain control. These patients brought their concerns to their physicians by using "convincing tactics" such as demands, disclosures, suggestions, or leading questions. Patients concurrently or subsequently resorted to "countering tactics" to counteract the effects of what is perceived to be an inappropriate treatment. Examples of such tactics include adding or substituting alternative treatments to the prescribed medical regimen, or altering the medication dosage. Hayes-Bautista found that both convincing and countering tactics were used within the course of an illness episode, with a sequential course (first attempting convincing, then utilizing countering tactics) being most common.[22]

Several years later, Conrad interviewed epilepsy patients to elicit their reasons for altering their medical regimen.[23] He found that, although many "failed to conform to their prescribed medication regimen,

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[20]Trostle(1988), p. 59.
[21]Hayes-Bautista.
[22]*Ibid.*, p. 235.
[23]Peter Conrad, The meaning of medications: another look at compliance, Social Science & Medicine **20**(1) (1985):29-37.

they did not define this conduct primarily as noncompliance with doctors' orders. . . .It was, rather, much more a question of. . .control."[24] Conrad found several reasons behind patient-initiated alterations of prescribed treatment, including testing medication efficacy, mitigating side effects, reducing stigmatization, and controlling dependency.[25] Trostle's interviews with epilepsy patients produced similar results, as did Donovan and Blake's study of patients at a rheumatology clinic.[26] These studies make a strong case that patients need to feel empowered when faced with illness, and often gain this by self-regulating treatment.

Physicians contribute to noncompliance as self-regulation by interacting with patients in ways which deny patient self-efficacy and decision-making capabilities. Physicians often enter the consultation with the unquestioned assumption that the patient desires and is prepared to fully comply with the recommendations of the "expert" physician. On the contrary, Zola points to a multitude of studies which show that "it takes a quite complex set of social events" to spur patients to see doctors, and they cannot be assumed to be "a group of willing supplicants."[27]

Once the interaction begins, more barriers arise which interfere with compliance. The methods by which physicians currently gather and record patient information are oriented to fact-finding and diagnosis. While these methods may be effective for such ends, they often undermine therapeutic goals by symbolically transforming the patient into an accessory to the

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[24]*Ibid.*, p. 31.
[25]*Ibid.*, pp. 32-35.
[26]Trostle(1988); and Jenny L. Donovan and David R. Blake, Patient non-compliance: deviance or reasoned decision-making? Social Science & Medicine 34(5) (1992):507-513.
[27]Irving K. Zola, Structural constraints in the doctor-patient relationship: the case of non-compliance, In The relevance of social science for medicine (edited by Eisenberg L. and Kleinman A.), (Dordrecht: D. Reidel Publishing, 1981),241.

diseased organ or system.[28] During the interview, the physician takes the active role, while the patient is expected to remain cooperatively passive. Patient autonomy is surrendered or lost, and physician expectations for patient behavior come to dominate the interaction.

Milton S. Davis found that compliance is a function of reciprocal interaction, with noncompliance increasing as physician feedback decreases.[29] Davis also found that authoritative patients who see passive physicians are less likely to comply with physician recommendations, again indicating the need for reciprocity.[30] Kaplan found that less patient control, less effective information seeking by and less involvement of the patient, and less exchange of opinions and emotion between the physician and the patient were correlated with poorer control of hypertension and diabetes.[31] These studies and others like them indicate that physicians must not deny the active role of the patient in his or her illness; rather, they should encourage patient collaboration and provide feedback throughout the interaction.

Research findings support the need of the patient to be active in consultation with the physician, as studies by Rost and others have demonstrated.[32] Based on audiotapes of medical visits, Rost found that patients who offer information in addition to answering physician questions are significantly more likely to comply with recommendations for

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[28]For more on this, see Joel C. Kuipers, "Medical discouse" in anthropological context, Medical Anthropology Quarterly 3(2) (1989):99-124.

[29]Milton S. Davis, Variations in patients' compliance with doctors' advice: an empirical analysis of patterns of communication, American Journal of Public Health **58**(2) (Feb 1968):283.

[30]*Ibid.*, p. 282.

[31]Sherrie H. Kaplan, Assessing the effects of physian-patient interactions on the outcomes of chronic disease, Medical Care **27**(3) (Mar 1989):S120.

