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# Factors Influencing Adherence to Antiretroviral Therapy for HIV-Infected Female Inmates

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## Abstract

New HIV cases are increasing among women, especially women of color. Moreover, the rate of infection for incarcerated women is twice that of incarcerated men. With advances in medication therapy, HIV has become a chronic illness that can be successfully treated, provided the patient is able to achieve adherence with the prescribed antiretroviral medication regimen. Incarcerated women, however, frequently come from environments burdened with violence, substance and physical abuse, homelessness, child-care issues, and mental illness. Such burdens negatively affect the ability of these women to adhere to the medication plan. This study explored incarcerated HIV-infected women's barriers to and facilitators of adherence to antiretroviral therapy (ART), the role of health care provider relationships in adherence, and the ways in which issues of medical privacy influence ability or desire to adhere while incarcerated. A secondary analysis of an existing set of qualitative interviews with HIV-infected female inmates was conducted.

### Keywords

adherence; antiretroviral therapy; directly observed therapy; female inmates; HIV

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With advances in medication therapies, HIV infection has become a chronic illness, but it requires management to prevent transmission to others and reduce the risk of developing AIDS. Antiretroviral therapy (ART) has been tremendously successful in reducing viral loads and improving CD41 T cell counts (Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Wood et al., 2006). However, a 95% adherence to ART is essential to maintain reduced or undetectable viral loads and prevent the formation of drug resistant viral mutations (Lewis, Colbert, Erlen, & Meyers, 2006; Spaulding et al., 2002; Wohl et al., 2003). Recommended ART regimens are often complex, including three or more different drugs designed to target the HIV infection at various stages of replication or growth (Department of Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents [DHHS Panel], 2008).

The rate of new cases of HIV infections in women in the United States has grown from about 8% in 1985 to over 25% in 2004 (Henry J. Kaiser Family Foundation, 2006). Most women were infected at a young age, adversely affecting the long-term health of the women and care of their children and families and increasing the costs of health care to the women and society (Henry J. Kaiser Family Foundation, 2006; Lewis et al., 2006). Research has reported higher rates of HIV in the poor, often attributed to social inequities (Arriola, Braithwaite, & Newkirk, 2006). Rates of HIV are higher in impoverished counties in the United States, of which 78% are found in the southern region (Aral, O'Leary, & Baker, 2006). The rate of HIV in women living in the southern United States is 12 times that of the national rate for women (Henry J. Kaiser Family Foundation, 2006). The majority of women becoming infected with HIV are of African American ethnicity (Arriola et al., 2006; Henry J. Kaiser Family Foundation, 2006).

African American and Hispanic women represent a disproportionate number of incarcerated women. Additionally, the prevalence of HIV infections among incarcerated women is roughly double that of incarcerated men (Arriola et al., 2006). Life circumstances tend to be very different for incarcerated women than for incarcerated men—women have higher levels of poverty, increased exposure to violence and abuse, more substance abuse, and unstable living conditions. Further, incarcerated women are more likely than incarcerated men to have used sex work to buy food and drugs, and thus they are at greater risk for HIV infection (Arriola et al., 2006; Fogel & Belyea, 1999; Lewis et al., 2006). Moreover, women tend to be diagnosed later in the course of the disease, which results in higher viral loads and greater risk of progression to AIDS (Holstad, Dilorio, & Magowe, 2006).

Major barriers to ART adherence include the expense, complexity of the regimens, and the side effects associated with most of the agents prescribed (DHHS Panel, 2006; Henry J. Kaiser Family Foundation, 2006). Because most women with HIV are of childbearing age (15–44 years of age), agent selection is crucial in preventing fetal exposure to teratogenic agents (DHHS Panel, 2006). Women, especially inmates, also deal with gender-unique barriers to ART such as socioeconomic factors, mental illness, substance abuse, physical violence and abuse, and family obligations (Lewis et al., 2006).

Stigma has been identified as a major barrier to adherence with ART. Stigma plagues HIV-infected women whether they are incarcerated or not. Fear that others will assume her HIV status from the medications she takes or the health care visits she makes may cause a woman to hide her diagnosis and potentially delay or refuse care (Holstad et al., 2006; Lewis et al., 2006; Sandelowski, Lambe, & Barroso, 2004; Spaulding et al., 2002). Holstad et al. (2006) reported that women hid their diagnosis more than their male counterparts, inadvertently setting themselves up for social isolation and increasing their vulnerability to adherence failure.

