Beyond "Compliance" Is "Adherence"

Improving the prospect of diabetes care

KAREN E. LUTFEY, MA
WILLIAM J. WISHNER, MD

The purpose of this study is to evaluate existing research in the area of patient "compliance," to endorse reconceptualizing "compliance" in terms of "adherence," and to discuss the benefits of such a change for medical practitioners. This study critically reviews existing medical, nursing, and social scientific research in the area of patient "compliance." We assert that the literature reviewed is flawed in its focus on patient behavior as the source of "noncompliance," and neglects the roles that practitioners, the American medical system, and patient-practitioner interaction play in medical definitions of "compliance." The term "compliance" suggests a restricted medical-centered model of behavior, while the alternative "adherence" implies that patients have more autonomy in defining and following their medical treatments. We suggest that while the change in terminology is minor, it reflects an important paradigmatic shift for thinking about the delivery of health care. By enabling practitioners to more accurately identify patients' social and economic constraints and to provide them with more efficient educational and financial resources, this type of change will improve patient care. In general, by moving to a more social paradigm for understanding patient behavior, practitioners can expand the types of explanations, and therefore the types of solutions, they have for therapeutic adherence.

Diabetes Care 22:635–639, 1999

The term "compliance" is pervasive in medical science, yet there have been relatively few efforts to critically examine the concept and the problems that accompany it. We contend that there are serious drawbacks to the use of "compliance" and, in its place, we advocate more regular use of the term "adherence." "Adherence" is certainly not new to medical care research, and its increased use in recent years has positively impacted diabetes care by making practitioners more aware of patients' independence and decision-making processes. However, the concept of "adherence" has several advantages over "compliance" that have not been fully explored and can potentially continue to improve diabetes care.

In medical usage, "compliance" is defined as "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (1). When this term came into popular use in the 1970s, it was intended to be a "nonjudgmental" alternative to a previous understanding of patient behavior as characterized by "recalcitrance" and "insensitivity" (2); it turned the chronic concern of patients not following their treatment regimens into a scientific problem that could be studied and potentially solved. Haynes and Sackett, the progenitors of the term, claimed "compliance" was interchangeable with "adherence." It has now become clear, however, that there are some critical differences between the two terms.

The very word "compliance" suggests that patients acquiesce to, yield to, or obey physicians' instructions; it implies conformity to medical or medically defined goals only. The term "adherence," on the other hand, captures the increasing complexity of medical care by characterizing patients as independent, intelligent, and autonomous people who take more active and voluntary roles in defining and pursuing goals for their medical treatment. The question of why patients might not adhere to regimens necessarily implies a broader social and personal range of issues than just the medical goals implied by "compliance." In recent years, some medical research has suggested that there is a need to replace the term "adherence" with "compliance" (3–9). None of this research, however, has addressed the underlying paradigms associated with the use of these two terms and the broader implications of switching from "compliance" to "adherence." As a result, current use of the phrase "treatment adherence" only superficially addresses some of the fundamental problems plaguing "compliance."

The general topic, however, has not been ignored. Currently, more than 11,600 English-language articles on "compliance" or "treatment adherence" are included in *Index Medicus* and other bibliographic collections, many of which have been published in recent years: 22 articles were published before 1960, 850 articles by 1978, and more than 700 in 1994 alone (10). We will consider some of the trends and limitations in this literature, discuss the importance of using the concept of "adherence" in place of "compliance," especially with respect to diabetes care (11–18), and propose some theoretical approaches we consider fruitful venues for future research. Specifically, we focus on reconceptualizing "compliance" as something that is socially constructed by patients and practitioners together, moving away from the notion that it is strictly a patient characteristic.

CAN WE DEFINE "NONCOMPLIANCE?" —

There is a massive and diverse literature in the area of patient compliance that spans medical, nursing, and social sciences. This research originally proliferated almost 3 decades ago, but has continued to grow and develop. Historically, researchers in this area have attempted to identify noncompliant patients and to understand their behavior by focusing on their demographic, psychological, and social characteristics, as well as by studying patient-practitioner interaction. While each of these perspectives has

From the Department of Sociology, Bloomington (K.E.L.), and the School of Medicine, Division of Endocrinology, Indianapolis (W.J.W.), Indiana University, Indianapolis, Indiana.