[32]Kathryn Rost, The influence of patient participation on satisfaction and compliance, Diabetes Educator **15**(2) (Mar-Apr 1989):139-143.

treatment. Rost also found that the degree to which patients interrupted their physicians correlated positively with patient satisfaction. Furthermore, patients who were active participants were more likely to have their perspective heard by the physician—a finding which relates back to the prior discussion of illness representations. Other studies support Rost's findings, demonstrating that mutual respect, cooperation, and interaction between physicians and patients have a positive influence on health outcomes.[33]

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[33] W. Vandereycken and R. Meerman, Chronic illness behavior and noncompliance with treatment: pathways to an interactional approach, Psychotherapy and Psychosomatics 50(4) (1988):182-191; and Ralph Hingson, N.A. Scotch, J. Sorenson and J.P. Swazey, In sickness and in health: social dimensions of medical care (St. Louis: Mosby, 1981).

V. To where from here? A strategy to improve health outcomes

"To write prescriptions is easy, but to come to an understanding with people is hard."
-Franz Kafka, *A Country Doctor*

For those interested in redefining compliance in order to better serve the people, it may be *physicians,* not patients, who need to be educated. An influential study by Inui *et al.* demonstrated that by providing tutorials to physicians on aspects of hypertension therapy, patient blood pressures were more effectively controlled and were sustained at lower levels for longer periods of time.[1] The tutorials, covering the subjects of hypertension, its therapy, and its relation to patient compliance, were administered to interns, residents, and attending physicians. Changes in compliance rates were comparable to the results of more paternalistic measures such as extended supervision, serum drug monitoring, and administration of medication by injection.[2] As has been mentioned, this study is commonly cited by researchers on patient education and compliance, who often ignore the fact that it was the providers, not the patients, who received the education.[3] The implications of this study for medical education and practice thus go unheeded.

Physician education must include more than disease-related tutorials, however. The implications of the patient-centered studies mentioned in the previous chapter are not only that the introduction of unsolicited information elicits a change within the patient, but that the patient-physician interaction is itself transformed from a didactic to a more truly interactive encounter. Patients turn to doctors for information

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[1]Thomas S. Inui, Edward L. Yourtee and John W. Williamson, Improved outcomes in hypertension after physician tutorials, Annals of Internal Medicine **84** (1976):646-51.
[2]*Ibid.*
[3]David Levine, The results: impact and outcome of patient education, Journal of Human Hypertension 4(Suppl. 1) (1990):35-37; Martha N. Hill, Strategies for patient education, Clinical and Experimental Hypertension--Theory and Practice **A11**(5 & 6) (1989):1187-1201; Lawrence E. Klein, Compliance and blood pressure control, Hypertension **11**(3 pt. 2) (Mar 1988):II 61-4; Richard N. Winickoff and Paul K. Murphy, The persistent problem of poor blood pressure control, Archives of Internal Medicine **147**(8) (Aug 1987):1393-6; and William W. Neal, Reducing costs and improving compliance, American Journal of Cardiology **63**(4) (Jan 17 1989):17B-20B.

concerning their illness, and doctors come to rely on patients for information on the social parameters of treatment possibilities.[4] Haynes and Sackett's definition of compliance as "the extent to which a patients' behavior coincides with medical or health advice"[5] still holds true; however, these studies show that the etiology of noncompliance may not be limited to "the patient's behavior." Unfortunately, "doctors do not seem to comply with patients' needs any more than patients comply with doctors' treatments."[6]

Bringing the two facets of compliance (patient behavior and provider behavior) into consonance might be accomplished by altering one, the other, or both. Until now, physicians have been influenced by historical precedent and social forces to focus on the alteration of patient behavior. The alternative suggested by studies cited above is a focus on modification of physician behavior. Medical advice can be adjusted to fit the needs of patients if patients are involved in decision-making from the start, and if physicians have been sufficiently sensitized to the issues surrounding each disease and its therapeutic options. Noncompliance, then, is a product of the patient-physician dyad, and may require physician education to be alleviated.