Privacy is necessarily limited in prison, and this may increase inmates' reluctance to access health care, thus creating a situation in which the women refuse care to keep others from learning their medical diagnoses (Frank, 1999; Stoller, 2003; Rosen et al., 2004; White et al., 2006; Wohl et al., 2003.) Lack of medical privacy has been shown to be a barrier to ART adherence for the imprisoned; however, the right to medical privacy while incarcerated is

controversial. By denying medical privacy to inmates, prisons may be inadvertently reducing ART adherence rates and increasing the risks of complications to inmates and the spread of the disease upon release in the community.

Although adherence to ART has been studied in HIV-infected populations, the unique facilitators and barriers to ART adherence and the experience that HIV-infected female inmates have had with adherence are not well understood. Limited research has been conducted on HIV-infected incarcerated women. Mostashari, Riley, Selwyn, and Altice (1998) conducted an early study that addressed the unique needs of HIV-infected female inmates. They reported that trust in the efficacy of ART and prison health care improved acceptance of ART. However, with changes in ART regimens and the introduction of new agents during the past 10 years, the barriers and facilitators to adherence may have changed. The importance of social support while incarcerated also has been emphasized (Centers for Disease Control and Prevention, 2001; Holstad et al., 2006; Lewis et al., 2006). Research describing the current barriers and facilitators for ART adherence viewed by HIV-infected female inmates, including issues of medical privacy, is needed. Additionally, the views of HIV-positive female inmates on relationships with prison health care providers in relation to ART adherence require exploration. Therefore, this study explored incarcerated HIV-infected women's views of the barriers and facilitators to ART adherence and the role of support, health care provider relationships, and issues of medical privacy as they relate to adherence while incarcerated.

## Research Design

### Method

This study used a secondary analysis of data collected through qualitative interviews with incarcerated HIV-infected women to identify barriers to and facilitators of adherence to ART while in prison. The data came from an original study designed to discover how HIV-infected female inmates perceived medication therapy in prison and to find ways to enhance adherence. Secondary analysis of the data set was similar to the original intent and was not in conflict with the purpose as stated on the original consent form. Approval from the institutional review board at the University of North Carolina at Chapel Hill was obtained, and an addendum was filed and approved to include the researchers who were involved in the secondary analysis. e original data set consisted of 12 individual interviews with HIV-infected women prisoners (see Table 1). According to the original principal investigator, the participants were purposefully selected from a sample of HIV-infected women inmates who were prescribed ART either by directly observed therapy (DOT), keep own prescription (KOP), or both. The women were selected because they seemed to be able to provide information on barriers to and facilitators of adherence; that is, they were HIV-infected, incarcerated, and currently taking ART (Miles & Huberman, 1994). Such purposeful sampling is important in descriptive studies to ensure adequate representation of those who live the phenomenon being studied (Sandelowski, 2000).

In the original study, a single female research assistant who was a medical student unaffiliated with the prison or the prison HIV clinic approached every woman visiting the HIV clinic during the recruitment period from November 2004 through March 2005. The

HIV clinic was held twice per month; a total of seven clinics were held during the recruitment period. Approximately 20 women were seen at each clinic session, and approximately 70 HIV-infected women were seen at least once during the recruitment period. The research assistant recruited during the clinics and provided the study description and obtained written informed consent. No monetary or tangible reimbursement was provided to the participants, in accordance with prison policy. The women who declined to participate stated that they did not want to use their clinic time for the interview. Those who agreed to be interviewed met the inclusion criteria of (a) receiving ART therapy and (b) English-speaking.

## Data Collection

The original interviews were conducted at a large state women's correctional facility in a private room at the prison health clinic. The interviewer recorded the interviews with each participant using a microcassette tape recorder. The women were asked what they perceived as barriers to and facilitators of ART adherence in the prison system, how their relationships with prison health care providers influenced adherence, and finally, how medical information privacy (or the lack thereof) while incarcerated affected adherence for the women.

