

Ethical Choices Regarding Noncompliance: Prescribing Protease Inhibitors for HIV-Infected Female Adolescents

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Since the advent of the HIV/AIDS epidemic, much effort has been taken to develop persuasive campaigns to promote, for example, safer-sex behavior through increased condom use. Specific messages were developed to persuade HIV-infected persons to: Use condoms, inform sexual partners about their infection, use clean needles, or do not share needles. One missing component has been an analysis of which persuasive strategies are most effective with HIV-infected persons. Given new changes in treatment of HIV and AIDS, understanding how to get HIV-infected persons to comply with health recommendations becomes even more crucial.

At the XI International Conference on AIDS (Vancouver, 1996), scientists met to discuss new treatment strategies and medical regimens for HIV-infected persons. For the first time there was some optimism about combating HIV/AIDS. This unprecedented optimism has come from the new antiretroviral therapies, drug combinations commonly called "cocktails." These cocktail therapies do, however, have associated difficulties. The treatment is expensive and not widespread at present. Side effects for some patients are barely tolerable (e.g., nausea, diarrhea). The antiretroviral therapies require individuals to adhere to strict treatment protocols; noncompliance can lead to the development of drug-resistant strains of HIV.

The advances in HIV/AIDS treatment, however, do not come without controversy. Many affected groups have not been included in new drug protocol studies, just as women were excluded from earlier drug trials (Bartlett, McGovern, Merkatz, Marte, & Mastroianni, 1997). Compliance with treatments (and HIV risk reduction behaviors) will continue to be crucial to combat the transmission of HIV. What will be needed, besides interventions to change behaviors, is a series of campaigns/strategies to maintain and reinforce healthy behaviors. This chapter examines two such behaviors, adolescents' adherence to medication regimens for themselves and for an HIV-exposed infant.

The Centers for Disease Control and Prevention (CDC) reported 3,041 adolescents ages 13–19 have been diagnosed with HIV infection and 2,574 adolescents ages 13–19 have been diagnosed with AIDS through June 1996. In people aged 20–24, 20,228 cases of HIV and 19,997 cases of AIDS were reported. Given that a median incubation period from HIV infection to the development of AIDS in adults is nearly 10 years, many of these individuals likely were infected as teens. HIV/AIDS is the sixth leading cause of death for adolescents

and young adults, ages 15–24. AIDS and other HIV-related illnesses have been the fourth leading cause of death among U.S. women aged 25–44 since 1992. AIDS, however, was the leading cause of death for African-American women in 1993, and the AIDS-related death rate for African-American women is nine times as high as for White women (CDC, 1996).

Adolescents with HIV/AIDS are a particularly important group because they are both unrecognized and difficult to reach. Little information is available at present about such adolescents, even less about how to gain compliance with treatment regimens for adolescents, and almost nothing about how to gain compliance with new treatments for HIV/AIDS. The period of adolescence has long been recognized as a likely period of infection. To this point, however, many persons infected as teens were not aware of their infection, and did not receive treatment as adolescents. Today there is a group of adolescents who are being treated for HIV infection. The identification of these adolescents is likely a result of increased HIV testing along with public health recommendations for the testing of pregnant women.

This study includes examination of a subpopulation of adolescents, African-American adolescent women infected with HIV. Teens with HIV/AIDS are likely to be poor and African American (Wortley, Chu, & Berkelman, 1997). Teen women are an especially interesting case because many are or have been pregnant, making it possible to study and compare compliance with treatment regimens for self versus other (care for baby) in relation to HIV/AIDS. The case has been made that socioeconomic status has affected adolescents' visibility as a risk group (King, 1996; Mastroianni, Faden, & Federman, 1994). In this chapter, we explore recommendations for compliance gaining for a particular group of adolescents after presenting case histories of HIV-infected adolescent mothers. First, we review compliance gaining in health care settings and research on compliance gaining.

COMPLIANCE GAINING IN HEALTH SETTINGS

Although communication is a crucial part of health care interactions, Wyatt's (1991) review found that less than 1% of medical literature focused on physician–patient relationships. There is a growing concern about what constitutes the best health compliance-gaining strategies and what verbal and nonverbal strategies physicians use to gain compliance (M. H. Burgoon & J. K. Burgoon, 1990). In the medical context, compliance is viewed as adherence to medical advice or treatment regimens (Stone, 1979), an outcome rather than a process (Charney, 1972). Alternatively, Friedman and DiMatteo (1979) argued for the term *cooperation* rather than *compliance gaining* to focus on the transactional nature of the physician–patient interaction. Physicians often blame patients for noncompliance (see Thompson, 1994), but this will not assist in developing effective strategies to deal with patient noncompliance.

Few other interpersonal contexts are characterized by the urgency of the health care interaction. The medical situation sets up a unique context for compliance gaining. Health care interactions are generally voluntary, patient focused, with varied effects of noncompliance (M. H. Burgoon & J. K. Burgoon, 1990). Although this set of circumstances should create a situation where expected and actual compliance is high (M. H. Burgoon & J. K. Burgoon, 1990), this is not the case. Noncompliance may be the most significant problem in medicine (Eraker, Kirscht, & Becker, 1984). Estimated noncompliance rates generally range from 40% to 60%, studied with behaviors such as appointment keeping and adherence to drug regimens. These surprisingly high levels of noncompliance create health hazards, waste resources, and create frustration (see Thompson, 1994). Stone (1979) phrased this problem more vividly: "Why would someone who has gone to the trouble and expense of seeking out a physician, of undergoing arduous or uncomfortable tests and other diagnostic procedures, and of

purchasing drugs and devices on the advice of the physician, then fail to follow the recommendations?" (p. 34). Unfortunately, this lack of compliance is not abnormal, and may be even higher for HIV/AIDS, as patients to this time believed there was no known treatment.