Suggested intervention strategy

With the above discussion in mind, an intervention can be developed which aids the physician in improving the health status of his or her patients by dealing with issues of "iatrogenic noncompliance." This intervention might consist of a workshop or a series of seminars designed

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[4]Alexandra D. Todd, Intimate adversaries: cultural conflict between doctors and women patients (Philadelphia: University Press, 1989).
[5]R. Brian Haynes, D. Wayne Taylor and David L. Sackett, Compliance in health care (Baltimore: Johns Hopkins University Press, 1979).
[6]Todd.

to elicit physicians' conceptions of noncompliance and incorporate them into specific interventions, modifying antitherapeutic conceptions with information from research, and capitalizing on those which may be useful.[7] The goal is to provide a more fruitful model which can (and will[8]) be applied to their daily interactions with patients. Below, a research trial of such an intervention is described, using hypertension as a model. Following this outline are suggestions for its institutionalization.

Entry

A consultant familiar with the issues of noncompliance will avail him- or herself to general medicine clinics to conduct a workshop on "Compliance issues in the management of chronic illness" (or "hypertension" specifically). Since hypertension accounts for approximately on third of patient visits to such clinics, this setting is appropriate.[9] From an interested clinic, one or two highly motivated providers will be trained to take part in planning and executing the intervention. These physicians will then be capable of going on to repeat the intervention strategy with others (for example, the control group). Funding for the workshop and research costs will be through research grants or directly from managed care organizations, as this is a trial which will serve as an example for future interventions.

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[7]Alexis M. Nehemkis, The eye of the beholder: staff perceptions of noncompliance. In Compliance: the dilemma of the chronically ill (edited by Nehemkis A.M.), (New York: Springer Pub. Co., 1986),175.

[8]Like their patients, physicians are notoriously noncompliant with therapeutic recommendations, and it is clear that education about noncompliance improves physician knowledge of the topic, but has little effect on behavior. It is because of this that a more interactive approach has been formulated. Cohen, *et al.* (1985) quoted by Donald Meichenbaum and Dennis C. Turk, Facilitating treatment adherence: a practitioner's guidebook (New York: Plenum Press, 1987),255.

[9]Inui, *et al.*

Defining the problem / planning the intervention

In order to define the problem as it exists uniquely in that particular clinic, a questionnaire will be administered to providers (see Appendix[10]). This instrument is designed to elicit physicians' attitudes toward and models of patient noncompliance. A small number of physicians will also be observed as they interact with patients. These providers will be scored based upon their adherence management techniques as outlined by Bartlett.[11] With this information, the consultant and physician collaborators will develop goals and design an intervention suited to the needs of the providers and patients at that clinic. Given that the needs of each clinic will vary, what follows is a hypothetical intervention strategy which will, of course, be modified by the consultant and collaborators as is appropriate.

Goals of intervention

Based on ideas discussed concerning illness representations and the role of physicians in noncompliance, goals for the intervention might resemble those suggested by Zola:

> 1) To appreciate what following a medical regimen means to an individual.

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[10]This survey contains original questions as well as questions from Jill Cockburn and colleagues' study of general practitioners' attitudes along several subscales. See Jill Cockburn, Douglas Killer, Elizabeth Campbell, and Robert W. Sanson-Fisher, Measuring general practitioners' attitudes towards medical care, Family Practice 4(3) (1987):192-199.

[11]Edward E. Bartlett, John C. Higginbotham, Steve Cohen-Cole and Julian Bird, How do primary care residents manage patient non-adherence? Patient Education and Counseling 16 (1990):53-60.

2) To acknowledge the role that health personnel have in contributing to noncompliance.[12]

Given what we have seen about the effects of these factors on medicine-taking behavior, it is hoped that reaching these goals will have a positive effect on patient health status as perceived by both physician and patient.