Address correspondence and reprint requests to Karen Lutfey, Department of Sociology, Ballantine Hall 747, Bloomington, IN, 47405. E-mail: klutfey@indiana.edu.

Received for publication 12 August 1998 and accepted in revised form 3 December 1998.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

Downloaded from http://diabetesjournals.org/care/article-pdf/22/4/635/448877/10189544.pdf by guest on 06 December 2023

contributed to our current knowledge about patient behavior, this body of work has generated many inconclusive findings, which we discuss in more detail below.

Demographic characteristics

The first major wave of research into "compliance" occurred in the 1970s as physicians gained access to a greater assortment of pharmaceuticals that could be used widely, increasing the need for understanding the frequency with which and conditions under which patients do not follow their treatment regimens (19). These investigations focused on three types of questions (20):

1. How many patients do not use their medicines as the doctor instructs?
2. What are the characteristics of these patients?
3. Why do they not follow instructions?

Findings in reference to these questions have generated generally inconclusive results. The percentage of patients "defaulting" from doctor's instructions varies from ~20 to 90%, with most estimates converging somewhere around 50% for chronic diseases (20–23). For diabetic patients, findings are similarly equivocal, yet also suggest an overall lack of treatment adherence: estimates of adherence to insulin injection regimens range from 20 to 80%; adherence to dietary recommendations converges around 65%; adherence to glucose monitoring regimens ranges from 57 to 70%; and adherence to exercise regimens ranges from 19 to 30% (5). An early study found that only 7% of diabetic patients are fully adherent to all aspects of their regimen (5). In some studies, factors such as social class, education, length of therapy, social isolation, and marital status have been correlated with "noncompliant" behavior. At the same time, other research has suggested that "compliance" is not related to education, duration of symptoms, or marital status (20,23). At best, these findings portray a confused profile of "noncompliant" patients.

Psychological, behavioral, and personality characteristics

When research indicated that "noncompliant" patients could not be readily identified by basic demographic characteristics, the question shifted to why patients do not follow practitioners' recommendations. Various accounts for this behavior suggest deficiencies in individual patients, including disliking side-effects of the drugs (20), thinking they are fully recovered before they actually are (20), not wanting to use drugs (20), having uncooperative personalities (24), being unable to understand physicians' instructions (24), exhibiting irrational behavior in general (25), having difficulty remembering the regimen (26), having a lack of motivation (19), having feelings of incompetence (27), and having a "lack of adequate environmental stimuli" (28). In the case of diabetes, "noncompliance" is often understood in terms of a patient's cognitive abilities to understand complex regimens and potential complications (3), psychological motivations to control blood sugars (11), and general willingness to learn about diabetes, test glucose levels, and follow diet recommendations (16,17).

In addition to studying individuals' psychological characteristics, psychologists have also tried to understand "compliance" by studying individuals' motivations and thought processes in following treatment regimens. Fogarty (29), for example, suggests that "noncompliance" can be understood in terms of reactance theory: in response to perceived threats to their freedom, patients may become motivated to recapture lost freedom by not following medical advice (30). Other psychological research has interpreted "compliance" in terms of control submission and dominance (31); mental health as it affects patients' abilities to avoid hospitalization (32); the importance of trust and commitment to work collaboratively with health care providers (33); medication education, patient counseling, and therapeutic drug monitoring (34); and sex differences between patients and providers (35). In diabetes care, these psychological patterns manifest themselves in specific ways: patients resist regimens because they want control over their daily eating and living patterns; they are insufficiently educated about diabetes management; or, simply, patients have different understandings of their diabetes management based on sociocultural differences between themselves and their practitioners.

Other theories incorporate larger social issues instead of focusing strictly on patients' individual personality characteristics. The Health Belief Model (8,36), for example, addresses the influence of patients' beliefs on their decisions about regimens, where health beliefs include such issues as understanding of susceptibility to illness and perceived efficacy of medications. In diabetes care, patients' health beliefs about the long-term benefits of glucose control are particularly salient for understanding "compliance" (4). The Socio-Behavioral Model (37), on the other hand, focuses on social and economic resources that enable people to seek and follow medical advice. Because diabetes is an expensive disease, patients' economic limitations also become important considerations for understanding "compliance." Still, by focusing only on characteristics of patients that cause them to be "noncompliant," this research continues to suggest that "compliance" is fundamentally a quality of individuals.