With HIV/AIDS, it is difficult to assess what might serve as effective compliance-gaining strategies from the perspective of the physician or health care worker. Most research has focused on verbal (rather than nonverbal) compliance-gaining strategies. M. H. Burgoon and J. K. Burgoon (1990) indicated severity of illness and past noncompliance should be best addressed by the most aggressive verbal compliance-gaining strategies (e.g., threat). Doctors, unfortunately, overrely on positive expertise strategies and do not use positive or reinforcing strategies (M. Burgoon et al., 1990). Clearly, HIV/AIDS classifies high on severity of illness, but because it has been previously discussed only as a terminal illness, patients perceive themselves as having "nothing to lose," and thus do not comply with their treatment (Rotello, 1995).

Compliance is often studied as an outcome, a special case of unidirectional communication where the physician holds most of the power and resources (cf. Penchansky, 1986). Unfortunately, little is known about the specific strategies health care workers use to gain patient compliance. M. Burgoon and colleagues (1990) stated, "The physician's right to seek the patient's compliance flows naturally from the physician's role and expert power in the situation" (p. 16). Results show physicians report predominant use of expertise strategies but will be verbally aggressive if necessary. Physicians often use liking (acting friendly), promise (offering a reward, such as next visit free), and pregiving (providing free medication samples).

Compliance-Gaining Research. The most widely accepted definition of compliance-gaining message strategies was presented by Seibold, Cantrill, and Meyers (1985): "anticipated and actual discourse patterns performed in the service of a personal or interpersonal agenda" (p. 556). This emphasis on messages and message planning is clear, although research has recognized the significance of patients' perceptions of compliance-gaining messages. The dominant strategy typology includes 16 strategies developed from exchange and power theories by Marwell and Schmitt (1967a, 1967b), later tested by Miller, Boster, Roloff, and Seibold (1977). Although typologies of compliance gaining have been critiqued (see Miller, 1983; Seibold et al., 1985), the 16-strategy system is still widely used. The major criticisms focus on lack of exhaustiveness and mutual exclusiveness. Table 27.1 reproduces the typology and includes an example of each strategy relevant for the present study, compliance gaining with HIV/AIDS drug treatment regimens.

Table 27.1 provides descriptions of the range of 16 compliance-gaining strategies, many positive/negative versions of the same strategy, and examples of compliance-gaining attempts by health care workers/physicians for drug regimen compliance of an HIV-infected patient. A second example is also included for each strategy, targeting compliance with treatment for an HIV-exposed infant. The actor in these examples is the source of the compliance-gaining attempts (the physician, health care worker, or social worker), and the recipient is the HIV-infected patient/client. The illustrations provide examples of the range of choices available and point out the importance of not overusing promise and positive expertise strategies.

One additional critique of compliance-gaining research has been the absence of studies of series of persuasive attempts or sequential messages; surely compliance attempts are not singular events and are likely related to one another. If one tactic works or fails, this would affect choice of subsequent strategies. In the case studies presented, it is possible to see how some sequential message strategies are enacted. Compliance-gaining attempts are not made in isolation; rather they are progressive (become more harsh, e.g., threat of reporting to social services as a last option). Health care workers could use liking and pregiving to establish

TABLE 27.1
HIV/AIDS Examples of Marwell and Schmitt's 16 Compliance-Gaining Strategies