Intervention

For research purposes, providers at the clinic will be divided into two groups—one of which will serve as a control group during the initial intervention implementation (the collaborating physicians may decide to provide a workshop for control group physicians at a later time). Often providers staff such clinics on a once-weekly basis, making assignment to groups relatively straightforward. For example, the experimental group might consist of Monday and Tuesday physicians, with the Thursday and Friday physicians serving as the control group. To ensure continuity of care, patients are often assigned to a physician and thus will have a regular pattern of clinic attendance as well.[13]

Physicians in the experimental group will be informed of the upcoming workshop and encouraged to attend. Upon registering, they will partake in a role-playing exercise designed to increase their awareness of issues in compliance.[14] Each participant will be asked to become a "patient". A short description of their situation will be provided, which will characterize him or her as an overworked intern or resident experiencing

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[12]Irving K. Zola, Structural constraints in the doctor-patient relationship: the case of non-compliance. In The Relevance of Social Science for Medicine (edited by Eisenberg L. and Kleinman A.), (Dordrecht: D. Reidel Publishing. 1981),241-252.

[13]Inui, *et al.*

[14]If this is not possible, it may be similarly illustrative to simply point out to participants the high rates of noncompliance with established criteria for delivery of treatment among physicians and other health care providers. Studies show that clinical performance ranges between 48% and 72% *below* levels of professional standards. Meichenbaum, p. 254.

frequent fatigue or hypertension. The "prescription" will be for a vitamin supplement or commonly used antihypertensive, to be "filled" by the researcher upon request. Instructions for taking the medicines and special dietary restrictions will be included. Predictions for follow-through can be made based on existing knowledge of rates of prescription filling and compliance. Participants will be asked to bring their "medicine" with them to the workshop, at which time the predictions will be tested against observed rates of compliance. This type of role playing has been shown to be effective in demonstrating to health care providers some of the difficulties patients encounter in taking medicines. The exercise also increases the impact of subsequent education.[15]

The workshop or seminar series will begin with a discussion of participants' experiences with the role play. Participants will be asked to compare these experiences to their responses to the initial questionnaire (see above, *Defining the problem*). Research findings will then be presented which demonstrate the strengths and weaknesses of the various strategies which prevail in this clinic setting, whether they be biomedical, behavioral, or other forms of intervention. The meanings of these strategies to the patient will also be discussed.

There will then be a brief introduction to control theory and illness representations. Case examples will be provided by the presenters and elicited from participants. Audio-visual material may also be incorporated at this stage (e.g. a film showing a patient going through the process of his or her illness). Special note will be made of situations where providers have

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[15]For more information on this innovative technique, see Barry Blackwell, Bill Griffin, Mike Magill and Robert Bencze, Teaching medical students about treatment compliance, Journal of Medical Education **53** (1978):672-75.

been "noncompliant" in some way. Studies demonstrating the usefulness of this approach will be reviewed.

In order to increase understanding of the impact of hypertension on the patient, patients familiar with the experience will be asked to participate in the workshop. Together with "experts" on the physiological effects of hypertension, they will work to improve the participants' understanding of hypertension as both a biomedical and a psychosocial phenomenon.

Suggestions for practical changes in the physician-patient consultation will then be developed by the participants and presenters working together in small focus groups. They will present their results to the larger group for discussion. Suggestions might include the following:

*Have periodic meetings with a group of your patients to exchange information. You can provide them with information on relevant medical topics, and they can provide you with information on steps you can take to improve as a care provider.[16]

*At each visit, spend time getting to know what your patient's main concerns are. What expectations are there for you?

*Ask patients what non-pharmacological methods they have tried or are interested in trying in the treatment of their high blood pressure. Be willing to provide them with accurate information when possible, or refer them to someone who can.

*Ask patients who are on medication about their patterns of medicine usage. (Asking patients in a nonjudgmental way about their compliance with medication has been shown to be as accurate as recording prescription refills, pill counts, or blood levels.[17]) Attempt to elicit and understand their motivations.

*Engage patients in developing a plan of action which will be useful to them, and which you believe will be effective. (Keep in mind that the *patient* exercises ultimate control over the management of his or her condition. Continuing to prescribe a "proven" medication to a patient who

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[16]Mark Renneker, M.D. UCSF complementary care seminar. 11/22/91.
[17]Klein; and Bartlett.

does not take it will not improve their health status and may in fact be deleterious).

*Encourage patients to actively seek information from you or any other health care providers. Encourage them to write down any questions they have before their next visit. This can be facilitated by providing a "question sheet" containing your phone number and call-in hours, or by providing a similar sheet at check-in, which the patient can fill out just prior to your consultation.[18]

*Periodically check your own representations of various medical conditions. How are they changing? What is influencing them? In what ways might they be influencing patients?