Social context

The next series of "compliance" studies focuses on the social contexts of patients' lives and addresses logical reasons that they might not follow medical advice. Researchers in this area assert that patients spend a minute portion of their lives in the doctor's office and that physicians are simply not as central to patients' lives as previous work would suggest. Furthermore, patients and physicians tend to use different information in their interactions with one another; professionals tend to refer to facts and technical knowledge, while patients use more personal information pertaining to their lived experiences (38–40). Patients may opt not to follow medical treatment regimens in an effort to attend to social issues in their lives, such as the stigma of diabetes (21,23,4), competing approaches to treating the illness (22), difficulties in navigating the medical system (41), conflicting ideologies about illness and treatment (42), or socioeconomic limitations (42). Additional explanations may also include constraints related to family or work (15), a lack of social support for leading a healthy and active lifestyle (9,12), the awkwardness of eating differently or timing meals, embarrassment about taking insulin injections in front of other people, or a lack of time to manage all parts of the regimen. Because people with diabetes independently manage the minutia of their diseases on a daily basis, we would expect them to be especially concerned with making diabetes fit with their life situations. Still, this "social context" perspective ultimately locates the source of "noncompliance" with patients and it seeks to solve "noncompliance" by changing patient behavior.

Practitioner-patient communication

Another perspective in "compliance" research focuses on patient-practitioner

Downloaded from http://diabetesjournals.org/care/article-pdf/22/4/635/448877/10189544.pdf by guest on 06 December 2023

interaction and how physicians can communicate information more effectively to patients. This approach suggests that if information is conveyed clearly and completely enough in doctor-patient communication, the patient will be compelled to follow instructions (19). In the case of diabetes, the task of conveying complex, individualized, and multifaceted treatment regimens to patients requires particularly strong practitioner communication skills. Professionally, the growth and development of the fields of certified diabetes educators and medical social workers has helped to improve communication and to assure that patients are getting as much information as clearly as possible. While these changes in the delivery of diabetes care information have certainly improved patients' health, this approach still focuses on "noncompliance" as a patient behavior that needs to be changed to meet the needs of the medical system.

THE FATAL FLAW OF "COMPLIANCE" — The theoretical approaches to "compliance" that we have discussed here are quite diverse, yet they share a flaw. They all conceptualize "compliance" as a characteristic of individual patients and seek to increase it by modifying patient behavior to fit with the demands of the medical system. Even "social context" research that sympathizes with a patient's social pressures sees "noncompliance" as a deviant, if understandable, quality located in the individual. The language used in these studies to discuss "compliance" reinforces the underlying model of a submissive patient obeying an authoritative practitioner: "obedience, negligence, refusal, deviation, and failure to cooperate, . . . non-compliers, defaulters, disobedient, unreliable, uncooperative" (20). Beyond locating the problem of treatment adherence in the patient, these words suggest a moral flavor to the social consequences of not adhering to a treatment regimen: a "noncompliant" patient is also a "bad" or "difficult" patient.

In his study of a small multiservice health care clinic, focusing on elderly, poor, white, single men, Fineman (43) found that patients were labeled "noncompliant" on the basis of several behaviors that had, at best, an indirect impact on following treatment regimens. As Fineman notes, "In addition to following medical advice, clients were expected to be honest, punctual, cooperative, reasonable, responsible, self-aware, self-interested, polite, open-minded and supportive of staff members' efforts." Here, we see that the behavioral label "noncompliant" is applied on the basis of broader, more profoundly social characteristics than what is implied in its conventional definition. These findings stand in direct contrast to the positivistic concept of "compliance" that was created by Haynes and Sackett, which continues to be a model for the vast literature that exists on this topic today. Following from this model, we suggest that medical practitioners and researchers should integrate studies of other parts of medical practice, such as patient-practitioner interactions, practitioners' expectations and goals for medical treatment, and the medical system as whole into traditional investigations of "compliance."