According to the original primary investigator, the interviews were conducted using basic nonthreatening questions first, followed by questions focused more on the research interests. During secondary analysis, it was noted that the interviewer paused to allow the participant ample time to respond, summarized the responses given, and asked for further elaboration with each question. Furthermore, the interviewer closed each interview by asking if the participant had any other information to share and maintained a relaxed tone throughout to provide reflection time and permission to speak. When the interviewee became distressed, the interviewer remained quiet, allowed the woman to regain control, and moved away from the topic.

The first author of this manuscript transcribed the taped interviews to improve her understanding of tone and emphasis of the responses by the interviewed women. Some answers were difficult to hear on the tapes; however, detailed field notes made by the original interviewer supplied insight into the nature of the participant's responses and helped to provide comprehensive interview transcripts. The transcripts and tapes were reviewed by an experienced nursing researcher for accuracy. Pseudonyms (as opposed to impersonal numeric designations) were assigned to each participant to present each participant as a real woman with real feelings and emotions. The researchers had access to the original interview sheet and informed consent during the data analysis period and were therefore sure that no pseudonym was related to the actual name of the participant.

## Data Analysis

Data analysis began with a review of the transcripts. The analysis required some interpretive considerations. For instance, the term medical privacy was not used by the women, and each woman's comments had to be read and reviewed before they could be interpreted as pertaining to privacy. The researcher's familiarity with the setting provided insight into

many of the comments about the prison setting and aided in data categorization. The women's transcribed responses to the questions were clarified by listening to the tapes for phrasing and emphasis. As the transcripts were read and tapes reviewed, the choice of words and phrasing clarified the women's responses to questions. A sample of types of questions asked in the original interview is listed in Table 2.

A flow sheet was maintained to record repeated phrases and words, (e.g., dislike of waiting). Counting was used to avoid discounting the responses of those who might not have been as verbal as others and to establish patterns or recurrences (Sandelowski, 2001). The use of counting also aided the researchers in categorizing responses by prevalence of remarks (Sandelowski, 2000). Notations made while listening to and reading the interviews became a set of special field notes (Hinds, Vogel, & Clarke-Steffen, 1997; Szabo & Strang, 1997). The original primary researcher reviewed the results from this study to validate results in the secondary analysis (Szabo & Strang, 1997).

Separate logs for the women's perceptions of barriers to and facilitators of adherence to ART in prison were created. It became apparent that the responses to questions related to changes the woman recommended for medication administration in prison were directly linked to barriers and facilitators; therefore, a third log outlining these suggestions was formed. Barriers were identified by reading each individual interview in its entirety, then rereading with a focus on answers to questions pertaining to problems with obtaining and taking medications in prison.

To describe the women's perceptions of the connection between relationships with health care providers and adherence, any mention of talking with a nurse or doctor was highlighted and noted in the log. It is important to note, however, that an inmate might say the word nurse, not allowing for the fact that many individuals who dispensed medications were medication technicians and were not trained or licensed nurses. Relationships with officers were discussed by the women in the interviews as a factor in successful medication administration. From personal experience in this prison setting, the authors knew that officers were instrumental in permitting inmates to move across the prison campus, including going to medication administration (med call). In some instances, an officer might also have to help with medication administration. For this reason, comments about the officers were included with other information on how relationships with health care providers affected adherence.

## Results

All of the women interviewed identified both barriers to and facilitators of adherence. Most spoke of a relationship with one or more prison health care providers or correctional officers. Although only 2 women mentioned the word privacy, much of what they said referred to privacy issues while incarcerated. The women's words were plain and often spoken with emphasis.

Many of the women in this study, whom the authors suspect were rarely asked for their opinions, explained or offered more information than was asked for. For example, as the

interviews were reviewed, it became clear that the women in the study had definite ideas about the medication line and how HIV medications were administered. Information about the medication line was not solicited, but it was volunteered in responses to questions about how the inmates received their medication. The women were interviewed separately and did not overhear each other's answers, yet common terms were used, suggesting the importance of this topic (Mason, 2002).

