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Adherence discourse among African-American women taking HAART

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Abstract

Low adherence is the single most important challenge to controlling HIV through the use of high acting anti-retrovirals (HAART). Non-adherence poses an immediate threat to individuals who develop resistant forms of the virus as well as a public health threat if those individuals pass on treatment-resistant forms of the virus. To understand the concerns and perceptions that promote or deter adherence to antiretroviral medication by HIV-positive African-American women, we conducted in-depth interviews with 15 African-American women taking HAART. We focused on the discourse and narratives women use in talking about their adherence practice. Discourse analysis was utilized to identify and explore the sources of influence used by these women in describing their adherence practice. Roughly a third of the sample fell into each of the three self-assessed adherence categories: always adherent, mostly adherent and somewhat adherent. Among the 'always adherent', 80% of the sources of influence cited supported adherence, while only 48% and 47% of the authoritative sources cited by women in the 'mostly' and 'somewhat' categories supported adherence. Each self-assessed adherence group was characterized by its own distinctive discourse style. Findings suggest that adherence to HAART among African-American HIV-positive women would be improved by identifying those influences undermining adherence. Focused study of the 'always adherent' types is recommended.

Introduction

The challenge of improving adherence to high-acting anti-retroviral therapies (HAART) is a major public health priority (Chesney *et al.*, 2000; Hogg *et al.*, 1999; Pequegnat & Stover, 1999; Singh *et al.*, 1999). Yet despite considerable research aimed at identifying the correlates of successful adherence practice, a single trait or a set of traits or conditions that would predict adherence practice has yet to be identified (Gordillo *et al.*, 1999; Horne, 1998; Rabkin & Chesney, 1999). Nor has a consistent association between adherence and patient-centred variables (Meichenbaum & Turk, 1987) or demographic characteristics (Besch, 1995) been established. Researchers in the field of adherence have begun to advocate moving away from efforts to isolate a single variable or set of variables. Instead, such

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researchers favour a patient-centred approach that incorporates the patient's own ideas about their illness and treatment, and seeks to reconcile views of patients and health practitioners (Horne, 1998), with attention to the cultural and social context in which adherence is practised (Diez-Rouz, 1998; Sumartojo, 1993). Following this direction, this paper explores how a woman's understanding of her disease and her medical regimen influence adherence practice within a specific, delimited group: HIV-positive African-American women living in Detroit, Michigan. To accomplish this, we examine talk about adherence by African-American women taking HAART, and identify the thoughts, beliefs and formulations that shape actual adherence practice. Utilizing discourse analysis (Goodwin, 1990; Tannen, 1990), we focus on three areas: (1) the identification of sources of authority that either promote or discourage adherence; (2) an exploration of how women resolve conflicts between conflicting sources of influence promoting adherence or selective adherence;[1] and (3) a description of the discourse styles characterizing different types of self-assessed adherence practice.

The problem

The current picture of HIV in the USA reveals that non-Hispanic Whites represent 45% of all diagnosed cases, African-Americans 36% and Hispanics 16% (CDC, 1999). Given that African-Americans represent only 12.1% of the overall population (Shinagawa & Lang, 1998), the incidence of HIV among African-Americans is clearly disproportionate. Women have been relatively neglected in HIV research (Cohen, 1995; Farmer *et al.*, 1996) and are an at-risk population in which HIV is emerging rapidly (Hader *et al.*, 2001). In a community cohort longitudinal study of African-Americans in New York City, researchers reported alarming increases in infection rates for African-American women, resulting in a male to female infection ratio of 1.5:1 (Brunswick & Flory, 1998). With increasing numbers of women—in particular African-American women—becoming infected, the need to understand their adherence practice becomes imperative.

Combination antiretroviral therapies have demonstrated clinical efficacy in decreasing mortality and in improving the quality of life for people with HIV. The success of such treatment, however, requires strict adherence to a complex and demanding dosing regimen. Failure to adhere rigorously to the regimen, even for a short time, can, in some instances, lead to the emergence of drug-resistant viral strains. Intermittent adherence suppresses the viral strains most susceptible to HAART, while allowing resistant strains to emerge. These drug-resistant strains can be transmitted (Flexner, 1998; Vanhoe *et al.*, 1996). Thus, non-adherence poses problems for the population beyond the threat to the individual patient (Chesney *et al.*, 2000; Rosenberg, 1995).

Adherence rates for HAART are similar to rates for medical treatments of chronic illnesses in general. These vary from 19 to 89% (Epstein & Cluss, 1982). In general there is an expectation of 50% adherence for medication in long-term therapy (Sackett & Snow, 1979). Yet even a week of less than 80% adherence to HAART can cause treatment-resistant

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[1] We use the term 'selective adherence' along with 'non-adherence' because volunteers in this study voiced an intention to be adherent and took at least some of their medications, although often according to their own dosing scheme. Most volunteers made conscious decisions about when and which medications they took, hence the term 'selective'.

strains of the virus to emerge (Rabkin & Chesney, 1999). The different medications involved in HAART must be taken at regularly specified intervals during the day; some must be taken on an empty stomach, others when full. The need for adherence along with the lack of flexibility in the HAART dosing regimen, has led researchers to seek answers by studying adherence practice in relationship to a wide range of variables (Proctor *et al.*, 1999). For example, studies have found that beliefs about the need for the treatment (Stall *et al.*, 1996) and the efficacy of the treatment (Blumenfeld *et al.*, 1990; Muma *et al.*, 1995) are associated with adherence. Attitudes of friends and trust in physicians are associated with adherence (Stall *et al.*, 1996). Research has identified that life setting (e.g. homelessness (Bangsberg *et al.*, 2000; Samet *et al.*, 1992)), substance use or a chaotic personal life may further affect the individual's ability to adhere. Finally, the cognitive impairment sometimes associated with advanced HIV can create memory problems that challenge the ability of the individual to follow their regime (Rabkin & Chesney, 1999), as do psychiatric disorders such as depression (Singh *et al.*, 1996; 1999).