Category	Description
(1) <i>Promise</i>	If you comply with my request, I will reward you in some way.
Ex. Self:	"If you take your AZT appropriately, the doctor will prescribe a protease inhibitor."
Ex. Other:	"If you give your baby AZT, the doctor may prescribe a protease inhibitor for you."
(2) <i>Threat</i>	If you do not comply with my request, I will punish you in some way.
Ex. Self:	"If you do not take your AZT, the doctor will not prescribe protease inhibitors for you."
Ex. Other:	"If you do not give the baby her medicine, I will report you to child protective services."
(3) <i>Expertise (Pos.)</i>	If you comply with my request, you will be rewarded because of the nature of things.
Ex. Self:	"If you take your medicine, your CD4 count will improve and you will feel better."
Ex. Other:	"If you take the AZT, your baby has a better chance of not being infected with HIV."
(4) <i>Expertise (Neg.)</i>	If you do not comply, you will be punished because of the nature of things.
Ex. Self:	"If you do not take the medication, you will develop an opportunistic infection sooner."
Ex. Other:	"If you do not take AZT, your baby might contract HIV."
(5) <i>Liking</i>	Actor is friendly and helpful to get target in good frame of mind so she or he will comply.
Ex. Self:	"Social worker makes home visits to build rapport with client."
Ex. Other:	"Social worker makes home visits to build rapport with client and child."
(6) <i>Pre-Giving</i>	Actor rewards target before requesting compliance.
Ex. Self:	"Give client free phone card, then ask her to take medication as directed."
Ex. Other:	"Give client free baby products, then ask her to give baby medication as directed."
(7) <i>Aversion Stimulation</i>	Actor punishes target, making stopping contingent on compliance.
Ex. Self:	"Social worker calls and visits repeatedly until client takes medication."
Ex. Other:	"Child protective services investigates and monitors medication given to baby."
(8) <i>Debt</i>	You owe me compliance because of what I did for you in the past.
Ex. Self:	"I helped you get money for medication, so you should take your medication."
Ex. Other:	"I helped get you food for your baby, so you should give baby the medication."
(9) <i>Moral Appeal</i>	Say to target, you are immoral if you do not comply with my request.
Ex. Self:	"Taking your medication is the right thing to do."
Ex. Other:	"It would be immoral not to protect your baby from HIV."
(10) <i>Self-Feeling (Pos.)</i>	Say to target, you will feel better about yourself if you comply.
Ex. Self:	"You will feel proud of yourself if you take your medication."
Ex. Other:	"You will feel proud of yourself to know that you are helping protect your baby."
(11) <i>Self-Feeling (Neg.)</i> ^a	Say to target, you will feel worse about yourself if you do not comply.
Ex. Self:	"You will feel ashamed if you don't take your medication."
Ex. Other:	"You will feel ashamed if you don't give your baby the medication."
(12) <i>Altercasting (Pos.)</i>	Say to target, a person with "good" qualities would comply.
Ex. Self:	"You are a very responsible and mature person if you take your medication."
Ex. Other:	"You are a really responsible mother for giving your baby medication to protect him/her."
(13) <i>Altercasting (Neg.)</i> ^a	Say to target, only a person with "bad" qualities would not comply.
Ex. Self:	"Only an immature person would not take the medication."
Ex. Other:	"Only an uncaring person would put a baby at risk by not-giving medication."
(14) <i>Altruism</i>	Say to target, I need your help very badly, so take your medication for me/parents.
Ex. Self:	"It will really help your parents if you take your medication."
Ex. Other:	"Your parents care about their grandchild, so give the medication to help ease their worries."
(15) <i>Esteem (Pos.)</i>	Say to target, people you value will think better of you if you comply.
Ex. Self:	"Your family will be proud of you if you take your medication."
Ex. Other:	"Your family will be proud of you if you give your baby the medication."
(16) <i>Esteem (Neg.)</i>	Say to target, people you value will think worse of you if you do not comply.
Ex. Self:	"Your family will be disappointed if you don't take your medication."
Ex. Other:	"Your family will be disappointed if you don't give the baby the medication."

^aThese strategies might not be used by social workers or other health care professionals because they could violate the principles of the profession (e.g., "unconditional positive regard").

rapport before asking for the crucial target request, taking their medication as directed. It might also be effective to first gain agreement with smaller requests (Freedman & Fraser, 1966), such as maintaining appointments or filling the prescription, before health care workers target the goal of take every single dose of medication as directed.

COMPLIANCE GAINING IN ADOLESCENCE: THE EFFECTS OF EGOCENTRISM

Compliance gaining of adolescents requires consideration of their special characteristics. Illegal drug use, drunk driving, and sex without contraception and/or with multiple partners occurs frequently among adolescents. Adolescents' own risk-taking behavior is one of the greatest threats to their development. One phenomenon, egocentrism, helps explain why this group is so difficult to reach.

In adolescence, lack of experience may lead to errors in judgment when they make decisions about risk behaviors. An egocentrism perspective emphasizes a specific type of error in judgment that results from a sense of uniqueness or specialness. According to egocentrism, teens focus their attention on their own thoughts, and they assume that others must also be thinking about them. That the assumption is irrational is not apparent to the adolescent. The adolescent is also "blinded" by feelings of invulnerability that accompany feelings of uniqueness. Egocentrism helps explain how adolescents could ignore health messages or compliance-gaining attempts because they feel the messages are not directed toward them, even when, in fact, they are the audience. Egocentrism is, very generally, an overall focus on self, and it refers to a lack of differentiation in subject-object interaction (Piaget, 1929, 1958). Elkind (1967, 1978) argued egocentrism emerges at each of the transitions between stages of cognitive development. For young adolescents, the egocentrism of interest occurs during the transition from concrete to formal operational thought. Elkind (1967) proposed the emergence of two expressions of egocentrism in this transition from concrete to formal operations in adolescence: (a) imaginary audience, where an inability to differentiate the object of thought leads to thinking that others are preoccupied with you because you are preoccupied with yourself, and (b) personal fable, where new ability to think about thoughts leads to a fascination with one's own thoughts, which are surely different from the thoughts of others, and thus a belief in one's uniqueness and invulnerability.

Adolescents have been found to be highest in both imaginary audience and personal fable in the eighth and ninth grades, with a steady decline with age and consolidation of formal operations (Elkind & Bowen, 1979; Enright, Shukla, & Lapsley, 1980). There are also consistent gender differences in egocentrism, with girls scoring higher on imaginary audience measures (e.g., Elkind & Bowen, 1979; Enright et al., 1980; Greene, Rubin, & Hale, 1995; Lapsley, FitzGerald, Rice, & Jackson, 1989) and boys scoring higher on personal fable measures (e.g., Greene et al., 1995; Lapsley et al., 1989). The age effects are significant when examining HIV/AIDS because the height of egocentrism (Grades 8/9) coincides with probable period of infection for many HIV-infected adolescents (most in the present study, particularly). It is possible that egocentrism (especially personal fable) contributed to decisions not to take precautions to avoid HIV infection or pregnancy. In fact, Greene and colleagues reported adolescents higher in personal fable had more negative attitudes toward behavior that could put them at risk for contracting HIV/AIDS. The gender effects are interesting as well. If women are more susceptible to imaginary audience, then it should be easier to persuade them based on what others are doing/thinking (see recommendations section for normative focus).

