Understanding Noncompliant Behavior: Definitions and Causes

By Fred Kleinsinger, MD

Abstract

Noncompliant behavior of patients frequently interferes with effectiveness of treatment for a variety of medical conditions and can have serious consequences. Most clinicians have had little training in identifying the common causes of patients' noncompliant behavior, and clinicians have few tools to cope with this type of behavior. The goals of this article are to define noncompliant behavior, to discuss the most common reasons for noncompliance, and to provide new insight into noncompliant behavior that clinicians can use to design more effective strategies for coping with noncompliant patients.

Introduction

Some of the more frustrating experiences I have had as a physician have involved patients who refuse to follow my perfectly good clinical advice. Whether it was advice for using prescription medicine, for follow-up visits, for important clinical tests or surgical procedures, or for making crucial lifestyle modifications, a few patients steadfastly refuse my well-intended prescriptions or recommendations.

The most helpful things I have ever done with noncompliant patients have been to ask questions …

Early in my career, I assumed that these refusals just indicated a lack of understanding; if my patients could comprehend the seriousness of their problems and the necessity of the recommended solutions, only the most dense and stubborn of people would fail to heed my advice. My solution, therefore, for all noncompliant behavior (NCB) was to repeat—more emphatically—why my recommendations were important and to reiterate my explanations and dire predictions until I felt that the patient could comprehend and would comply.

The frequent failure of this approach led me, during the course of more than 25 years in clinical medicine, to adjust my attitude and to try to understand the causes of NCB. I am now attempting to share some of what I have learned with other frustrated clinicians. This article arises from a presentation I developed for a Medicine-Behavioral Medicine conference on this topic. In preparing this talk, a Medline search revealed a dearth of relevant articles in the medical literature. My goal is to approach the topic in a way that speaks directly to the problems we encounter in our daily practice and to apply a holistic and practical understanding to the issues involved.

But first I want to give credit where credit is due: Almost everything useful I know about NCB I have learned from my patients themselves. The most helpful things I have ever done with noncompliant patients have been to ask questions, not to lecture, and to be willing to listen to what patients say. These activities are often very difficult to do within the time constraints of clinical practice. Sometimes I have to "suspend" the clock and my usual clinical approach and just tell the patient that I'm frustrated and concerned and that I need to know what he or she understands about the disease process and problems being faced. And then I'll just be quiet and listen as nonjudgmentally as possible.

Defining Noncompliant Behavior

"Noncompliant behavior" is an awkward phrase, although widely used. It conveys what the patient isn't doing, a negative concept, rather than what the patient is doing. I believe that were we able to sufficiently understand our patients, their lives, what their illnesses mean to them, and how they cope with their illnesses, every act of noncompliance would seem to make sense—at least at some level. I know that the term "nonadherence" has replaced "noncompliance" in some circles because "nonadherence" is less value-laden and does not imply a rigid hierarchical relationship between physician and patient. I have used "noncompliance" or "noncompliant behavior" in this article because I believe it is in the lexicon of the audience of frustrated physicians I am attempting to ad-

Fred Kleinsinger, MD, is a primary care physician in the Department of Medicine at the Kaiser Oakland Medical Center. He has an active outpatient panel practice, is physician team leader for a group of 11 medicine physicians, and manages the Mentoring Program for the Medicine Department. E-mail: fred.kleinsinger@kp.org.

dress and because I believe that the tone and content of this article explore and critique the concept of patient "compliance."

In defining NCB, I use the following four criteria: 1) the patient's medical problem is potentially serious and poses a clinically significant risk to length or quality of life; 2) at least one treatment exists that if followed correctly, will markedly reduce this risk; 3) the patient has easy access to the treatment or treatments; and 4) the patient deviates significantly from most patients (with similar medical problems) in degree of compliance with medical advice, treatment, or follow-up in a way that directly or potentially jeopardizes the patient's health or quality of life.

Few patients fully comply with all of our recommendations. Most Type II diabetic patients never lose much weight; many hypertensive patients forget to take a few pills and miss a few medical appointments; some patients with advanced cancer shun conventional (and predictably ineffective) treatment and instead pursue alternative therapy. The NCB I discuss here is more dramatic and more obviously damaging; for example, Type II diabetic patients who visit their physician less than once a year, who frequently run out of medication, and whose blood glucose levels are always poorly controlled (with HbA_{1c} >13%, for example) are demonstrating NCB. Patients who have obvious (palpable) breast cancer but who refuse surgery illustrate a different and less common type of NCB.