## Barriers to Adherence

The medication line, where DOT takes place, was perceived as a barrier to adherence. The medication line was described as a source of frustration because of long waits, a vehicle for stigma, and the means by which medical privacy was lost. Jane, a 41-year-old White woman on ART, this time for 6 months, called waiting in the line "a hassle." Women observed that the medication line was where other inmates and the officers made assumptions about a woman's HIV status based on her presence in the line and the number of medications she took. Dorothy, a 41-year-old African American woman who had been on ART for just 2 months, was the most vocal about the medication line. Dorothy noted how waiting, dealing with inmates breaking in line, and dealing with the stigma of taking large numbers of medications made adhering to ART difficult. She said, "You know, the inmates assume HIV if you take a lot of medicines. You could be a diabetic."

Those who did not have to obtain their ART medications from the medication line also had opinions about the line. Maria, a 22-year-old Hispanic woman on ART for 17 months, believed KOP afforded her an opportunity to be in control and avoid the line. When asked what to change about medication administration, Maria suggested that all women do KOP and "change the line." Kristie, a 38-year-old White woman who had been infected for 15 years and was using KOP, said waiting to receive the medication made it more difficult to receive and take the therapy. She preferred taking the medications herself with no waiting. Janet, a 42-year-old White woman who had been infected for 14 years and on ART for about 5 years, liked KOP because with DOT, she said, the person was not sure when she would get the medications.

Jane recognized the structure of DOT as helpful to ensure adherence, but said waiting was problematic. She described a situation in which she was waiting for an appointment and missed her medication call (med call). She had to wait for the next med call to get her medications. Jane wanted more personal control and less waiting for medications. Angela, a 45-year-old African American woman who had had HIV for 2 years, had started ART just 2 months before her interview. She liked KOP because it avoided the line and it let her take her medications herself. Barbara was a 39-year-old African American woman who had been infected for 4 years and was receiving ART by KOP. Barbara agreed with Angela's statements. "I like taking my medications myself, and I like there is no line." The majority of the complaints about the medication line were centered on long waits, with additional concerns about lost privacy and stigma by virtue of one's presence in the line. Fear of stigma was reflected when Dorothy talked about the line as an open assumption of a person's HIV status by other inmates and prison staff. Angela and Dorothy both commented on being treated "badly" when correctional officers and other inmates assumed they had HIV. Angela

also complained that the white bottle the medications came in indicated HIV to other inmates. She remarked, “Even the officers, the inmates, don’t understand about HIV, but the officers don’t treat you right, [they are] mean, because of HIV.” Janet described another barrier to adherence with ART in the prison setting: the logistics of movement in the prison and KOP and DOT. She clearly defined the issues as follows:

> I had a few problems. I had, I had surgery and it takes days to get your medicines. Go to lockup, you don’t get your medicine. Anytime they have to package up your property from your locker, there is a chance you won’t get your medicines. There is usually a delay in getting your medicines. If you get transferred from one camp to another camp, you might have a problem. Person gets locked down for a riot or a storm or anything, there is a possibility of problems with DOT. Sometimes there aren’t enough nurses to give out the meds. PRN replacement [refilling prescriptions] takes time, really a lot of time charts are lost.

Janet called for the prison health system “to be overhauled” to make adjustments for medication adherence if an inmate was in lockup (seclusion) or the facility was in lockdown (when movement on the campus is restricted). She was distressed by the lack of access to medications at the dispensing window during lockdown. Janet also said that medication administration was either delayed or omitted when an inmate was in lockup.

### Facilitators of Adherence

The women interviewed gave many examples of facilitators to ART adherence. The majority believed the routine in prison made obtaining and taking ART easier. Laura, a 34-year-old White woman who had been infected since 2003 and on ART 1 month, explained the advantages of the routine: “Taking my medicines between 9:30 and 10 o’clock every night [pause], the lights go out at 9:30 so I have my medicines out and I know it is time because the lights go out. It helps me remember to take my medicine.” Reliable refills and access to regular refills in prison were also noted as a facilitator for ART adherence. The med call helped remind inmates to take medications, and when thenurses, friends, or officers reminded a woman to take her medications, this was especially helpful.

A total of 7 of the women advocated KOP as the best way to encourage adherence. Being in control, having easier access, and not having to wait to take medications were examples given of how KOP facilitated ART adherence. Carmen, a 39-year-old Latina woman, had been infected for 15 years and received her medications by DOT, had a history of a stroke with residual memory problems, and spoke in a deliberate, monotonic manner. She gave one-word answers for the most part until asked what changes she would make in medication administration. Carmen clearly stated, “Giving them to myself.. Keep the medicines here.” This was not a realistic option for her, but her comments were echoed by the majority of those interviewed.