NEW HIV/AIDS TREATMENTS: PROTEASE INHIBITORS

Standards of treatment for people infected with the AIDS virus are changing rapidly as new studies are reported. Previously, those treated with only one antiretroviral drug, such as AZT, improved initially, but the virus eventually reproduced a version of itself that was resistant to the treatment. This resulted in decreased t-cell counts and increased susceptibility to opportunistic infections. ACTG 175 and the Delta Study showed that combining AZT with another antiretroviral drug such as ddI or ddC prevents the virus from mutating as rapidly (Treatment Review [TR] #20, 1995). In late 1995, the Food and Drug Administration approved the use of 3TC (lamivudine) in conjunction with AZT.

The newest addition to this combination therapy is a group of drugs called protease inhibitors. Protease inhibitors block a part of HIV called protease enzymes, resulting in HIV making copies of itself that cannot infect new cells. Subsequent to the presentation of new studies at the International Conference on AIDS in Vancouver (1996), physicians have been prescribing what has come to be known as cocktails. These triple combination treatments include drugs such as AZT, ddI, d4T and 3TC, along with a protease inhibitor (e.g., Crixivan, Norvir, Ritonavir). Most of the people in one study combining AZT, 3TC, and indinavir (Crixivan) maintained very low or undetectable levels of HIV for nearly a year (TR #22, 1996). Although the initial data are promising, these studies are only entering their second year of tracking, so long-term benefits and risks cannot yet be assessed. Nevertheless, "Researchers are issuing strong warnings that people should try and avoid the development of drug resistance" (TR #22, 1996, p. 2)

None of these trials, however, have included women in sufficient numbers to adequately assess the effects of protease inhibitors on the female body (Bartlett et al., 1997). The recommended dosage, thus, is based on effectiveness in men. As one HIV-infected woman observed, "I don't have the muscle mass that a man does. I think I am taking too high a dose of Crixivan, but no one will listen to me." Inclusion in clinical trials are often based on rigid compliance measures. The necessity for repeated medical visits may hinder a woman's involvement if she is the sole provider of young child(ren). Women are also, at times, excluded because of the possible risk to potential children, but no such concern is expressed in regard to potential genetic damage in men (Bartlett et al., 1997). Moreover, adolescents are not included in clinical trials and often are grouped under the heading "adolescents and adults." Thus, nothing is known about the effects of these cocktail drugs on bodies that are still developing. Anecdotal evidence shows that physicians have begun prescribing protease inhibitors for children, adjusting dosage based on body weight. Adolescents, however, are treated with the same dosage as adults, a questionable practice given the present limited data (King, 1996).

Compliance Problems With New HIV/AIDS Treatments

With these new drugs, compliance with treatment regimens becomes even more crucial. The risk of drug resistance is a major concern with protease inhibitors. If the virus becomes resistant to one of the drugs such as AZT, there are other similar drugs that can be tried. It is believed, however, that if the virus develops resistance to one protease inhibitor, it will be resistant to all. Persons enrolled in early studies of indinavir (Crixivan) were given a lower dose than the one now recommended and subsequently developed resistance to the drug (*Indinavir Fact Sheet*, 1996). All data indicate that it is crucial to take the protease inhibitor as prescribed to keep a constant level in the body, to reduce the possibility of the HIV becoming resistant.

All of the currently prescribed protease inhibitors have side effects, which may contribute to noncompliance. Indinavir (Crixivan) should be taken with lots of water on an empty stomach to avoid dehydration and kidney stones (*Indinavir Fact Sheet*, 1996). With zidovudine (AZT), side effects included nausea, vomiting, weakness, and diarrhea (*Ritonavir Fact Sheet*, 1996), and should be taken with a full high-protein, high-fat meal (TR #22, 1996)—which many patients report is difficult to consume first thing in the morning. The third protease inhibitor approved is saquinavir (Invirase). This drug produced few side effects; however, studies have shown that very high doses are required for the body to absorb Saquinavir (*Saquinavir Fact Sheet*, 1996). These side effects have a strong association with noncompliance, as patients report many of these problems as reasons why they fail to take medication as directed.

Infectious disease physicians who were interviewed all agreed they face ethical dilemmas when considering prescribing protease inhibitors. One physician (a primary investigator in an AIDS clinical trials unit) responded, "It is definitely an ethical issue. If I prescribe a protease inhibitor and the patient does not take it as prescribed, her virus becomes resistant. If she then transmits that virus, we have an entirely new generation of HIV which is resistant to the one drug that has shown promise of eradicating it." Other health professionals repeated this sentiment. "We don't play. If you are not going to be compliant, you don't get protease inhibitors," stated a physician's assistant in an adult infectious disease clinic. Making this kind of determination requires consistent monitoring of compliance with previous treatments, including the use of patient-completed daily medication calendars, counting the number of pills left in the bottle, and/or telephone calls to pharmacies to determine when prescriptions have been filled and refilled, and how much was dispensed. All of these indicators are considered before deciding to prescribe protease inhibitors.

It is difficult to estimate all the effects of refusal to prescribe the protease inhibitors. The use of threat may increase compliance, but there are other views of effects of choices not to prescribe cocktails to noncompliant patients. For example, physicians may perceive homeless and drug-addicted people as high-risk groups for noncompliance and not prescribe new cocktail treatments for them. Nevertheless, these people are aware of the benefits from the new treatments and may find ways to acquire the medication, including the use of the black market. Those who "acquire their treatment via the black market, would be treating themselves without any supervision, increasing the threat of poor compliance and drug resistance" (Baxter, 1997, p. A35). Although such developments are only speculative at present, it is important to consider consequences of not prescribing these drugs.