The approach

Being HIV-positive changes an individual's expected life course, requiring those afflicted to rethink their life goals and the ways in which they will attain them (Rabkin, 2000). The advent of HAART—while providing a respite from a terminal diagnosis—poses its own set of problems, requiring those taking the medication to restructure significantly their daily routines. This fundamental restructuring makes denial of the disease difficult to maintain. Adherence is a continuous reminder of being HIV-positive. Put differently, it requires one to rethink who one is. The challenge people with HIV face is to rebuild their goals and redefine the meaning of their lives in light of this change (Bruner, 1986; 1990; Cohler, 1982; 1991). In discourse analysis, the organization of meaning and goals is called 'the narrative structure of life' (Gordon & Paci, 1996; Whitbourne, 1986). Because adherence requires continuous attention, and serves as a constant reminder of being HIV-positive, the process of adherence must either be integrated into, or actively excluded from, the restructured life narrative.

Discourse analysis can help to identify the narrative frameworks that people use to make sense of their world. These frameworks represent what individuals have done, and foretell what they are likely to do in the future, by organizing their beliefs, expectations, feelings and concerns teleologically and directing them toward desired outcomes (Bruner, 1986; Cohler, 1991; Luborsky, 1991; 1993; Gordon & Paci, 1996). Narratives highlight the goals of and directions for behaviour by making desired outcomes explicit. In so doing they embody notions of the good and the bad in a culture. As personal frameworks for interpreting one's own behaviour, narratives serve to promote or emphasize some aspects of life while marginalizing others. Thus, we examine adherence narratives for insights into how patients think about their adherence practice, and for guides to their future behaviour. For some research volunteers, being HIV-positive was equivalent to being adherent to their medicines: this identity is exemplified in one woman's comment that, ' I am HIV; I take my medicine.' For others, the need for adherence was actively contested. Because narratives help people rethink the goals of a life disrupted by illness, discourse analysis allows us to observe the extent to which being adherent is integrated into goal formation.

Prior HIV researchers have utilized discourse analysis to understand the logic behind decisions by young, sexually active heterosexual adults to forgo safe sex (Rosenthal *et al.*, 1998). In that study, narratives revealed that young adults sought the emotional safety of a love relationship in casual sex; consequently, messages concerning unsafe sex were counter-productive, as they implied a lack of trust and safety in the sexual encounter, and thus undermined the idealized goal.

Setting

Volunteers for the study were drawn from HIV-positive African-American women living in Detroit. Of Michigan's 12,500 reported HIV cases as of 1999, 24% are women and of these, 93% are African-American women (Michigan Department of Community Health, 1999). African-American women have the second highest infection rate of any group in Michigan. African-American men have the highest rate. A 1999 survey of HIV-positive individuals in Detroit conducted as part of the Supplement to the HIV/AIDS Surveillance Project of the Michigan Department of Community Health (IBID), 58% of HIV-positive African-American women had equal to or greater than 12 years of education; 35% were employed; 55% had an income exceeding $10,000; and 69% of these women reported using an illegal substance, with 53% naming crack as that substance.

Methods

Design

The study was designed to interview African-American women attending an inner-city infectious disease clinic, for whom HAART was prescribed by their physician. It used open-ended interviews with discussion prompts designed to explore the beliefs and practices that promote or deter self-assessed adherence to antiretroviral medication among HIV-positive African-American women.

Procedure

A clinic nurse approached volunteers sequentially in the clinic while they waited for their medical appointments, explained the study, and invited participation. None of those invited to participate declined. Recruitment continued until we achieved the sample size of 15. There is no ‘gold standard’ for qualitative sample size (Morse, 1994). Instead sample size is based on the aims and goals of a project, available resources to carry out the project, and complexity of the issues. In the current research the goal was to study a predefined clinic population of HIV-positive African-American women taking HAART. In a relatively homogenous population such as this, a convenience sample is appropriate to allow researchers to strengthen the comparability within the sample and to permit the identification of major topics of interest and explore similarities and differences within the sample (Luborsky & Rubinstein, 1995). The research team judged that a sample of 14–16 was suitable to meet these goals, and using continuous evaluation criteria to gauge category redundancy or pattern saturation (Bertaux, 1981), determined that no new information was being discovered by the time 15 subjects were completed. A trained, female, Anglo-American interviewer conducted interviews in a private consulting room, following a structured, open-ended, discussion guide. Audio-tapes were made. Interviews averaged 40–55 minutes. Volunteers were paid ten dollars.

