EDITORIALS

Adherence and Health Care Utilization in HIV/AIDS—Rational or Rationalizing?

Stock in rationality seems banefully low these days, hovering somewhere around the level of the Euro. Surveys seem to indicate that many Americans have no more regard for rational thinking than they do for feng shui, relegating logic to “one way to think about things” when making decisions. Numerous studies show that people repeatedly violate the basic principles of rationality.¹

Some might find this situation emblematic of the gulf between current therapy for HIV and the behavior of people at risk for and living with HIV. Herculean efforts, including rational drug development, have yielded agents that can arrest viral replication and prolong survival in a disease that was uniformly fatal. However, many patients do not benefit fully from the availability of such therapy. Studies suggest that adherence rates as high as 95% may be necessary to avoid drug resistance.² In the real world, less than 40% of patients starting protease inhibitors are able to maintain full viral suppression for a prolonged period.³ In addition, while the incidence of potentially fatal opportunistic complications of HIV can be lowered dramatically by prophylactic medication such as trimethoprim-sulfamethoxazole, nearly a third of patients with advanced disease do not take this medication, and others with known HIV infection nonetheless first present to medical care in the throes of a potentially preventable infection.⁴

What are patients thinking? Is thinking even the right word to describe medication-taking behavior, risk behaviors, and health care utilization? This issue of the *Journal* features three articles that help us to understand the behavior of people with HIV/AIDS. Taken together, they shed light on behavior and its determinants.

Laws and colleagues used in-depth interviews and qualitative methods to study adherence to antiretroviral medications.⁵ Despite initial assertions of good adherence, when probed, many patients reported behavior to the contrary. Significantly, they did not recognize these omissions as nonadherence; many also failed to appreciate the likely adverse consequences. Perhaps the most important insight was that many patients tend to rationalize “adherence” as synonymous with whatever level of adherence they can achieve. Another notable finding was that several patients considered the taking of so-called “drug holidays” to be normal and even health-promoting. A third finding was that even in the absence of a language barrier (many patients in the study were Spanish speaking), communication between physician and patient was

often insufficient. Like much qualitative research, some of the study’s results just sound right, supported by verbatim quotes that echo what our own patients try to tell us. Once one hears patients thinking out loud, it is more understandable that they behave as they do. One patient was told that if she took her medication without food, it would make her sick. So when she skipped a meal, she also skipped her medication. The study benefitted from the use of one-to-one interviews, which seem to have allowed patients to admit behavior that might disappoint their physicians. It is evident that physicians and other members of the care team have more explaining and much more targeted questioning to do.

The study has some limitations. The sample of 25 interviewees was restricted to Massachusetts and included a large proportion of native Spanish speakers. It is likely that interviews conducted with patients in different regions of the country would yield additional insights. In addition, we did not get the physicians’ side of the story. However, even in the absence of this, what is most important is what patients understand and retain.

Rigsby et al.⁶ conducted a small, unmasked clinical trial to improve adherence to antiretroviral therapy. The interventions were based on using individualized cues (e.g., tooth brushing) to help patients remember when to take medication, accompanied by feedback about medication taking using electronic (MEMS) pill bottle caps, with or without a cash incentive. The only significant improvement occurred in the cash reinforced group, and this effect disappeared soon after the intervention was stopped. Patients with high baseline adherence were generally able to maintain their performance, whereas alcohol dependency was associated with poorer adherence.

The investigators are in the vanguard of adherence research in HIV, as published studies of adherence interventions are in very short supply. However, several factors may have attenuated this study’s ability to draw firm conclusions. Very high baseline levels of reported adherence may have created ceiling effects and also limited generalizability. The study could not determine if patients took their medication in addition to periodically opening the MEMS device. Finally, selection for monitoring of the drug for which baseline adherence was lowest allows the possibility of regression to the mean. We are left with an urgent need for randomized designs to evaluate adherence interventions, and additional confirmation of the value of money to enhance adherence.^{7,8} Current provider

options are limited with regard to prescribing money, but the importance of financial considerations should not be ignored in disadvantaged populations.

Gifford and colleagues used the nationally representative sample from the HIV Cost and Services Utilization Study to examine how patients would seek care if they were to experience different HIV-related symptom complexes.⁹ One finding (that will not be news to emergency medicine physicians) was that even for minor problems, many patients said they would go to the emergency room rather than to same-day primary care. Those who favored the emergency department for less ominous symptoms tended to be those who were also most disadvantaged—African Americans, the poor, and patients with psychological symptoms. On the other hand, an important minority of patients reported that they would not seek immediate care for symptoms that could represent a life-threatening illness. HIV physicians presented with the same scenarios were unanimous that these symptoms could not wait.

Research based on clinical scenarios is prone to be interpreted differently than investigators intend. In this study, it is possible that patients responding to the questionnaire would behave differently if confronted with actual symptoms. The study design did not permit more detailed exploration of why patients answered as they did. Nonetheless, this research helps to explain why patients both over- and under-utilize emergency services, contributing to both inefficiency and bad outcomes.