Two of the women reported DOT helpful in both obtaining and taking ART. Jackie, a 40-year-old African American woman, had had HIV since 1999 and had been on ART for 3 months with this incarceration. She took two medications independently, and one was administered by DOT. Jackie liked the routine medical visits and the opportunity to receive regular refills. She seemed surprised by the question regarding changes in the prison

medication system, “Well, wow! Well [pause] DOT [pause] I think it’s given in the right way. Some need to be watched, some don’t. I would not change.” She liked contact with the nurses as well as having some independence in her self-care. Lisa, a 34-year-old African American woman, had been infected since 2001 and on ART for 2 months. Lisa liked DOT because she got her medications on time and felt better. She talked about the benefits of having the nurse watch her take her medications and having the officers call her for med call. Dorothy saw benefits of both KOP and DOT. She said the following: Keeping my own medications makes you feel good, proud when you take your meds. You know what I’m saying? DOT is good too. To make sure you are taking them. Both keeping it and having DOT is good because you don’t want to keep all your meds.

The women also talked about less visible adherence facilitators, speaking of “a will to live.” Acknowledging the disease and learning more about their health made acceptance of ART easier. Jackie noted, “I understand how imperative it is to take your medicines. Not missing any and taking it more seriously as far as taking care of yourself.” Laura had similar sentiments saying, “I take care of my-self when I take my meds.” Adherence was better when the women took their health more seriously. Lisa thought the prison was doing a good job with her DOT administration because, with regular medication therapy, her health had improved. Maria expressed fear that her CD4+ T cell counts would drop and thought appointments once a month to evaluate CD4 and viral load values would be beneficial. For those who had been in denial and not taking ART, acceptance of their HIV status helped them be adherent to ART.

The majority of the women discussed how having fresh (unexpired) medications and access to refills (PRN slips) helped them acquire ART in prison. A total of 2 said that when they needed a refill, the nurse had already requested it for them and the new medications were waiting in the infirmary for them. A total of 9 of the women had not taken medications outside of prison; most did not elaborate on why, but liked staying “up to date” on the medications while incarcerated.

### Health Care Provider Relationships and Adherence

All of the women except Kristie mentioned their relationships with health care providers in prison.

Some relationships were barriers to and others were facilitators of adherence. Laura, Jackie, Maria, and Monique enjoyed talking with the chronic disease nurse and believed that this relationship supported their adherence. Carmen, Angela, Jackie, and Lisa believed that the nurses were reliable and facilitated distribution of medications. Carmen said she could talk with the nurse about side effects. Angela believed the nurses could be relied on and expedited the refill process. Jackie reported the chronic disease nurse to be approachable and said she helped solve problems related to medications. Lisa remarked that the nurses were patient and helpful with DOT and making sure she made med call.

However, Dorothy’s experience with the nurses was very different. She said the nurses did not listen and might talk about medications where others could hear them. Barbara did not like waiting for the nurses and thought the wait impeded adherence. Janet complained that

there were not enough nurses; they “can be hard-pressed,” and she believed this slowed down the distribution of medications. Janet’s experience with the nurses made her feel the nurses needed “more compassion,” and she wanted the nurses to treat inmates better— “treat you like you matter.” She said, “It hurts [being treated like you] don’t matter.” As previously stated, both nurses and medication technicians administered medications in this setting. None of the interviewed women distinguished between the two but referred to all providing medication as “nurses.” The specific title of “chronic disease nurse” mentioned by four of the women did indicate a nurse and not a medication technician.

The women had varying experiences with the doctors and prison officers. Carmen said the doctors were “no good.” Yet Dorothy said that “you can count on” the doctors. Jackie believed that the doctors helped make it easier to get ART. Talking about her doctor, Jackie said, “She’s real good, easy to relate with.” Being comfortable talking to the doctor helped Jackie, Maria, and Lisa adhere. Officers who “looked out for you” and reminded inmates of med call helped them take medications regularly. Jane said the officers could help or hinder medication adherence based on whether they helped an inmate get to the medication line. Lisa reported that the officers who let her know when it was medication time helped her adhere. It was important for health care providers (nurses, doctors, officers) to listen and help the women with acquisition of medications, in addition to listening and problem solving adherence issues.