Approval for the ethical conduct of this project was obtained from Wayne State University's Institutional Review Board

Measures

Three measures were constructed: adherence profile, self-reported adherence and sources of authority or reference groups in adherence practice (see Table 1). In assessing adherence, volunteers were asked to classify themselves in one of nine categories: always adhere with no variability over time; always adhere with some variability; always adhere with a lot of variability; mostly adhere with no variability; mostly adhere with some variability; mostly adhere with a lot of variability; somewhat adhere with no variability; somewhat adhere with some variability; and somewhat adhere with a lot of variability. An additional set of three 'rarely' categories was offered, but no volunteer self-rated as such. In their review of the HAART adherence literature, Rabkin and Chesney (1999) note that several recent, large studies documenting substantial rates of non-adherence indicate the willingness of people to admit to non-adherence, suggesting that self-reporting may be more reliable than previously thought.

Women were also asked about whether they missed clinic appointments. Their physicians were then asked to voluntarily rate the women on adherence and clinic attendance.

An adherence profile describing the entire sample was created, using items identified in the literature as being associated with adherence. These include, along with demographic indicators: access to primary care (Cunningham *et al.*, 1995; Shea *et al.*, 1992); the nature of the relationship with the physician (De Mateo *et al.*, 1993; Muma *et al.*, 1995; Stall, 1996); access to transportation to clinic appointments (Shelton *et al.*, 1993); knowledge about the medications and the drug regimen (Elred *et al.*, 1997); and the presence of side effects.

Analyses were conducted using content, theme and discourse techniques to discover which sources of influence women cite in discussing their adherence practice, and how they resolve conflicts between sources in this practice. Prior to discourse analysis, a content analysis was performed of all open-ended items, to identify patterns and variables associated with adherence practice. Procedurally, the first step in the data analysis was to create tables summarizing responses to each interview discussion topic. Next, free lists—an inventory listing all topics identified in response to an item—were constructed for each open-ended item. These served to establish the range of types and frequency of responses, and were later used as a validity check on the discourse analysis. Summaries of individual cases were created. These preliminary analyses were used in the construction of two measures: self-assessed practice, and perceived sources of influence on adherence practice. Content analysis was performed with open-ended items. Category codes for the content analysis, e.g. stigma, spirituality and popular culture, were supplied from the topics identified in the free list.

Discourse analysis was performed on the adherence narratives. We asked informants to tell us about a recent time when they had not taken their medication, and to explain the circumstances surrounding the event. To conduct the discourse analysis we followed three steps. First, we looked for the key topics and for repetition of specific words or phrases. We paid close attention to key indexical terms for moral authority such as *could, would, should, hope and pray*, that marked core cultural values (Labov, 1972; Linde, 1987). These terms have been further identified as culturally appropriate indexical markers in previous research (Sankar & Luborsky, in press). Discourse markers of importance supplied by respondents, such as 'They say', 'I hear her voice saying' or 'That's the main thing', were located in verbatim interview transcripts and used as indications of the salience of particular sections of text. Second, we looked at the structure of the overall story. We examined situations where conflicting sources of influence were identified, and studied how the women resolved those conflicts. Here we were interested in how women utilized cultural values to make sense out of conflicting sources of influence—e.g. their physician versus popular culture—and their resolution of the conflict. The examination of conflict resolution provides insight into how narrative is associated with adherence practice. We noted the sources of meaning and social influence which women used to justify their behaviour. Finally, we compared these findings to the topic frequencies created in the previous analysis.

Results

Our analyses describe the main study constructs: the adherence profile; the self-assessment of adherence; and the perceived sources of influence in adherence practice, including sources of support for adherence and barriers to adherence.

Sample characteristics

The average age of the study volunteers was 36. Most were unemployed, and had less than a high school degree. All were HIV-positive, and half had AIDS. Volunteers fit the general profile of people considered to be adherent: all had access to primary care, 93% had a positive relationship with their physician, and a similar percentage had access to transportation to clinic appointments. Volunteers took an average of four anti-retroviral medications, and general knowledge concerning these medications was high. All volunteers knew the general purpose of their medication; 93% knew the names of each medication, the appropriate doses and possible side effects; and 53% knew the purpose of each medication in detail. Although 67% said they had experienced side effects—only one woman—who had had to be hospitalized for a side effect—said it had affected her adherence (see Table 2).

Self-assessment of adherence

Volunteers were asked to self-rate their adherence. Roughly equal percentages were present; 24% were in the range of 'always complied'; 45% were in the' mostly complied' range; and 31% were in the 'sometimes complied' range. In a subjective assessment, the physician treating the study participants assessed their adherence differently from the volunteer evaluation in five of the 15 cases. In 26% of the cases, the women rated their adherence as somewhat adherent, while their physician rated them as always adherent. In one case the volunteer rated herself as always adherent, while the physician rated her as somewhat adherent. Clinic records for missed appointments coincided closely with volunteers' self-assessments (see Table 3).

Sources of influence in adherence practice

The volunteers' adherence narratives clearly and frequently contained references to various sources of influence, referred to as 'authority', on their adherence practice. By sources of influence we mean a culturally or personally valued voice either embodied as the physician, family or god, or a more general moral voice as in 'they say', that the woman cites as a source that she 'listens' to or considers in regard to her adherence practice. In Table 4 we summarize the various sources and report them according to the frequency with which they appeared in narratives. In response to questions on the purpose, dosage and method of adherence—e.g. timing, the need to take medications with or without food, etc.—the physician's voice was the most frequently mentioned. Volunteers recited verbatim the admonitions of their physicians:

> That comment Dr S. made about this medicine, that it can help you before you get sick but after it's out of their hands. I think about it. I do. Every morning, it goes through my mind. Okay, I make sure I take the morning dose, but then I'm thinking I'm doing okay and she's saying missed doses can mean like not getting the proper medicine in you. So I guess I'll have to take it twice a day (volunteer #5, somewhat adherent, 38 years old, AIDS).