Common Causes of Noncompliant Behavior

I have found that, similar to many other problems in medicine, NCB is caused by multiple, often intertwined factors. For example, problems in communication are often related to cultural issues. Any patient may be influenced by more than one of these causative factors, and I am sure many other factors exist that I have not yet encountered or do not yet understand. Instead of my earlier ineffective tactic of repeatedly hammering the same advice and information into the resistant ears of my noncompliant patients, I found that making the effort to understand the causes of each patient's NCB helps me tailor an approach to removing obstacles and encouraging the patient's full participation in their own health care.

Failure of Communication and Lack of Comprehension

As I have stated, early in my career I thought most NCB was caused by my failure to communicate and thus by a patient's inability to comprehend my advice. Patients differ greatly in levels of education, intelligence, and language skills. An explanation of a disease process delivered in English may be perfectly clear to a native English speaker who graduated college but may be totally unintelligible to someone who did not graduate from high school or who speaks English as a second language. One of our duties as physicians is to give patients our explanation of their health problems and our recommended solutions using terms that are clear and meaningful to each patient. However, very little of our physician training is designed to facilitate this vital communication. We also lack tools and time to monitor how successfully we are communicating with our patients. Many patients are too polite—or too embarrassed—to speak out when their physician unintentionally confuses or mystifies them. These patients suffer in silent bewilderment.

Physicians are highly educated, typically have above-average intelligence, and belong to a culture that values education and intelligence; we often do not understand how intimidating we can be to others. Although some of our patients may have below-average intelligence, our duty to effectively communicate with them remains. Many years ago, I was a medical consultant for an organization that supported independent living for developmentally disabled young adults; many of their clients were my patients. They were, almost without fail, wonderful patients. They looked forward to their visits with me; they worked hard to understand what I said and recommended; and they appreciated my attention. People who have limited intelligence can be excellent and compliant patients.

Few patients fully comply with all of our recommendations.

Patients may be unable to comprehend our explanations and advice for other reasons. For example, progressive dementia can have an insidious onset in older patients, who may remain well-adapted socially and whose behavior may seem appropriate. Sometimes NCB in a patient who previously had been compliant is the first clue to what may be a significant degree of dementia. I now use the Mini-Mental State Examination for a newly noncompliant elderly patient and am often surprised by poor scores.

Cultural Issues

We filter our understanding of life's important experiences through the values and concepts of the culture in which we grew up. This filtering process certainly applies to our understanding of good health, causes of medical problems, and effective medical care. The greater the discordance between the cul-

tures of the practitioner and of the patient, the greater the opportunity for miscommunication and misunderstanding. Even when ostensibly from the same cultural roots, the physician and patient can be divided by differences in class or education.

Clinicians who see patients with markedly different cultural backgrounds must be aware of the many ways cultural differences can impede successful communication, mutual comprehension, and cooperation. Language barriers may complicate communication even when the patient speaks English, because words used in the English language can have slightly different definitions in different cultures.

Denial in mild forms is of considerable value … Denial in more severe form can be crippling and maladaptive.

When faced with a patient's apparent NCB as well as with cultural difference between patient and physician, the physician's responsibility is to explore possible cultural factors that may obstruct effective health care. Some cultures value a direct and explicit communication style; others favor a more indirect and subtle style. In some cultures, to challenge or disagree with a physician is considered improper; therefore, a patient's lack of agreement or understanding may lead to silence during the office visit or passive noncompliance afterward. Culturally sensitive health communication is an enormous issue worthy of much research and training.

"Psychological" Issues

I put "psychological" in quotes to emphasize that my understanding of this term includes biological, environmental, cultural, and patient-specific factors. Psychological issues that commonly result in NCB include denial and depression and, less commonly, severe psychiatric illness such as psychosis.

In this context, denial is the process by which painful or upsetting thoughts and issues recede from consciousness—a very common response to bad news. Denial in mild forms is of considerable value—otherwise, we would all be preoccupied with our problems and unable to function within our daily life. Denial in more severe form can be crippling and maladaptive. In my experience, denial is especially common in long-term diabetic patients whose diabetes was either of juvenile or of midlife onset. Good blood glucose control demands enormous effort compared with control of signs or symptoms of other common chronic illnesses, such as hypertension. The diabetic patient must pay close attention to diet and exercise; monitor blood glucose levels at home, a process requiring finger sticks; schedule frequent blood tests; and take pills, insulin injections, or both. Contemplating these complex requirements along with the long-term risk of blindness, kidney failure, and cardiovascular complications may stimulate denial in many patients.