Suggestions for change can then be tested through role playing with workshop participants broken into pairs. The assigned "patient" can be given a written profile of a patient with uncontrolled hypertension. The "physician" may then exercise these new tools to increase his or her understanding of the patient's illness representation, decrease any physician factors which may be promoting noncompliance, and negotiate with patients a therapeutic regimen which both parties feel will be useful and effective. Participants will be encouraged to try out these new strategies in their practices, discuss them with one another, and modify the tools where appropriate.

Process evaluation

In order to determine to what extent changes are actually made in practice patterns, the questionnaires designed to elicit attitudes and beliefs about compliance (see above, *Planning the intervention*) will be administered to physicians in both groups at three and six months post-intervention. Observations of those physicians who were observed at the planning stage will also be repeated. Post-intervention results of the

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[18]Kathryn Rost, Patient activation interventions: research issues in dissemination, The Diabetes Educator 15(1) (Jan-Feb 1989): 80-82.

experimental group will be compared with both pre-intervention results and control group results in order to determine the amount of change attributable to the intervention.

Outcome evaluation

Four outcome measures are commonly used in health care research: subjective health status of patients, functional health status, compliance, and physiological measures.[19] Since uncomplicated essential hypertension does not significantly alter functional health status, this will not be used to evaluate the effectiveness of this intervention strategy. Thus, three measures will be utilized to assess outcomes: patient assessment of health status, compliance, and blood pressure recordings. All measures will be taken at both pre- and post-intervention, and in patients of both experimental and control group physicians.

Compliance rates are expected to be sensitive to changes in medical advice as well as changes in patient behavior, for a change in advice which acknowledges the patient's expectations will result in an increased tendency to follow that advice (especially if the advice is jointly constructed by physician *and* patient). Compliance rates will be ascertained at six months post-intervention by "blind" researchers as they concomitantly measure subjective health status by use of a survey instrument.[20] Rates of compliance will be reflected in degrees of blood pressure control[21] as measured by a "blind" observer—either a clinic staff person or an electronic cuff.

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[19]Sherrie H. Kaplan, Sheldon Greenfield, and John E. Ware, Assessing the effects of physician-patient interactions on the outcomes of chronic disease, Medical Care, 1989 March, **27**(3) (Mar 1989): S110-S127.

[20]*Ibid.*

[21]Neal.

These outcome measures have been chosen because they serve to evaluate the intervention's effect on the physician's ultimate concern: the health status of the patient from both the physician's and the patient's point of view.

Institutionalization of change

Should this intervention strategy have significant positive effects on health outcomes, there will be a need to institutionalize the strategy in a way which is not only cost-effective but also sensitive to the community of physicians who are the targets of this intervention. The first step will be publication of research findings in widely read medical journals such as JAMA, The New England Journal of Medicine, and Annals of Internal Medicine. However, in a managed care setting, institutionalization of change can take place immediately within the context of staff meetings and changes in organizational regulations.

The next step will involve "teaching the teachers." Short faculty development courses on teaching compliance strategies can be provided to academic physicians through their continuing education programs.[22] This will encourage teachers of medical interviewing and patient care to incorporate the strategies into their curricula for medical students.

Finally, physicians already in practice must be encouraged to develop compliance strategies of their own through the use of workshops, seminars, and informal discussions. Motivation for interested physician leaders may come through the availability of staff development resources

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[22]Kathryn Rost, Geoffrey H. Gordon and the SGIM Task Force on the Medical Interview, The teacher simulation exercise: changes in physician teaching emphasis and strategy, Journal of General Internal Medicine 4 (Mar-Apr 1989):121-126.

from affiliated hospitals or other health care facilities. The strategy can be modified to address the issues of other chronic and acute illnesses.

Addressing the issue at a policy level

Physicians' attitudes and beliefs about noncompliance in their practice are not created in a vacuum, nor are they promoted by their teachers and colleagues alone. Rather, the roots of the prevailing notions of noncompliance are deeply embedded in the history of western medicine, and are fostered today by publicists and policymakers. As we have seen, suggestions for improving compliance in clinical practice remain within the traditional boundaries of the role of the physician. Seldom are suggestions advanced for actions which might significantly alter the *status quo*. Physicians and others who are interested in improving the ways in which health care is delivered must strive for change within their own work—however, to effect lasting change efforts must also be made to bring an end to the structural reinforcement of stereotypes which continue to affect the well-being of all people.