Other repeated sources of influence included science, God, members of a woman's family and popular media outlets such as the television programme *60 Minutes* and the *Discovery Channel*:

> I had to put faith in god, you know, and pray on my medication before I take it. And then it just all of a sudden, it just became a normal thing to do (volunteer #12, always adherent, 38 years old, HIV-positive).

> I just hear my mother bugging me: 'You take your medication?' You know she try to remind me (volunteer #1, somewhat adherent, 46 years old, AIDS).

> I watched a lot of programs on TV about this, people were on their deathbeds, you know, with all different types of viral infections they thought this was going to be the end, and then they started this new trio of medication with one of them being the crixivan; they was up and okay (volunteer #14, mostly adherent, 42 years old, HIV-positive).

Sources of influence reported that undermine adherence practice

In some narratives, the influential social 'voices' that guided women's behaviour served to undermine adherence. Such voices provided a justification or rationale for selective adherence. Popular or street culture was prominent in these narratives. In particular, stories from support groups were cited:

> I heard on them news shows like *60 Minutes* that the medication don't do no good. Some people in my group say that if you take the medicine, all you going to do is get sicker (volunteer #2, mostly adherent, 36 years old, HIV-positive).

In the area of daily adherence practice, the individual's own feelings, including physical sensation, appeared in narratives that continually evaluated whether and when to adhere, and to which medications: 'When my body starts to feeling weak,' one informant said, 'then I take it.'

Substance use constituted a strong voice against adherence:

> Drugs make you think about nothing else. When you come down, reality is devastating. So what I would do is, take my medicine, and try to sit still for a while you know. But they clashed. Drugs and medicine clashed. If I took the AZT and the 3TC today, I couldn't get high. I would have to wait until like 24 hours later in order to feel the drugs. The drugs wouldn't let me come to my appointments (volunteer #2,, mostly adherent, 36 years old, HIV-positive).

Satan, too, was a voice undermining a woman's determination to be adherent.

> So that's what made me forget this morning about taking my medication, Satan. All these other things on my mind. Worrying about a test in school that I'm supposed to take today, you know. And you know like the devil walked in and just tried to mess up things for me. 'Cause that's all it is, Satan (volunteer #2, mostly adherent, 36 years old, HIV-positive).

Confusion arose for several women because they believed they were healed or 'almost' healed.

Situations of conflict in adherence practice

All women in this study expressed difficulty in meeting their goal of being adherent; the majority (76%) reported being only partially successful. When asked to describe a recent episode when they missed a dose, the resulting narratives demonstrated tensions between different sources of influence concerning the appropriate, or even the morally correct, actions regarding adherence. Women felt they should follow their physicians' orders; yet they were also aware of other authoritative voices emphasizing the potential toxicity of HAART, the need to heed side effects, and the risk of being involved in something seen as experimental. With the exception of two women—one of whom said that she simply forgot, the other of whom asserted her right to take medications when and how she wanted—the dominant narrative explaining missed doses referred to the fear of stigma which served as the moral justification for selective adherence. Unlike the embodied influence of the physician or god's voice or even the voice of drugs, fear of stigma represents an internalized moral judgement that association with a stigmatized condition—HIV—diminishes one's status as a full person (Luborsky, 1995). The fear of stigma was cited by participants to account for missed appointments, unfilled prescriptions, failure to adhere when outside the family home and failure to get the financial support to purchase medications:

> I never go to pick up my medicine anymore because people look at me funny. At least that's how I feel. You know what I mean? And because you always have to sign for it, and when I sign then they know, 'oh, she's that one.' And it's that look I can't deal with. It's almost like they look you in your face, like, 'Oh,' and then they drop their head, like 'She's infected.' You know what I mean? And it tears right

> through me. So I had to stop going to the pharmacy. I'll send someone (volunteer #5, somewhat adherent, 38 years old, AIDS).

The fear of stigma narrative contradicts the alleged moral laxity associated with being non-adherent because it focuses on the psychological wellbeing of the participants' children—thus creating a morally defensible rationale for selective adherence: namely, the secondary gain of protecting themselves and their children from social denigration and cruelty by others:

> My main reason for keeping quiet was my son because I don't want him to have to go through that with ignorant people. I mean, that's my, that was my main reason, my two kids was my reasons why it wasn't important that the world should know. I think if it wasn't for my kids, it wouldn't of mattered to me because I don't live with those people. I wrap my dose up and put it in my pocket when I go to work. That ways no one will see me take it. But I forgets a lot then (volunteer #7, mostly adherent, 27 years old, HIV-positive).

Underscoring the dilemma the women faced, it must be noted that all but two women acknowledged their failure to adhere as a serious behaviour. As one woman noted, making the moral connection clear:

> If I pass, I don't want it to be because I didn't try to take care of myself, you know. So, I'm just doing like I'm supposed to (volunteer #2, mostly adherent, 36 years old, HIV-positive).