Is this behavior irrational? One can surmise from the paper by Laws⁵ that patients may not have a good understanding of information relevant to decision making. It is likely that no one had explained to them the many ways that complications of HIV can present and what they should and should not do in each situation. One can also speculate that patients who favor the care available in the emergency department, or those who would just rather wait and see if it gets better, might be those for whom primary care was less available or less satisfactory.

All three articles were well-based on conceptual models, and employed state-of-the art methods. The quantitative studies took advantage of existing measurement tools with previous evidence for usefulness in HIV infected populations. Taken as a group, the articles speak well for the diversity of research methods and high quality of research being used to improve the care of people with HIV/AIDS.

There are several practical messages that can be gleaned from these papers. One would be to banish the pernicious term “drug holiday” from the lexicon of HIV caregivers. This expression sounds far too much like an enticing perk that everyone should observe periodically.¹⁰ More preferable would be something more neutral, such as “treatment interruption,” or even negative, like “medication disruption.” Another implication is that medication regimens tailored to fit the individual patient and his or her life have the best chance for success, perhaps as part of multiple interventions that appear to maximize the potential for successful adherence.¹¹

Much of the work of internal medicine has been defined as cognitive, but this gives short shrift to the importance of communication. Communication in an HIV practice is time-consuming and difficult work, particularly with patients whose lives, assumptions, and expectations are very different from those of the provider. In frustration, physicians will let patients go elsewhere for care or even “fire” those who are unwilling or unable to adhere even to scheduled appointments. While this may be the only practical solution to maintaining a coherent practice, this does nothing to alleviate the alienation experienced by disadvantaged patients and may help to perpetuate reliance on emergency departments.

Some components of patient education and adherence coaching have already been taken up by other members of the care team, including peer counselors. Given the potential for misinformation and misunderstanding, rigorous training of adherence counselors is crucial. Some educational materials are becoming available for patients with limited literacy¹² but this is an area in which more research and development are sorely needed.¹³ It is also possible that information about medication-taking behavior could be obtained using questionnaires administered by interviewers or computers. While this is no substitute for human contact, it could play a screening function and help identify areas of need.¹⁴

A close reading of these papers does not support the contention that patient behavior is devoid of logic. Rather, the various ways in which patients explain their nonadherence to medical advice seem quite rational, given their perceptions of HIV disease and treatment and its personal implications for each of them. Many of the factors driving patient behavior are nonmedical and not immediately apparent to the physician. Better understanding by health professionals of such perceptions may improve therapeutic alliances.

Medicine is a practical rather than a theoretical human science. As such, rational behavior is that which interprets general knowledge and applies it to specific situations. This practical wisdom is the basis for sound clinical judgment and actions by patients. It is important for us to learn more about the lives of our patients. If we can achieve this, our decisions and those of our patients will make more sense.—

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REFERENCES

1. Kahneman D. New challenges to the rationality assumption. *J Inst Theoret Economics*. 1994;150:18–36.
2. Paterson DL, Swindells S, Mohr J, et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med*. 2000;133:21–30.
3. Lucas GM, Chaisson RE, Moore RD. Highly active antiretroviral therapy in a large urban clinic: risk factors for virologic failure and adverse drug reactions. *Ann Intern Med*. 1999;131:81–7.
4. Shapiro MF, Morton SC, McCaffrey DF, et al. Variations in the

- care of HIV-infected adults in the United States: results from the HIV Cost and Services Utilization Study. *JAMA*. 1999;281:2305-15.
5. Laws MB, Wilson IB, Bowser DM, Kerr SE. Taking anti-retroviral therapy for HIV infection: learning from patients' stories. *J Gen Intern Med*. 2000;15:848-58.
 6. Rigsby MO, Rosen MI, Beauvais J, et al. Cue-dose training with monetary reinforcement: pilot study of an antiretroviral adherence intervention. *J Gen Intern Med*. 2000;15:841-7.
 7. Giuffrida A, Torgerson DJ. Should we pay the patient? Review of financial incentives to enhance patient compliance. *BMJ*. 1997;315:703-7.
 8. Chaix-Couturier C, Durand-Zaleski I, Jolly D, Durieux P. Effects of financial incentives on medical practice: results from a systematic review of the literature and methodological issues. *Int J Qual Health Care*. 2000;12:133-42.
 9. Gifford AL, Collins R, Timberlake K, et al. Propensity of HIV patients to seek urgent and emergent care. *J Gen Intern Med*. 2000;15:833-40.
 10. Drug holidays may be beneficial. *Aids Patient Care STDS*. 1999;13:375.
 11. Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. *Med Care*. 1998;36:1138-61.
 12. Kalichman SC, Benotsch E, Suarez T, Catz S, Miller J, Rompa D. Health literacy and health-related knowledge among persons living with HIV/AIDS. *Am J Prev Med*. 2000;18:325-31.
 13. Kalichman SC, Ramachandran B, Catz S. Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *J Gen Intern Med*. 1999;14:267-73.
 14. Wu AW, St Peter R, Cagney C. Health status assessment: completing the clinical database. *J Gen Intern Med*. 1997;12:254-5.