CAN "ADHERENCE" REALLY MAKE A DIFFERENCE IN HEALTH CARE? — The shift from "compliance" to "adherence" reflects a fundamental change in understanding relationships between patients and practitioners. By changing some of the conceptual foundations of "compliance," we can make more systematic changes that will improve medical care. Seeing patients as more active participants in their own care will facilitate this process (44), particularly in the case of diabetes, where patients have the responsibility for independently managing their own illnesses and practitioner-patient relationships are often well-developed over time. In this context, changes in thinking about issues of "compliance" can have real effects in the delivery of health care.

To briefly illustrate the potential broader benefits of this process, we offer examples of the ways in which changes in the underlying paradigm of patient "compliance" might manifest themselves in medical care. If we increase practitioners' awareness of the role of social labeling in defining patients as "noncompliant," we can attempt to more directly address the social and economic limitations that prevent patients from following regimens, in lieu of attributing differences solely to characteristics of personality. Similarly, as physicians become increasingly aware of these labeling issues, they can more accurately tailor treatment regimens, including referrals to dieticians, social workers, and diabetes educators, to the specialized needs of individual patients. In diabetes care, labels of patient "compliance" affect the types of regimens they have, which, in turn, affects their likelihood of incurring long-term complications. Patients who do not manage regimens well and are not able to maintain tight control are more likely to be labeled "noncompliant," and, as a result, are often advised to manage their blood sugars in ways that will minimize hypoglycemia and its accompanying danger at the expense of maintaining higher overall glucose levels. Because patients with these regimens maintain higher average glucose levels, they are more likely to have complications. Insofar as the process of labeling patients as "noncompliant" has social aspects that have not been thoroughly explored, the shift to an "adherence" paradigm can improve our understanding of patient behavior and thereby further improve glucose control.

Granted, there are patients who are simply unwilling to follow medical advice or to adhere to complex medical regimens. By moving to a more social paradigm for understanding patient behavior and working more collaboratively with patients to develop treatment regimens, however, practitioners can expand the types of explanations, and therefore the types of solutions, they have for patient "noncompliance." The concept of "compliance" implies that practitioners unilaterally pronounce which regimen patients should follow, and patients who do not adhere to those recommendations are perceived as "noncompliant." "Adherence," on the other hand, minimizes the authoritative practitioner-submissive patient model of health care. While physicians certainly have special expertise to design regimens and frequently need to be in control of regimen design to provide safe and effective medical care, willingness to communicate more openly and work more collaboratively with patients can solve even very difficult problems. By asking patients which parts of their regimen are most challenging to follow and which kinds of changes they would like to see, practitioners can help turn some instances of perceived "noncompliance" into improved health care and tighter diabetes control.

CONCLUSION — Assumptions underlying the term "compliance" pose serious limitations for our understanding of treatment adherence, especially in patients with diabetes. Under the "compliance" model, patients are saddled with complex daily responsibilities for their own medical care, yet they surrender most decision-making and control to medical practitioners. While this concept may have been appropriate at

Downloaded from http://diabetesjournals.org/care/article-pdf/22/4/635/448877/10189544.pdf by guest on 06 December 2023

earlier points in history, when patients had fewer options for self-management, "compliance" is not appropriate in today's diabetes care. With the increased complexity of diabetes treatments, we must pay attention not only to changes in terminology (e.g., "compliance" to "adherence"), but also to the ideological paradigms underlying this terminology.

We should replace the term "compliance" with "adherence" and begin addressing the broader issue of treatment adherence. Research is needed to address the processes by which patients are labeled "noncompliant" so we can better understand how a wide range of patient characteristics feed into perceptions that they are "noncompliant." Patients and practitioners need to work together to collect accurate information to determine what sorts of treatment goals practitioners have for patients. Having a broader interpretation of how to think about patient behavior creates more opportunities for physicians to potentially do something productive in response to patient behaviors instead of labeling them "noncompliant" and lowering treatment goals. This issue is especially critical given the rapid changes and increasing complexities of current and future diabetes regimens. The better our understanding of these processes, the better we can meet the future social, personal, and biomedical needs of patients.

Acknowledgments — K.E.L. is supported by grants from the National Institutes of Mental Health and the National Institutes of Health Diabetes Research and Treatment Center.

The authors would like to thank Jeremy Freese, Kathy Wishner, Doug Maynard, and Bernice Pescosolido for their helpful comments on earlier drafts of this article.