### Medical Privacy and Adherence

A total of 7 of the participants had comments about privacy and ART. Monique, a 35-year-old African American woman diagnosed with HIV in 1996, said the privacy and independence of KOP made adherence possible for her. She mentioned several times that she was “loving giving it myself” and being responsible for herself. Monique explained that she had been in denial about her HIV status before coming to prison, but with psychiatric help she was feeling better about herself and enjoyed being in control of her health.

Maria liked the privacy of KOP. “Let the ladies keep their own medications.” Dorothy was again the most verbal about privacy. She liked KOP but believed KOP presented a potential for dormmates to learn of a woman’s status if they saw the woman with medications. Dorothy was offended when nurses talked in front of others in the medication line about the medications she was taking. Angela had issues with the bottle that medications were dispensed in, considering it a violation of her privacy if only HIV medications came in the white bottle. Jane wanted a separate place for HIV dispensing—but not for privacy reasons. She wanted more efficiency in dispensing and did not mention concern about a breach in confidentiality. Most women, however, wanted medications given in a manner that prevented others from learning their HIV status and the nature of their medications.

## Discussion

### Barriers to ART Adherence

The necessarily coercive nature of prison often requires medication lines that, while orderly, have little regard for efficiency or privacy. Inmates have little choice, because prisons have

set times for medication administration, and prisoners are called to the medication line by correctional officers to wait their turn (Spaulding et al., 2002). The medication line, with the frustration of waiting and the perceived visibility to others, was a major concern for the women in this study. Other authors have also reported that those who receive ART by DOT often complain of inconvenience, loss of privacy, and intrusiveness (Lucas, Flexner, & Moore, 2002; Santos, Adeyemi & Tenorio, 2006; White et al., 2006; Wohl et al., 2003). The women in this study, even those who did not receive ART via DOT, clearly saw the difficulties of depending on the system for timely medication administration. Based on comments by 9 of the 12 participants, having control over one's own medications afforded some small self-determination in the prison world where choice is neither an option nor a goal. However, 3 women saw value in DOT for ART administration, and 1 woman saw advantages in both KOP and DOT.

Some investigators have suggested that HIV-related stigma has decreased as treatment has progressed and HIV has become less of a death sentence and more chronic in nature (Lekas, Siegel, & Schrimshaw, 2006). However, according to the women in this study, stigma continues to be a concern and a barrier to adherence. Stigma indicates loss of value, dehumanization, or worthlessness to others (Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004). Many of these women faced multiple forms of stigma including incarceration, HIV infection, being a drug user, being homeless, and/or having a mental illness (Ware, Wyatt, & Tugenberg, 2006). Also, prisoners are seen as dirty or dangerous by others (Glaser & Greifinger, 1993). HIV and people with HIV continue to be feared by the public (Lekas et al., 2006). Being treated differently, less compassionately, and even "mean" was a result of DOT (being seen in the line more frequently or with large numbers of pills) and KOP (dormmates questioning number and type of medications). Stigma created a sense of loneliness and hopelessness associated with decreased adherence (Rintamaki et al., 2006; Sandelowski et al., 2004; Ware et al., 2006). These women suggested that limiting stigma through protecting HIV status from others was viewed as desirable, and it enhanced the ability to adhere.

Angela's perception that only HIV medications come in white bottles was interesting. In the authors' experience, rumors and gossip fuel false perceptions in the prison setting, and Angela offered a prime example, because white bottles were used for all medication, although her perception was that only HIV medications were dispensed in white bottles. True or not, this perception made her believe her status was open to any who saw the medication bottle. Stigma has been conceptualized as a dual process response—one in which the person reacts in both a conscious and unconscious manner (Pryor et al., 2004). The dual process response to HIV was manifested as an impulsive reaction to the HIV-infected person as well as deliberate actions. These dual responses are learned from the culture (Pryor et al., 2004). Data from the interviews illustrated the reflexive reaction (an assumption of having HIV based on number of medications and being in the line) and subsequent deliberate actions (attitude and poor treatment) against the HIV-infected woman in prison.