Another ethical issue with adolescents' noncompliance is that of possible conception. To date, no studies have been published or released regarding the effects of protease inhibitors and other drugs used to treat HIV/AIDS on the development of a fetus. Some physicians require women of child-bearing age to utilize a reliable contraceptive before they will prescribe protease inhibitors. Is it ethical to intervene in the reproductive choices of female adolescents? Often these requirements do not even consider the adolescent's level of sexual activity or sexual orientation; they simply demand that she use a birth control method, whether she needs or wants it. This intrusion into the reproductive choices of adolescents does not extend to men. Physicians argue that men do not carry a fetus; however, there are no data to indicate that men are not at risk from genetic effects of protease inhibitors.

The new cocktails are expensive, averaging about \$1,000 per month. The issue of who will pay for the drugs cannot be overlooked, especially with adolescents. Most adolescents infected with HIV/AIDS are poor (Wortley et al., 1997). If a family is aware of an adolescent's HIV infection, and if it receives public assistance such as Medicaid, the medications will be covered. Many adolescents, however, do not tell their parents. Who then pays? Are they to

be denied treatment because they are young and poor? Adolescents cannot apply for Medicaid on their own, as long as they are residing in a parent's home. Other federal or state programs designed to assist HIV-infected people to pay for treatment will not allow a minor to sign consent forms. This creates dilemmas for health care workers who want to prescribe the cocktails but cannot find funding for this long-term prescription treatment.

Adolescents' rights and responsibilities are not federally regulated, and, therefore, may vary from state to state. For example, a North Carolina adolescent may seek birth control or treatment for sexually transmitted diseases without parental consent. In fact, health care providers are prohibited from disclosing this information to parents without the teen's consent. Thus, many adolescents treated for HIV have not disclosed to their parent(s). The only provision for disclosure in most states involves the notification of sexual and/or needle-sharing partners. In these cases, the partner is notified that she or he has had a possible exposure to HIV and is encouraged to be tested, but the name of the HIV-infected individual is not disclosed.

CASE STUDIES OF HIV-INFECTED ADOLESCENT WOMEN

Little data currently exist to examine how health care workers deal with ethical choices regarding (non)compliance in prescribing medication to adolescents. The following case studies are drawn from the pediatric infectious disease clinic in a public tertiary care facility in the Southeast. The following three cases are a representative sample from 35 clients attending the clinic in 1996–1997. The names and personally identifying information have been altered to protect confidentiality.

Janice. Janice is a 16-year-old African-American adolescent who tested positive for HIV when she was 14. Her mother took Janice to be tested because she knew Janice had been involved with an older man who was rumored to have HIV. Initially, Janice was not put on any therapy. Her virus began progressing rapidly, and she was given a prescription for AZT and ddI within 6 months. She reported that the ddI made her gag and did not take the medication. Many efforts were made to increase compliance. The social worker employed the compliance-gaining strategy of negative expertise: "If you do not take your medication, the virus will weaken your body and you will get sick." A pill crusher was purchased so that she could mix the ddI with applesauce or other food (possible example of promise strategy), but this did not improve compliance. Eventually her physician changed her regimen to AZT and 3TC, which Janice said was much easier to take.

Janice's immune system continued to deteriorate. Phone calls to the pharmacy revealed that Janice did not refill her prescriptions. Several attempts were made to get her mother to accompany her to clinic to discuss the severity of her HIV infection and the compliance problem. When her CD4 count reached 90, her physician became alarmed and lamented the fact that she could not prescribe protease inhibitors because Janice had not been compliant with the previous therapy. In an effort to involve Janice's mother in the process and to utilize an aversive stimulation strategy, the social worker reported medical neglect to the county department of social services. Social services determined that the mother was neglectful in assuring that Janice took her medication, but the strategy was not effective because the agency did not follow through with monitoring or counseling.

The social worker talked at length with Janice about taking her medication. Janice revealed that she felt that her mother did not care. In her words, "The only time we talk

about the HIV is when she is throwing it up in my face.” She said that she would die anyway and figured that if she did not take her medicine, it would happen sooner and be over with.

As Janice’s CD4 count continued to drop, those working with her became even more frustrated. Finally, Janice told her father that she is HIV infected. Her father asked her to please take her medication because he loves her and does not want to lose her. He insisted on going to clinic with her. At this clinic visit, Janice reported that she had started taking the medicine because “my dad asked me to” (compliance-gaining strategy altruism). The physician and the social worker talked at length with Janice, her mother, and her father. Following this meeting, Janice’s compliance improved greatly. Janice reports that she has missed only one dose and is working hard to show her physician that she will be faithful at taking her medications, “so I can get that other medicine” [protease inhibitors]. This is an example of the successful implementation of another compliance-gaining strategy (promise), offering the reward (protease inhibitor) for compliance.

Recently, the social worker connected Janice with another HIV-infected teen. The resulting peer support appears to have strengthened Janice’s determination to comply with therapy. Three questions remain: How long will she have to adhere to the regimen to convince her physician that she will comply with the dosing schedule for the protease inhibitor? Will she be able to tolerate the side effects, or stop the medication as she did with the ddi? What decisions will be made regarding the possibility of pregnancy? Janice admits she is sexually active, reports using condoms, but not notifying her sexual partner of his risk for HIV infection. Although Janice assures everyone that she uses condoms during sex, she also has asked for several pregnancy tests. Additionally, she has been treated for three different sexually transmitted diseases (STDs) since the discovery of her HIV infection. These facts make it difficult to believe that Janice is complying with safer-sex precautions. Choices to place Janice on protease inhibitors will be complicated by these indicators of possible transmission.