References

1. Haynes BR, Taylor WR, Sackett DL: *Compliance in Health Care*. Baltimore, MD, Johns Hopkins Univ. Press, 1979
2. Lerner BH: From careless consumptives to recalcitrant patients: the historical construction of noncompliance. *Soc Sci Med* 45:1423–1431, 1997
3. Boehm S, Schlenk EA, Funnell MM, Powers H, Ronis DL: Predictors of adherence to nutrition recommendations in people with non-insulin-dependent diabetes mellitus. *Diabetes Educ* 23:157–165, 1997
4. Boyer BA, Lerman C, Shipley TE, McBrearty J, Quint A, Goren E: Discordance between physician and patient perceptions in the treatment of diabetes mellitus: a pilot study of the relationship to adherence and glycemic control. *Diabetes Educ* 22:493–499, 1996
5. McNabb WL: Adherence in diabetes: can we define it and can we measure it? *Diabetes Care* 20:215–218, 1997
6. Kern RM, Penick JM, Hamby RD: Prediction of diabetic adherence using the BASIS-A inventory. *Diabetes Educ* 22:367–373, 1996
7. Mendez FJ, Belendez M: Effects of a behavioral intervention on treatment adherence and stress management in adolescents with IDDM. *Diabetes Care* 20:1370–1375, 1997
8. Pham DT, Fabienne F, Thibaudeau MF: The role of the health belief model in amputees' self-evaluation of adherence to diabetes self-care behaviors. *Diabetes Educ* 22:126– 132, 1996
9. Tillotson, LM, Smith S: Locus of control, social support, and adherence to the diabetes regimen. *Diabetes Educ* 22:133–139, 1996
10. Trostle, JA: The history and meaning of patient compliance as an ideology. In *Handbook of Health Behavior Research II: Provider Determinants*. Gochman DS, Ed. New York, Plenum Press, 1997, p. 109–124
11. El-Kebbi I, Gael AB, Ziemer DC, Musey VC, Gallina DL, Dunbar V, Phillips L: Diabetes in urban African Americans. V. Use of discussion groups to identify barriers to dietary therapy among low-income individuals with non-insulin-dependent diabetes mellitus. *Diabetes Educ* 22:488–492, 1996
12. Fitzgerald JT, Anderson RM, Funnell MM, Arnold MS, Davis WK, Aman LC, Jacober SJ, Grunberger G: Differences in the impact of dietary restrictions on African Americans and Caucasians with NIDDM. *Diabetes Educ* 23:41–47, 1997
13. Glascow RE: A practical model of diabetes management and education. *Diabetes Care* 18:117–126, 1995
14. Golin CE, DiMatteo MR, Gelberg L: The role of patient participation in the doctor visit. *Diabetes Care* 19:1153–1164, 1996
15. Hanson CL, DeGuire MJ, Schinkel AM, Kolterman OG: Empirical validation for a family-centered model of care. *Diabetes Care* 18:1347–1356, 1995
16. Jones PM, Remley C, Engberg RA: Development and testing of the barriers to self-monitoring blood glucose scale. *Diabetes Educ* 22:609–616, 1996
17. Travis T: Patient perceptions of factors that affect adherence to dietary regimens for diabetes mellitus. *Diabetes Educ* 23:152– 156, 1997
18. Wysocki T, Taylor A, Hough BS, Linscheid TR, Yeates KO, Naglieri JA: Deviation from developmentally appropriate self-care autonomy. *Diabetes Care* 19:119–125, 1996
19. Svarstad BL: Patient-practitioner relationships and compliance with prescribed medical regimens. In *Applications of Social Science to Clinical Medicine and Health Policy*. Aiken L, Mechanic D, Eds. New Brunswick, NJ, Rutgers Univ. Press, 1986, p. 438–459
20. Stimson G: Obeying doctor's orders: a view from the other side. *Soc Sci Med* 8:97–104, 1974
21. Conrad P: The noncompliant patient in search of autonomy. *Hastings Cent Rep* 17:15–17, 1987
22. Trostle JA, Hauser WA, Susser IS: The logic of noncompliance: management of epilepsy from the patient's point of view. *Cult Med Psychiatry* 7:35–56, 1983
23. Conrad P: The meaning of medication: another look at compliance. *Soc Sci Med* 20:29–37, 1985
24. Davis MS: Variations in patients' compliance with doctors' orders. *J Med Educ* 41:1037–1048, 1966
25. Norman SE, Brown TK: Seizure disorders. *Am J Nurs* 81:893–897, 1981
26. Ley, P: Psychological studies of doctor-patient communication. In *Contributions to Medical Psychology*. Rachmann S, Ed. Oxford, U.K., Pergamon Press, 1977, p. 9–42
27. Caplan RD, Harrison RV, Wellons RV, French JRP: *Social Support and Patient Adherence: Experimental and Survey Findings*. Ann Arbor, MI, Institute for Social Research, Univ. of Michigan Press, 1980
28. Zifferblatt SM: Increasing patient compliance through the applied behavioral analysis. *Prev Med* 4:173–182, 1975
29. Fogarty JS: Reactance theory and patient compliance. *Soc Sci Med* 45:1277–1288, 1997
30. Kuhlman TL: Reactance and the therapeutic alliance. In *Treatment Compliance and the Therapeutic Alliance: Chronic Mental Illness*. Vol. 5. Blackwell B, Ed. Singapore, Harwood Academic, 1997, p. 181–191
31. Cecil DW: Relational control patterns in physician-patient clinical encounters: continuing the conversation. *Health Commun* 10:125–149, 1998
32. Mumford E, Schlesinger HJ, Glass GV, Patrick C, Cuerdon T: A new look at evidence about reduced cost of medical utilization following mental health treatment. *J Psychother Theory Res Pract* 7:68–86, 1997
33. Cohen N: Treatment compliance in schizophrenia: issues for the therapeutic alliance and public mental health. In *Treatment Compliance and the Therapeutic Alliance: Chronic Mental Illness*. Vol. 5. Blackwell B, Ed. Singapore, Harwood Academic, 1997, p. 239–250
34. Trott JC, Botts SR: Compliance and the treatment alliance in serious mental illness: the pharmacist's role. In *Treatment Compliance and the TherapeuticAalliance: Chronic Mental Illness*. Vol. 5. Blackwell B, Ed. Singapore, Harwood Academic, 1997, p. 201–210
35. Burgoon M, Klingle RS: Gender differences in being influential and/or influenced: a