The conflicts resulting from adherence practice were successfully resolved in several ways. Those who doubted that they were HIV-positive, and were therefore concerned about taking unnecessary medications that might be toxic, referenced a belief in the wisdom of physicians, sometimes along with God, to justify following a regimen made superfluous by their supposed cure:

> I'm a religious person and I believe that all the medication, it's given to me, and you know, if our father had told me not to take it 'cause he's already confessed to me that I'm healthy, he's already told me I'm healed, but I take the medication because he has come back to tell me that I'm putting a blessing through the medication, so you know (volunteer #14, mostly adherent, 42 years old, HIV-positive).

Others created their own medication hierarchy that they used to guide adherence:

> I used to miss taking the AZT and the 3TC, I would never not take my Dapsone or Bactrim because the PCP. Some people make it through it and some don't. And that's the most important medicine to me. This other stuff is just a way of prolonging the inevitable. That's how I see it. But, the Dapsone and the Bactrim, stuff like that, that prevents pneumonia, that deadly one. And I really believe in taking that; I really do (volunteer #8, mostly adherent, 38 years old, HIV-positive).

Some who struggled against the public opinions of popular culture—especially those voices heard in support groups where medication is regarded with suspicion—reported on their own observations of actual behaviour to resolve their ambivalence and concern:

> At first its like ‘I don’t take that stuff. I’d never take it.’ But when they found they got close to dying, I noticed every one of them jumped on some kind of medication. First it was like, I’m not taking that stuff, and the next thing you know they on it, cause they get scared. But they be macho at first, you know to convince you, you don’t need to take it (volunteer #12, always adherent, 38 years old, HIV-positive).

In other situations resolution of the conflict between the various sources of influence could not be achieved, leaving women debating among the moral imperatives associated with the various influences on their behaviour:

> You might wish you hadn’t done stopped the medicines because now you see that that don’t work… You might think that ‘you should have took this,’ and you did this, and then you found no, you shouldn’t have took it. So it’s a challenge. Everything you do is not right or wrong. I’ll put it that way (volunteer #10, mostly adherent, 41 years old, AIDS).

Adherence narratives and adherence practice

No demographic factors differentiated among the three self-assessed groups of adherence. They are similar in terms of education, with the always adherent group averaging 12.5 years, mostly adherent 11.2, and somewhat adherent 12 years. Each group contained at least one active substance user. One area of difference is in average number of HIV-related medications: 4, 2.8 and 3.6, respectively. This is not associated with self-rated expected adherence, however, because the mean of four medications was associated with the most adherent group. Another difference is in the percentage of people with AIDS in each group: 75%, 0% and 60%, respectively. The discourse styles, however, differentiated the groups according to self-assessed adherence (see Table 5).

Always adherent—Narratives associated with those who rated themselves as always adherent had few reports of voiced opinions of family, friends or popular culture urging selective or outright non-adherence. Although the authoritative voice of the physician is sometimes heard (‘the doctor makes me take the medication the way I’m supposed to’), the always adherent woman is more likely to refer to a quasi-scientific rationale as the logic behind her adherence. This statement demonstrates some grasp of the functioning of both HIV and the HAART:

> Believe me, HIV’s still there because the virus hides. It’s like a cell that’s an alien and it hides behind the other cells, you know. It could change its form and look like a regular cell. It’s a tricky disease (volunteer #12, 38 years old, HIV-positive).

Religiosity appears as a reference point in this narrative not as active support from God for adherence, but rather as a general support in times of crises (‘I pray my health won’t worsen’). Members of the always adherent group had decided to take the medication after consideration, whereas the mostly adherent group cited acquiescence to the physician’s recommendations. The strongest pattern appearing in narratives associated with the always adherent group is the referencing of a popular secular cultural prescription, the belief in the power of positive thinking and individual responsibility:

- You gotta think positively.

- I am living not dying with HIV.
- I realized that my thinking was causing me a whole lot of illness and I changed.

Although the always adherent individuals acknowledged the presence of stigma, most said that it no longer bothered them, or concerned them only in regard to their children. No one indicated that it affected their adherence practice:

> In the beginning I used to worry a lot that people would know. I don't worry now because I don't care. I mean, if it takes for everyone to know, for me to stay healthy, I'll do it. Nothing gets in the way of my drugs (volunteer #6, 27 years old, HIV-positive).

Members of this group cited multiple influences supporting full adherence, and few supporting selective adherence. This group was further characterized by its acceptance of being HIV-positive ('I'm HIV'), along with a belief in the core American value of individual responsibility, and a somewhat more sophisticated understanding of HIV and the medication than the other two adherence groups.

Mostly adherent—The narratives of this group contained multiple sources of social authority; some of these were in conflict. The physician's voice was most important to this group, followed closely by God, and by a fusion of God and the physician:

- God told me to take the medication.
- The doctor said, the medication was the only thing that was going to help.
- It work for me, the doctor and God, you know, cause doctors work through God.

Television programming was another source of information reported as supporting adherence.

Influences that undermined adherence or directly challenged the physician's authority were frequently heard. The role of individual judgement and the body's wisdom is heard here ('My body will tell me when to take it'). Both ambivalence and outright challenges to the physician's knowledge and authority characterized these narratives:

> The only thing they [the people at the clinic] going to say, 'you have to start taking your medicine, or you'll get sick.' They don't know that. They're doctors. They're not God (volunteer #7, 27 years old, HIV-positive).

In this group the doubts expressed about professional authority sometimes extended to doubts concerning whether the individual was in fact HIV-positive at all. Further, those who self-identified as mostly adherent experienced ambivalence about which source of influence they should follow and, poignantly, about what was the morally responsible behaviour. Citing a need to live for their children or simply for themselves, they wanted to 'do what I should to keep alive', but were conflicted as to what the right choice was. The group tended not to identify with being HIV-positive ('I'm still the same person I always was; HIV hasn't changed me').