Shaniqua. Shaniqua is a 17-year-old African-American adolescent who was diagnosed with HIV at age 15. No one in her family knows she is infected. Although state law provides for adolescents to be treated for STDs without parental consent, no provision is made for its payment. Through a technicality (living temporarily with her grandmother), Shaniqua was permitted to enroll in a state-funded medical program without parental consent. If she had been living with her parents, she would not have been able to enroll in the program and would have had no source of payment for her clinic visits or medication. Shaniqua is now on Medicaid.

Five months after her diagnosis of HIV infection, Shaniqua was found to be pregnant, indicating noncompliance because she had not notified her partner of her HIV status nor used a condom as required by law. Initially, all clients are informed about the need to (a) use condoms if they are sexually active, and (b) inform potential partners of their risk for HIV infection—using strategies of threat (you can go to jail if you knowingly expose someone to HIV) and two types of positive expertise (use condoms to prevent him from getting HIV, and you from getting an STD, which would be very dangerous given your compromised immune system).

Shaniqua was given a prescription for AZT to reduce the possibility of transmission of the HIV to her child. A moral compliance-gaining appeal was made urging her to take the AZT because it was “the right thing to do” for her unborn child. Because no one in her home knew that she was HIV infected, Shaniqua hid the pills in her room and took them sporadically at best (self-reported and calls to pharmacy). She did not want “anyone asking too many questions.” Shaniqua is nearing a point in her disease that medication for herself (not just to protect her baby) will be a consideration. If she was not able to maintain the dosing

schedule of a single drug during pregnancy, can she possibly manage compliance with a "cocktail"?

Monisha. Monisha is a 17-year-old African-American adolescent who was diagnosed HIV infected at age 15. Monisha has dropped out of high school, and she has been evaluated by a psychologist and found to be clinically depressed and borderline mentally retarded. Monisha's entire family knows of her HIV infection. She moves between her mother's home, her father's home, and the home of a friend. Her mother is an alcoholic and is not a reliable source of support for compliance.

Monisha's physician prescribed AZT and ddI for her within 2 months of diagnosis. Since being on medication, Monisha has encountered many obstacles. First, her mother lost her public assistance and, therefore, her Medicaid coverage. Monisha moved in with her father; his income was too high to qualify for her Medicaid coverage. Payment assistance came through a pharmaceutical company's indigent drug program and later through the state's HIV drug program. Monisha then moved from her father's home to a friend's home. Not living with either parent, she again qualified for Medicaid. This constant fluctuation in payment sources has drastically affected Monisha's compliance. Although the social worker tries to ensure that she has a source for payment (strategy of pre-giving or debt), Monisha often does not notify her until long after she has lost eligibility and run out of medicine.

Strategies employed by the social worker to gain compliance have included negative expertise (If you do not take your medicine as prescribed, you will get sick sooner). Utilizing the rapport that had developed between them, the social worker implemented compliance-gaining strategy liking with some success. The lack of stable social support, a funding source, and Monisha's limited cognitive functioning have contributed to noncompliance with treatment. Additionally, Monisha wants to have a baby. This desire for a child may provide an opportunity to appeal to Monisha to comply with treatment for herself for the good of a child she may carry (altruism). Medically, Monisha is a good candidate now for protease inhibitors, but the indicators of past compliance behaviors for her have been poor. The failure to notify the health care worker until she has missed several days dosage of her medication is alarming, considering the resistance problems with protease inhibitors.

Case Studies of Infected Teen Mothers

Another compliance indicator has come not from the treatment of adolescents themselves, but from their compliance with treatment for their HIV-exposed infants. Following the recommendations of the AIDS Clinic Trials Group (ACTG) Study 076, pregnant women take daily doses of AZT through pregnancy; infants born to HIV-infected mothers require a 6-week course of AZT, followed by a daily dose of Septra to protect the infant from pneumocystis carinii pneumonia (PCP) until the baby's HIV status is determined. The infant's HIV status is determined through two blood tests, both done at birth, and one is repeated at 6 weeks and between 4 and 6 months. If all tests are negative, the child is taken off all preventive medication.

After delivery, mothers/families are educated on the importance of the medication (expertise and liking) and are warned that if noncompliance is suspected, a medical neglect report will be made to the county department of social services child protective services (threat or aversive stimulation). During 1996, the leading cause of reports of medical neglect generated at one pediatric infectious disease clinic was noncompliance with medication. Although this noncompliance with infants' medication was not limited to mothers from the adolescent population, the percentage was higher than for nonadolescent mothers. These adolescents

often do not want to consider their own infection; daily doses of medication to their infants are a reminder that the child is HIV exposed. The child looks fine to them, so they can easily deny the need for medication. Some medical providers believe that noncompliance with a child's medication strongly suggests that a mother may not comply with her own therapy. Two cases are described, Reanna and Jeanelle.