Prison policy resulted in a third major barrier for these women. The loss of access to medications during lockdowns and lockups, although usually temporary, disrupted adherence and served as another source of frustration. Security necessitated the close control

of inmate movement when storms or rioting occurred. An inmate who required lockup (often for violations such as fighting), could not have personal belongings while sequestered. Medications necessary for sustaining life (diabetes medications, for example) were not withheld in these situation, but were given as DOT for safety reasons (Blanco, Perez, & March, 2005; Spaulding et al., 2002). Janet's complaints about transfers had some validity. An inmate could be transferred to another prison with little or no warning. The woman's belongings were packaged and sent to the new prison where processing and inspecting could delay receipt of KOP medications and personal effects. Shortage of staff capable of administering ART presented another challenge for prison medication administration (Lucas et al., 2002). Although short-staffing issues were recognized, the women wanted access to their medications during lockdown as a means to continue therapy as prescribed. Additionally, DOT presented problems if the woman, while at another appointment, missed the med call. With little flexibility in medication administration times, a missed opportunity presented a problem of nonadherence for many.

## Facilitators of Adherence

The way to improve adherence, noted by most of the women, was KOP. The sense of pride and responsibility not only improved self-esteem but also gave the women a reason to adhere. White and colleagues (2006) had similar results; in their study, the majority of participants preferred KOP. For the women in this study, KOP avoided the "hassle" of the line and had the potential to be more private. Additionally, KOP offered a chance for self-determination in a setting in which inmates had little choice or control over their daily routine.

Before DOT is totally discounted, however, it should be noted that there was support for DOT by some women in this study. They believed DOT helped them by offering a routine and an opportunity to talk with a nurse. Clearly some people can benefit from DOT, whereas others can handle KOP effectively. The women who saw the benefits of both types of administration were advocating for individualized treatment plans.

Other facilitators of adherence were described as a concern for health, a desire to live, and evidence of improved health by increased CD4+ T cell counts. Several comments about access to refills and unexpired medications indicated that the supply of ART in prison was advantageous to adherence. The comments about having ready access and the fact that few (3 of the 12) took ART outside of prison suggested that access to medications on the outside was problematic. Jane, who was concerned with being first in line to get her ART, became emotional and cried when asked about taking ART when not in prison. She reported the "red tape" and referral from doctor to doctor difficult, "I lost my pride.. This disease is not easy." Thus, the structure of the prison can be a positive factor in adherence.

## Health Care Provider Relationships and Adherence

The women in this study emphasized the importance of a comfortable relationship with the health care provider while incarcerated. The chronic disease nurse, the physicians, and sympathetic officers provided support for taking ART. The ability to ask questions and believe that their concerns were heard improved the women's ability to take ART. Poor

relationships such as beliefs that the staff were uncaring or unsympathetic hindered taking ART. Several comments were made about nursing care as a barrier to adherence. However, the prison often employed medication technicians rather than licensed nurses, although most inmates did not distinguish them (all were referred to as nurses). The staff (nurses and technicians alike) were often overburdened and burned out in a system that was frequently under-staffed. Licensed nurses were usually placed in clinics, taking sick calls and tending those in the infirmary. Medication technicians tended to dispense ART at the medication window and often seemed rushed, emotionally distant, and even disrespectful or rude. This indicated a need for fully licensed staff with adequate numbers and education to provide professional care.

Individualized care and support for adherence from a physician have been reported to enhance ART adherence outside of prison (Beach, Keruly, & Moore, 2006; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). Similarly, when Young (2000) interviewed incarcerated women about general health care, she reported that the most positive experiences were related to being treated as an individual with caring and compassionate attention from the health care providers. The women with HIV in this study were no different. These studies suggest that individualized care and physician support could also enhance ART adherence among incarcerated women.

## Medical Privacy and Adherence

The majority of the women interviewed in this study expressed concern about the loss of medical privacy. This loss of privacy was painful and detrimental to adherence. White et al. (2006) have also noted the problems with DOT and the potential for loss of privacy to reduce adherence among inmates. Wohl et al. (2003) reported that loss of confidentiality made KOP the preferred ART administration method, especially when correction officers, privy to medical information, dispensed medications in the absence of medical staff.