Somewhat adherent—Narratives of the somewhat adherent group contained fewer references to non-personal sources of influence in general, and far fewer of those clearly advocated adherence. When the physician's voice was heard at all, its message was ambivalent:

> I didn't decide to take it (HAART). I didn't decide. I came to, you know, I didn't decide. I just took the advice of my doctor. That's why I come to see her (volunteer #1, 46 years old, AIDS).

This group was characterized by a passive stance toward adherence, including suggestions that they would be more adherent if the clinic would call them each day, or if God gave them the strength to be so.

Discussion

The findings of this study are subject to four main limitations. First, the study relies on self-reporting of adherence. A difference between evaluations of adherence by physician and patient is consistent with findings from self-report research in asthma (Bosley *et al.*, 1995), as well as HIV (Paterson *et al.*, 1998). However, research on self-reporting has found that patients tend to be most accurate when reporting non-adherence (Catz *et al.*, 2000). Second, the volunteers were people who were already in treatment, thus they had been judged by the clinic personnel as potentially adherent. They do not represent the full range of African-American women who are HIV-positive. Third, the interviews for this study were all conducted in a private room at the clinic. However, several volunteers indicated that they did not wish to criticize the staff, suggesting that the clinic setting may have conditioned the volunteers' comments. Finally, this study focused on a small qualitative sample, and is not representative; however, our adherence profile is in line with a larger study of women and adherence to HAART. In the HIV Epidemiology Research Study (HERS), 49% of the volunteers ($N = 453$) assessed themselves as adherent most of the time, 29% almost all of the time, 6% little of the time and 8% never (Schuman *et al.*, 1998). The current study's combined total of 69% assessing themselves as basically compliant is only slightly less than the combined rate of 78% reported in the HERS study.

Table 5 shows a relative balance between mentions of those sources of influence that support and those that undermine adherence, among both the mostly and somewhat adherent groups. The distribution of sources for the always adherent group stands out at 80% in support of adherence, suggesting that those who are most adherent are not the norm. Further investigation is needed to discover how they support this ambitious regimen.

The fear of stigma presents a strong challenge to adherence, but does so in a complicated way. In some cases it constitutes a moral justification for selective adherence as a means to protect oneself and one's children. But in other narratives the prominent role of stigma in discouraging adherence among both the mostly and somewhat adherent may be associated with a lack of identification with the disease. Stigma is a kind of self-awareness of an undesired status. The women's intense concern for being recognized as HIV-positive reflects their desire to remain unmarked to themselves as well as to others to avoid the implied moral judgement associated with a stigmatized condition. This association is seen most clearly when women state that they miss doses because taking the medication reminds them of their disease. The comparative absence of references to stigma among the always adherent, plus their acceptance of their status, supports this interpretation. Conversely, fear of stigma in the mostly and somewhat adherent groups served to amplify the impact of competing sources of influence on adherence that undermine the authoritative voices that support adherence.

Conclusion

By identifying the multiple sources of influence that women attend to in structuring their adherence practice, professionals can learn about the rationales that support full, as well as selective, adherence. This knowledge can serve as the basis for interventions that address the confusion felt by many HIV-positive women about what is the correct, safest and morally responsible behaviour.

Sources of influence that provide some understanding of the mechanisms of HIV and/or HAART appear to support adherence more effectively than could the physician alone. Basic patient education may thus enhance adherence to the HAART regimen.

References

Bangsberg DR, Hecht FM, Charlebois ED, Zolopa AR, Holodniy M, Sheiner L, et al. Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. AIDS. 2000; 14(4):357–366. [PubMed: 10770537]

Besch CL. Compliance in clinical trials [editorial review]. AIDS. 1995; 9:1–10. [PubMed: 7893432]

Blumenfield M, Milazzo J, Wormser G. Noncompliance in hospitalized patients with AIDS. General Hospital Psychiatry. 1990; 12:166–169. [PubMed: 2335302]

Bruner, J. Actual minds, possible worlds. Cambridge, MA: Harvard University Press; 1986.

Brunswick AF, Flory MJ. Changing HIV infection rates and risk in an African-American community cohort. AIDS Care. 1998; 10(3):267–281. [PubMed: 9828971]

Catz SL, Kelly JA, Bogart LM, Benotsch EG, McAuliffe TL. Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. Health Psychology. 2000; 19(2):124–133. [PubMed: 10762096]

Centers for Disease Control and Prevention. HIV/AIDS surveillance report. 1999; 11(1)

Chesney MA, Morin M, Sherr L. Adherence to HIV combination therapy. Social Science and Medicine. 2000; 50:1599–1605. [PubMed: 10795966]

Cohen J. Women: absent term in the AIDS research equation. Science. 1995; 269(11):777–780. [PubMed: 7638589]

Cohler, B. Personal narrative and life course. In: Baltes, P.; Brim, O., editors. Life-span development and behavior. Vol. 4. New York: Academic Press; 1982.

Cohler B. Life story and the study of resilience and response to adversity. Journal of Narrative and Life History. 1991; 1:169–200.