Reanna. Reanna is a 17-year-old African-American adolescent with two children, a 2-year-old daughter and a 3-month infant son, Raheem. Reanna was diagnosed with HIV 18 months ago. Reanna and her children live with her mother, sister, and sister's children. Only Reanna's mother knows she is HIV infected and Raheem is HIV exposed. During her pregnancy, Reanna reported that she took the AZT as prescribed, an example of compliance through use of moral appeal ("Taking the AZT is the right thing to do to protect your baby"). Following Raheem's birth, any effort by the social worker to talk with Reanna about her own health care was met with a shrug and a reply of, "I'm fine. I don't think about it." She reported giving Raheem his AZT for 6 weeks and started giving him Septra at 6 weeks.

When Raheem was 2 months old, the social worker called the pharmacy to determine the amount of Septra dispensed and when a refill would be needed. She was told that no such prescription was ever filled. A medical neglect report was made to the county department of social services child protective services unit to exert aversive stimulation in the form of investigation and monitoring by a recognized authority. During the investigation, Reanna repeatedly stated that Raheem was not sick and therefore did not need to take any medicine. She had thrown away the prescription. Raheem's physician called the pharmacy to reorder the prescription.

In an effort to assure compliance, the physician ordered a home health nurse to visit the home 3 days a week. The nurse was to measure and mark the amount of Septra left in the bottle and provide education on caring for an HIV-exposed infant (positive expertise). Reanna allowed the nurse to visit only once. The nurse's repeated attempts to visit or call were unsuccessful. Reanna would not answer the door when the nurse knocked. When the nurse called, Reanna would pretend to be her sister and say that she was not home. Reanna told the department of social services social worker that she did not want the nurse visiting because her family and neighbors asked too many questions. The social worker arranged for Reanna and Raheem to meet the home health nurse at the department of social services, but Reanna failed to make this appointment. After several weeks, the department of social services determined that there was insufficient evidence to support medical neglect and closed the case, removing the aversive stimulation. Within a few weeks, Raheem had his third negative test and no longer needed to take Septra.

At present, the medication for her son is not an issue for Reanna. In the course of Reanna's treatment, however, her refusal to comply with her son's prescribed medication strongly indicates she will not adhere to her own treatment regimens (making her a poor choice to start cocktail therapies). Currently, Reanna refuses to keep appointments scheduled for herself, and Reanna's physician will not consider protease inhibitors for Reanna because of past noncompliant behaviors.

Jeanelle. Jeanelle is a 22-year-old African-American woman who discovered she was HIV infected after HIV testing during pregnancy. Jeanelle is not on medication for herself at this time but did take AZT during her last pregnancy. She has three children: two boys, ages 5 and 3, and a 2-month-old girl, Jazmyn. Jeanelle lost custody of her two older children following the court's determination that she was neglectful. She is determined to do whatever it takes to keep Jazmyn. The social worker uses the strategy of promise (if she complies with

the treatment regimen for Jazmyn, the social worker will assist Jeanelle in retaining custody of Jazmyn). Additionally, the social worker reinforces Jeanelle's positive feelings about herself by praising her for continuing compliance.

Jazmyn's second test returned positive, indicating that she is HIV infected, and must continue with daily doses of Septra until she is a year old. The social worker stressed the importance of continuing Septra as prescribed to protect Jazmyn from infection (positive expertise). She also will receive a regimen of antiretroviral therapy (i.e., AZT and 3TC). The social worker must maintain the bond with Jeanelle (liking) to provide the support she will need to comply with the treatment. As protease inhibitors become available for children, Jeanelle's compliance with the initial therapies will be considered when deciding to offer them to Jazmyn.

RECOMMENDATIONS FOR COMPLIANCE WITH HIV-INFECTED ADOLESCENTS

There are no easy answers to the dilemmas presented here. On one hand, there is now a group of drugs that, for the first time, give hope to those infected with HIV. The possibility of a future for HIV-infected adolescents is real. These drugs, however, have numerous side effects and require strict adherence to complicated dosing schedules that prevent drug resistance. Physicians and other health care workers will continue to be placed in positions to make judgments or recommendations about who will and who will not comply not only with treatment regimens, but also with public health laws to reduce the risk of transmission. Because it is impossible to monitor patients 24 hours a day, developing compliance-gaining strategies that are effective and meaningful to patients is essential. Based on past research on compliance gaining and adolescent egocentrism, combined with experiences from the case studies presented, recommendations for increasing compliance with HIV-infected female adolescents are presented next.

Recommendations for Self. Based on the case studies, several strategies appear to encourage HIV-infected adolescents to take their medications. Altruism was effective for some adolescents, along with promise (offering the cocktail if she is compliant) and at times liking (creating rapport). What was *not* effective for these adolescents was use of threat or aversive stimulation ("You could go to jail if you expose a partner to HIV"). Thus, traditional fear appeals likely will be ineffective (they often threaten death, not a useful approach for someone who has what to this point has been a terminal disease). Also ineffective was expertise, either positive or negative; this is crucial because physicians often use this strategy (M. Burgoon et al., 1990).

Recommendations for Other. Based on the case studies, several strategies appear to encourage HIV-infected adolescents to give their newborn infants medication. For the "other"-directed strategies, moral appeals and positive self-feeling were effective; these strategies often focused on being a good mother. Positive expertise worked in some but not all cases ("giving your baby AZT can help prevent infection"). What also worked in several cases was threat and aversive stimulation (reporting parental neglect), but this was not consistent and should be considered only as a last resort because of the potential damage to the relationship with the client (loss of rapport).