Downloaded from http://diabetesjournals.org/care/article-pdf/22/4/635/448877/10189544.pdf by guest on 06 December 2023

challenge to prior explanation. In *Sex Differences and Similarities in Communication: Critical Essays and Empirical Investigations of Sex and Gender in Interaction*. Canary DJ, Dindia K, Eds. Mahwah, NJ, Lawrence Erlbaum, 1997, p. 257–285
36. Rosenstock IM: Why people use health services. *Milbank Memorial Fund Q* 44:91–124, 1966
37. Andersen R: *A Behavioral Model of Families' Use of Health Services*. Chicago, Center for Health Administration Studies, Univ. of Chicago, 1968 (Research Ser., no. 25)
38. Mishler EG: *The Discourse of Medicine: Dialectics of Medical Interviews*. Norwood, NJ, Ablex, 1984
39. Peyrot M, McMurry JF, Hedges R: Living with diabetes: the role of personal and professional knowledge in symptom and regimen management. *Res Sociology Health Care* 6:107–146, 1987
40. Conrad P: The experience of illness: recent and new directions. *Res Sociology Health Care* 6:1–31, 1987
41. Becker G, Janson-Bjerklie S, Benner P, Slobin K, Ferketich S: The dilemma of seeking urgent care: asthma episodes and emergency service use. *Soc Sci Med* 37:305–313, 1993
42. Hill S: Taking charge and making do: childhood chronic illness in low-income black families. *Res Sociology Health Care* 12:141–156, 1995
43. Fineman N: The social construction of noncompliance: a study of health care and social service providers in everyday practice. *Sociology of Health and Illness* 13:354–374, 1991
44. Assal J-P, Golay A, Visser AP, Eds: *New Trends in Patient Education: A Trans-Cultural and Inter-Disease Approach*. 1st ed. Amsterdam, Elsevier, 1995 (International Congress Ser., Vol. 1076)

Downloaded from http://diabetesjournals.org/care/article-pdf/22/4/635/448877/10189544.pdf by guest on 06 December 2023