Cunningham W, Hays R, Williams K, Beck K, Dixon W, Shapiro W. Access to medical care and health-related quality of life for low-income persons with symptomatic human immunodeficiency virus. Medical Care. 1995; 33:739–754. [PubMed: 7596212]

Diez-Roux A. Bringing context back into epidemiology: variables and fallacies in multilevel analysis. American Journal of Public Health. 1998; 88(2):216–222. [PubMed: 9491010]

Di Matteo M, Sherbourne C, Hays R, Rodway L, Mc Glynn E, Kaplan S, Rogers W. Physicians' characteristics influence patients' adherence to medical treatment: results from the Medical Outcomes Study. Health Psychology. 1993; 12:93–102. [PubMed: 8500445]

Elred, L.; Wu, A.; Chaisson, R.; Moore, RD. Adherence to anti-retroviral therapy in HIV disease. Paper presented at the 4th conference on Retroviruses and Opportunistic Infections; Washington, DC. 1997.

Epstein L, Cluss P. A behavioral medicine perspective on adherence to long-term regimens. Journal of Consulting and Clinical Psychology. 1982; 50:950–971. [PubMed: 6816844]

Farmer, P.; Connors, M.; Simmons, J. Women, poverty and AIDS: sex, drugs, and structural violence. Monroe, ME: Common Courage Press; 1996.

Flexner C. HIV-protease inhibitors. New England Journal of Medicine. 1998; 338(18):1281. [PubMed: 9562584]

Goodwin, M. He said/she said: talk as social organization among black children. Bloomington: Indiana University Press; 1990.

Gordillo V, del Amo J, Soriano V, Gonzalez-Lahoz J. Sociodemographic and psychological variables influencing adherence to antiretroviral therapy. AIDS. 1999; 13(13):1763–1769. [PubMed: 10509579]

Gordon, D.; Paci, E. Narrative and quality of life. In: Spilker, B., editor. Quality of life and pharmacoeconomics in clinical trials. Raven: 1996. XXX.

Hader SL, Smith DK, Moore JS, Holmberg SD. HIV infection in women in the United States: status at the millennium. Journal of the American Medical Association. 2001; 285:1186–1192. [PubMed: 11231749]

Hogg RS, Yip B, Kully C, Craib KJ, O'Shaughnessy MV, Schechter MT, et al. Improved survival among HIV-infected patients after initiation of triple-drug antiretroviral regimens. Canadian Medical Association Journal. 1999; 160(5):659–665. [PubMed: 10102000]

Horne, R. Adherence to medications: a review of existing research. In: Myers, L.; Midence, K., editors. Adherence to treatment in medical conditions. London: Harwood; 1998. p. 285-311.

Labov, W. The transformation of experience in narrative. In: Labov, W., editor. Language in the inner city. Philadelphia: University of Pennsylvania; 1972.

Linde, C. Explanatory systems in oral life stories. In: Holland, D.; Quinn, N., editors. Cultural models in language and thought. Cambridge: Cambridge University Press; 1987.

Luborsky M. Socio-cultural factors shaping technology usage. Technology and Disability. 1993; 2:71–78.

Luborsky, M. Identifying themes and patterns. In: Gubrium, J.; Sankar, A., editors. Qualitative methods in aging research. New York: Sage; 1994.

Luborsky M. The process of self-report of impairment in clinical research. Social Science and Medicine. 1995; 40(11):1447–1459. [PubMed: 7667650]

Luborsky M, Rubinstein R. Sampling in qualitative research. Research on Aging. 1995; 17(1):89–114. [PubMed: 22058580]

Meichenbaum, D.; Turk, D. Facilitating treatment adherence: a practitioner's handbook. New York: Plenum; 1987.

Michigan Department of Community Health. Annual report, State of Michigan. 1999

Morse, J. Designing funded qualitative research. In: Denzin, N.; Lincoln, Y., editors. Handbook of qualitative research. Thousand Oaks, CA: Sage; 1994. p. 220-236.

Muma RD, Ross MW, Parcel GS, Pollard RB. Zidovudine adherence among individual with HIV infection. AIDS Care. 1995; 7(4):439–447. [PubMed: 8547359]

Paterson, DL.; Swindels, S.; Mohr, JA.; Brester, M.; Vergis, EN.; Squier, C.; Wagener, MM.; Singh, N. Adherence with protease inhibitor therapy for human immunodeficiency virus infection. Paper presented at 38th Annual ICAAC; 1998.

Pequegnat, W.; Stover, E. Behavioral research needs and challenges of new treatments: AIDS as a chronic illness. In: Ostrow, D.; Kalichman, S., editors. Psyochosocial and public health impacts of new HIV therapies. New York: Kluwer; 1999. p. 183-191.

Proctor VE, Tesfa A, Tompkins DC. Barriers to adherence to highly active antiretroviral therapy as expressed by people living with HIV/AIDS. Aids Patient Care. 1999; 13(9):535–544.

Rabkin JG. Psychological effect of HAART: a 2-year study. Psycho Medicine. 2000; 62(3):413–423.

Rabkin, J.; Chesney, M. Treatment adherence to HIV medications: the Achilles heel of the new therapies. In: Ostrow, D.; Kalichman, S., editors. Psychosocial and public health impacts of new HIV therapies. New York: Kluwer; 1999. p. 61-79.