Based on the comments by the women here, medical privacy is an important privilege. There is no legal provision for medical privacy in corrections settings in the United States; however, nurses could advocate for policy changes to protect the medical information of all inmates. Some of the measures used to protect medical information in the private sector could also work in prison. For example, discrete dispensing windows, an area for private counseling, and covered or shielded medication bottles are used in pharmacies, and these could also be used in prisons. Education of all staff, medical and correctional, to dispel myths and improve general knowledge and understanding would reduce stigma (Arriola et al., 2006). Education for medical staff would ensure adequate training to counsel HIV-infected people (Tugenberg, Li, Ware, & Wyatt, 2006). Counseling for the women in this study improved willingness to adhere to ART and created a sense of pride when they realized they were behaving in a manner that improved their health.

## Limitations

The use of secondary analysis in qualitative research has not been widely used in nursing research. The major limitation of this study was the inability to clarify or further question an inmate about her answers to initial interview questions. Listening and relistening to the tapes

was invaluable and offset some of the difficulties of not being present for the original interviews. Being able to use existing data rather than losing information was a substantial benefit to secondary analysis. Although the study was conducted in one prison, it was similar to other large prisons providing health care to HIV-infected female inmates in the United States.

## Conclusions

HIV-infected women who are incarcerated represent a growing population. The women in this study described both barriers to and facilitators of adherence to ART while incarcerated. The major factors influencing ART adherence were the medication line, stigma, the routine (regular administration times and access to medications), administration choice (DOT or KOP), a relationship with the health care provider, the policies in the prison, receiving education and counseling about the disease, and medical privacy. Interventions to improve adherence of incarcerated women should consider the key elements identified by this study: inmate input into the preferred medication administration method, protection of medical information for all inmates, methods to foster relationships between the inmate and health care providers, and education for both inmates and corrections staff aimed at reducing stigma.

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### Clinical Considerations

- Positive interactions with prison health care providers, including time for private conversations about medications, can help female inmates with HIV infection adhere to antiretroviral medication regimens.
- Individualized decisions as to administration method—keeping their own prescription or directly observed therapy—can improve adherence for HIV-infected female inmates.
- Education of prison staff, prison health care providers, and all inmates can reduce stigma, improve desire to protect health, and increase adherence behaviors.

**Table 1**

Demographics, HIV, and Antiretroviral History[a]

| Name | Age | Ethnicity | Time Since HIV Diagnosis | Time on ART | Length of Time in Prison | ART Method |
|---|---|---|---|---|---|---|
| Maria | 22 | Hispanic | 22 months | 17 months | 17 months | KOP |
| Lisa | 34 | African American | 4 years | 2 months | 2 months | DOT |
| Laura | 34 | White | 2 years | 1 month | 2 months | KOP |
| Monique | 35 | African American | 9 years | 1 year | 1 month | KOP |
| Kristie | 38 | White | 15 years | 4.5 years | 3 months | KOP |
| Carmen | 39 | Hispanic | 15 years | 15 years | 5 years | DOT |
| Barbara | 39 | African American | 4 years | 2. 5 years | 2 months | KOP |
| Jackie | 40 | African American | 13 years | 3 months | 3 months | KOP and DOT |
| Dorothy | 41 | African American | 4 years | 2 months | 4 months | KOP and DOT |
| Jane | 41 | White | 13 years | 2 years | 6 months | DOT |
| Janet | 42 | White | 13 years | 5 years | 3.5 years | KOP |
| Angela | 45 | African American | 2 years | 2 months | 6 months | KOP |

NOTE: ART 5 antiretroviral therapy, DOT 5 directly observed therapy, KOP 5 keep own prescription.

[a]None of the women had taken ART continuously except while incarcerated

**Table 2**

Brief Sample of Questions Used in Original Interviews

- **Do** you keep your medicines and take them yourself, go to the medication line and take your medicines in front of nurse/correctional officer, or both?
- **Do** you ever have difficulties getting medications in prison?
- **Are** there things that make it easier for you or help you get your medications in prison?
- **Are** there things that make it easier for you or help you take your medications in prison?
- **Is** there anyone in prison whom you rely on to help you take your HIV medications in prison? Please list for me ways that these people/this person helps you to take your HIV medications in prison.
- **Is** there anyone in prison who makes it difficult for you to take your HIV medications?