In evaluating depression as a cause of NCB, I do not only include patients with a clear diagnosis as defined by the Diagnostic and Statistical Manual of Mental Disorders but also patients whose depressed mood and defeatist attitude sabotage their ability to deal with their medical condition. Patients who have more severe depression may engage in NCB that appears suicidal and that may lead to an abrupt and early death, for example, a patient with insulin-dependent diabetes who will not self-monitor blood glucose levels and who is frequently hypoglycemic.

Patients with bipolar disorders are often unpredictable, and their degree of compliance varies, depending on their mood state.

Patients who are clinically psychotic or who have thought disorders with psychotic features present one of the greatest challenges to addressing NCB. For example, a patient who is delusional and paranoid may refuse psychiatric care and live independently. This patient could refuse treatment for a serious disease, such as early-stage breast cancer. Despite enormous effort, a physician may be unable to convince the patient of the seriousness of the disease; in fact, the patient may stop coming to office visits and may stop answering letters or phone calls from the physician.

Secondary Gain

Some patients feel rewarded for remaining sick. In my experience, the most common reward is being classified as medically disabled: the patient is considered unable to work or requires long-term modification of duties. In this way, NCB (and a worsening or stationary health status) is financially rewarded, and the patient is removed from a stressful or onerous work situation. I believe that often this is not a conscious process, such as deliberate malingering or premeditated self-sabotage, but instead that subconscious positive reinforcement occurs when NCB results in the patient continuing to be classified as medically disabled.

Patients who receive and enjoy special attention from family members while in poor health may engage in NCB.

Psychosocial Stress

An overwhelmed patient is often ineffective at self-care. Many of our patients face complex and stressful living situations. Realities such as

poverty, long hours working in multiple jobs, difficult parenting problems, or troubled relationships can leave people exhausted, feeling besieged, and simply unable to cope with the added time and energy required to fully manage a chronic illness. Feeling trapped and hopeless destroys that sense of optimism for the future that usually helps motivate good self-care for chronic illness.

For many chronic illnesses, such as hypertension, noncompliant patients may feel perfectly healthy until complications such as congestive heart failure or stroke occur. These patients must truly believe the diagnosis and the physician's advice, have a clear understanding of the consequences of NCB, and develop the ability to prioritize their own needs to take daily medication and keep regular medical appointments even while they feel healthy—in the hope of a healthier future.

Drug and Alcohol Dependence

People who are addicted to alcohol or drugs often fail to take care of business in many of life's arenas and are often erratic or noncompliant with regard to their health care. These patients often suffer from medical complications of their addictions, such as hepatitis C or cirrhosis; because of poor self-care, they are also prone to many other chronic illnesses. Treating the addiction is often prerequisite to treating comorbidities, but the denial that these patients usually have impedes effective medical care. Stress and disorganization in the lives of many addicted patients—as well as health problems—create a formula for massive NCB and poor health outcome.

Recommendations

The next time one of the patients in your practice engages in NCB, take a minute to think about what may be causing this behavior. Ask questions: Does the patient understand the health problem (or the consequences of NCB) or have suggestions on how self-care behavior could be improved? Using the general categories I have suggested—and any of your own creation—develop a differential diagnosis for the cause or causes of the patient's NCB. As with many complex medical problems, a deeper understanding of the roots of the problem can suggest steps toward its solution. Discussing the case with a colleague may help generate a fresh perspective and a new approach.

Most important, I suggest that you consider NCB a challenge—not a failure. In a planned future paper on this topic, I will present solutions and some practical tools, with case examples, to help deal with noncompliant behavior. ❖

Acknowledgment

Kate Scannell, MD, reviewed the manuscript.

For many chronic illnesses, such as hypertension, noncompliant patients may feel perfectly healthy until complications such as congestive heart failure or stroke occur.

To Learn from the Experience of Others

Human beings, who are almost unique in having the ability to learn from the experience of others, are also remarkable for their apparent disinclination to do so.

Last Chance to See, Douglas Adams, 1952-2001, author