Rosenberg PS. Scope of the AIDS epidemic in the United States. Science. 1995; 270:1372–1375. [PubMed: 7481828]

Rosenthal D, Gifford S, Moore S. Safe sex or safe love: competing discourses? AIDS Care. 1998; 10(1):35–47. [PubMed: 9536200]

Sackett, D.; Snow, J. The magnitude of compliance and noncompliance. In: Haynes, R.; Taylor, D.; Sackett, D., editors. Compliance in health care. Baltimore: Johns Hopkins University Press; 1979. p. 309-333.

Sankar A, Luborsky M. Developing a community-based definition of needs for persons living with chronic HIV. Human Organization. (in press).

Schuman, P.; Ohmit; Cohen, J. NIDA health care utilization collaborative HERS/WIHS sub-study. Poster; Session presented at the Geneva XII International AIDS Conference; 1998.

Shea S, Misra D, Ehrlich MH, Field L, Francis CK. Correlates of nonadherence to hypertension treatment in an inner-city minority population. American Journal of Public Health. 1992; 82(12): 1607–1612. [PubMed: 1456334]

Shelton D, Marconi K, Pounds MB, Scopetta M. Medical adherence among prenatal, HIV seropositive African-American women: family issues. Family Systems Medicine. 1993; 11(4):343–356.

Shinagawa, L.; Jang, M. Atlas of American diversity. Walnut Creek: Altimra Press; 1998.

Singh N, Squier C, Sivek C, Wagener M, Hong Nguyen M, Yu VL. Determinants of compliance with antiretroviral therapy in patients with human immunodeficiency virus: prospective assessment with implications for enhancing compliance. AIDS Care. 1996; 8(3):261–269. [PubMed: 8827119]

Singh N, Berman SM, Swindells S, Justis JC, Mohr JA, Squier C, et al. Adherence of human immunodeficiency virus-infected patients to antiretroviral therapy. Clinical Infectious Diseases. 1999; 29:824–830. [PubMed: 10589897]

Smith D, Warren D, Vlahov D, Schuman P, Stein M, Breenberg B, Holmberg S. Design and baseline participant characteristics of the Human Immunodeficiency Virus Epidemiology Research (HER) study: a prospective cohort study of human immunodeficiency virus infection in US women. American Journal of Epidemiology. 1997; 146(6):459–469. [PubMed: 9290506]

Stall R, Hoff C, Coates T, Paul J, Philips K, Ekstrand M, Kegeles S, Catania J, Daigle D, Diaz R. Decisions to get HIV tested and to accept antiretroviral therapies among gay/bisexual men: implications for secondary prevention efforts. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology. 1996; 11:151–160. [PubMed: 8556397]

Sumartojo E. When tuberculosis treatment fails: a social behavioral account of patient adherence. American Review of Respiratory Disease. 1993; 147:1311–1320. [PubMed: 8484650]

Tannen, D. You just don’t understand: women and men in conversation. New York: Ballantine; 1990.

Vanhove GF, Shapiro JM, Winters MA, Merigan TC, Blaschke TF. Patient compliance and drug failure in protease inhibitor monotherapy [letter to the editor]. Journal of the American Medical Association. 1996; 276(24):1955–1956. [PubMed: 8971062]

Whitbourne, S. The me I know: a study of adult identity. New York: Springer-Verlag; 1986.

Table 1

Measures

Construct	Measure	Items
Adherence profile	Demographics	Demographics
	Knowledge of drug regimen	• Knowledge of treatment
		• Actual practice
	Doctor–patient relationship	• Assessment of
		• Assessment of clinic relationship care
		• Communication with clinic personnel
	Clinic attendance	• Clinic attendance
Assessment of adherence	Self-assessment	• Self-assessment
	Clinic assessment	• Blood tests
		• Clinic attendance records
		• Physician assessment
Sources of authority	Sources of authority	• Suggestions for improving practice
		• Episodes of non-adherence
		• Social and personal consequences of non-adherence
		• Cultural meaning of adherence

Table 2

Patient characteristics

Characteristic			
Age		Children at home	3
24–46			
m = 36			
Education		Substances	
< HS	9	Heroin/crack	2–4x/wk 4
post HS 6		alcohol	2–4x/wk 6
HIV status		Marital status	
HIV	8	Married	6
AIDS	7	Single	9
Employment status		Self-rated health	
Employed	3	M = 50	
Unemployed	12	m-54	
Average number medication	4	Medication coverage	15
Good relationship with physician	14	Knows names of medication	14
Knows side effects	14	Understands dosage	14
Understands purpose of medications	8	Access to transportation	14

Table 3

Self-assessment of adherence

Adherence	**%**
Always adhere	24%
Mostly adhere	45%
Sometimes adhere	31%

Table 4

Sources of authority for adherence and selective adherence

Source of authority	**Frequency of support for adherence**	**Frequency of support for selective adherence**
Physician	11	0
Science (as in ‘they’)	10	0
Belief(if you believe, it will work)	9	0
God	5	0
Family (I can hear my mom saying)	5	1
Popular culture (they say)	2	3
Television (talk shows, *60 Minutes, The Discovery Channel*)	2	3
The body	0	2 (my body tells me when I need the medicine)
Friends	1	1
Substances	0	2
Self	0	5 (I know when I should take it)

Table 5

Mentions of sources of authority for or against adherence

Type of authority	**Always adherent (*n* = 4)**		**Mostly adherent (*n* = 6)**		**Somewhat adherent (*n* = 5)**	
Authority in support of adherence	26	80%	24	48%	15	47%
Authority in support of selective adherence	7	20%	26	52%	18	53%
Total mentions	35	100%	50	100%	33	100%