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Appendix

Physicians and patients:
A survey of health care providers

Thank you for agreeing to fill out this brief survey. Your thoughts and comments are appreciated.

Please circle the number which most closely corresponds to your feeling about the statement: **1= strongly disagree 2=disagree 3=mildly disagree 4=neither agree nor disagree 5=mildly agree 6=agree 7=strongly agree.** Keep in mind that **"patients" refers to adult patients only.**

	Strongly Disagree						**Strongly Agree**
1. I feel that it is a waste of time trying to persuade patients to give up smoking.	1	2	3	4	5	6	7
2. Noncompliance is an important issue in health care today.	1	2	3	4	5	6	7
3. Most of my patients follow my advice.	1	2	3	4	5	6	7
4. I believe that I should always inform patients about their prescribed treatment, making sure they understand my explanations.	1	2	3	4	5	6	7
5. An important part of my role as a physician is simply to listen to patients' worries.	1	2	3	4	5	6	7
6. Counselling patients with personal problems can help them to cope better in the future.	1	2	3	4	5	6	7
7. Patient compliance has a lot to do with the patient's social support.	1	2	3	4	5	6	7
8. Providing emotional support for patients is important for my personal satisfaction.	1	2	3	4	5	6	7
9. Identification of modifiable risk factors such as smoking is a very important aspect of my work.	1	2	3	4	5	6	7
10. A good way to handle noncompliance is to educate the patient.	1	2	3	4	5	6	7
11. I believe that effective medical treatment depends on a partnership in which the patient plays an active part.	1	2	3	4	5	6	7
12. It is important for me to be frank and open with patients.	1	2	3	4	5	6	7
13. When asked, my patients are honest with me about their medicine-taking behavior.	1	2	3	4	5	6	7
14. Side effect profiles are key determinants of medicine-taking behavior.	1	2	3	4	5	6	7

	Strongly Disagree						Strongly Agree
15. Sometimes I think that patient noncompliance is my fault.	1	2	3	4	5	6	7
16. I believe that physicians are very influential in persuading patients to change their lifestyles.	1	2	3	4	5	6	7
17. I think that it is my job to treat physical disease and leave tasks such as counselling to other professions.	1	2	3	4	5	6	7
18. After awhile in practice, it is easy to spot noncompliant patients.	1	2	3	4	5	6	7
19. Noncompliance can occur due to financial barriers.	1	2	3	4	5	6	7
20. Patients are more likely to follow my advice concerning their physical complaints than advice concerning their social or emotional problems.	1	2	3	4	5	6	7
21. Whether or not they succeed, most of my patients try to follow my advice.	1	2	3	4	5	6	7
22. The majority of patients do not wish to be involved in decision making about their treatment.	1	2	3	4	5	6	7
23. Noncompliance is mostly related to the patient's personality.	1	2	3	4	5	6	7
24. The more information I give patients about their diagnosis and treatment, the more likely they are to comply with instructions.	1	2	3	4	5	6	7
25. I usually don't attempt to help patients with psychological problems because they are the result of life situations over which I have little or no control.	1	2	3	4	5	6	7
26. Patients who don't follow my advice often have adverse physical outcomes.	1	2	3	4	5	6	7
27. Most patients would prefer the doctor to take responsibility for their medical problems.	1	2	3	4	5	6	7
28. Noncompliance is a fact of life in this branch of medical practice.	1	2	3	4	5	6	7

29. Noncompliant patients are:

		always	usually	often	both	often	usually	always	
a)	old	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	young
b)	male	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	female
c)	rich	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	poor
d)	independent	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	dependent
e)	intelligent	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	unintelligent
f)	educated	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	not educated
g)	aggressive	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	passive
h)	informed	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	uninformed
i)	relaxed	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	worried
j)	on time	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	often late
k)	vocal	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	quiet
l)	similar to me	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	different from me
m)	chronically ill	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	|.....|	acutely ill