Social support is also important for compliance gaining. For example, Janice's parental interest and support were critical to gaining compliance with treatment protocols. Because

of her father's pleas to "do it for me" and his interest in what is happening with her medically, Janice became more interested in her own treatment. Linking the adolescent with others who are HIV infected, either on an individual basis or through a support group, can also decrease the teen's personal fable and sense of uniqueness (by seeing that others have similar problems and feelings). Janice has voiced more confidence in the expertise, both positive and negative, expressed by members of such a support group because she sees them as similar to herself.

Understanding adolescent egocentrism can be useful in choosing compliance-gaining strategies. Some adolescent risk taking (and associated decision making) is developmental; adolescents will work through some poor decision making themselves in time. Unfortunately, adolescents still are at great risk (and can pose HIV risks to others) until they move beyond these stages. The personal fable component of egocentrism encourages health care workers to avoid threat or aversive stimulation strategies. Using imaginary audience, health care workers could focus on strategies such as altruism, positive esteem, and moral appeal. Indeed, Greene et al. (1995; Greene, Hale, & Rubin, 1997) reported that adolescents' imaginary audience norms were a good predictor of their intentions to avoid higher risk behavior.

Adolescents receive mixed messages about risk behavior, especially sexual behavior. Parents, teachers, and religious organizations tend to promote abstinence (Keeling, 1987), yet other significant figures (e.g., peers or media) may promote risk-taking behavior (Keeling, 1987). Adolescents are particularly influenced by peer opinions (Cohen, Brook, & Kandel, 1991; Gayle et al., 1990), especially regarding sex (Reardon, 1989). For moral issues parent(s) or adults outside the family are reported to be the most influential for adolescents (Niles, 1981; Young & Ferguson, 1979). Thus, to encourage adolescent compliance, it might be possible to change parent attitudes (if they are aware of HIV infection) and get them to support taking medication. Also, peers could support behavior. Respected adults, perhaps a teacher or minister, might also support the behavior. What is crucial is to create social support for the recommended behavior, or compliance.

One finding from this study is that lack of support can contribute to problems with compliance. Many times, this lack of support is associated with unwillingness to disclose their infection. HIV disclosure decisions are extremely difficult. Members of the marital subsystem (lovers, spouses, exspouses, friends) are generally viewed as the most appropriate recipients of disclosure of HIV infection, with the nuclear family rating next highest (Greene & Serovich, 1996; Marks et al., 1992; Serovich & Greene, 1993), and lowest disclosure to extended family and general public. Additionally, the best predictors of willingness to disclose HIV infection are quality of relationship with the recipient and anticipated response to disclosure (Greene & Serovich, 1995). It is understandable, given associated risks, that HIV-infected adolescents would choose not to disclose. Health care workers dealing with these adolescents should be aware of the possible effect of nondisclosure on compliance.

Other approaches have also been shown to increase compliance in some health settings. Inui, Carter, and Pecoraro (1981) recommended asking a question to facilitate discussion about the difficulty of compliance (and assess the directness of responses). They recommended saying to patients, "Most people have trouble remembering to take their medication. Do you have trouble remembering to take yours?" Opening this kind of dialogue could lead to greater compliance; at least it will establish rapport. Behavioral contracts and weekly phone contacts have also increased compliance significantly, but not specifically using an adolescent population (Cummings, Becker, Kirscht, & Levin, 1981). These approaches may have some value, but they also have the potential to increase costs by using additional resources in often already overburdened health settings. Likely, if these plans were implemented, it would be social workers, physicians assistants, or nurses who would perform these behaviors, not the physicians themselves. Because of the psychosocial issues surrounding HIV/AIDS (e.g., poverty

and drug abuse), physicians are increasingly dependent on social workers in the management of these complicated cases.

Limitations. There are three important limitations regarding this study; likely, ethical choices regarding compliance gaining vary by context. First, the clients described here may not be representative of adolescent HIV/AIDS cases in other areas. Specifically, these adolescents are female, African American, many are/have been pregnant; they contracted HIV through heterosexual contact. Thus, it may be inappropriate to generalize to other populations, for example, inner-city adolescent Hispanic men who contracted HIV through homosexual contact. Second, the type of clinic or health care setting is significant here. In the clinic described here, the social worker rather than a nurse or physician made the most persuasive attempts. Other clinics may be set up differently (e.g., structurally, staffing, funding), and compliance-gaining attempts may be different. Third, and finally, is the status of treatment with protease inhibitors. Currently, no one knows how new treatments will affect HIV/AIDS stigma and unwillingness to disclose HIV infection. If the stigma is reduced, compliance gaining might become easier for health care workers.

Future Research. The introduction of protease inhibitors has changed the treatment of HIV/AIDS dramatically. These changes, however, do not come without associated problems. The case studies presented here, HIV-infected female adolescents, provide but one example of the dilemmas associated with prescribing these new cocktails. If HIV/AIDS treatment remains linked with these cocktail therapies, continued study of access to the medication and compliance with medical regimens will be crucial. The information reported about oft-changing funding sources for medication could have disastrous effects. Careful choices will need to be made to assure equal access to and funding for medication. Health care workers cannot simply exclude adolescents from treatment because they have higher rates of noncompliance or do not have the same funding sources as adults; the matter is clearly complex. Adolescents' absence from trials is additionally disturbing.

The compliance-gaining strategies recommended here for adolescent women may or may not be similar to effective strategies for other groups. The target, compliance with medical regimens, will remain the same, but what constitutes effective compliance-gaining strategies will differ. As research with protease inhibitors continues, much additional work is required to look at the effects, particularly with compliance.

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