Interruption of Antiretroviral Therapy among Recently Incarcerated Men:

Cultural and Situational Factors

BY

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THESIS

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DEDICATION

To my parents, Bruce and Tami, whose devotion to learning and unconditional support for my education have carried me to each new shore - a student of the world.
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<table>
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<th>Description</th>
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<tr>
<td>ADAP</td>
<td>AIDS Drugs Assistance Program</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>CJS</td>
<td>Criminal justice system</td>
</tr>
<tr>
<td>CO</td>
<td>Correctional officer</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly active antiretroviral therapy</td>
</tr>
<tr>
<td>HCCN</td>
<td>HIV Community clinical network</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>INT</td>
<td>Interviewer</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>RES</td>
<td>Respondent</td>
</tr>
</tbody>
</table>

N.B. Each participant quotation is followed by a three-letter/number code randomly generated and assigned to that participant at enrollment for coding and analysis as well as the date and transcript page number for longer quotations. These codes, interview dates, and transcript pages have been included here to permit the reader to assess the breadth, depth, and representativeness of the viewpoints contained herein.
SUMMARY

About one in five men living with HIV in the U.S. passes through a correctional facility annually. Jails and prisons are seen therefore as key intervention sites to promote HIV treatment as prevention, and the National Institutes of Health has specifically funded “seek, test, treat, and retain” projects focused on correctional facilities. However, almost no research has examined inmate’s perspectives on HIV treatment or their strategies for retaining access to antiretroviral therapy (ART) during incarceration. This paper presents the results of a descriptive, cross-sectional study examining whether, how, and why HIV positive men access health services and adhere to ART as they enter and exit the criminal justice system. Data were obtained from qualitative, semi-structured interviews conducted with HIV positive men and male-to-female transgendered persons [n=42] recently released from male correctional facilities in Illinois, USA. Interviews focused on disclosure and taking ART while incarcerated. Over 60% of study participants reported missed doses or sustained treatment interruption (>2 weeks) because of incarceration. The leading causes of treatment interruption were failure to disclose their HIV status and delayed prescribing, followed by intermittent dosing, out-of-stock medications, confiscation of medications, and medication strikes. Interpersonal violence, a lack of safety, and perceived threats to privacy were frequently cited as barriers to one’s willingness and ability to access and adhere to treatment. Strategies for continuing treatment in jail/prison among those receiving ART when arrested included requesting an HIV test, timing disclosure, managing relations with correctional officers, enlisting family members, avoiding conflict with other inmates, faking mental illness, and hiding medication. Substantial improvements in ART access and adherence are likely to follow organizational changes that make incarcerated people feel safer, facilitate HIV status disclosure, and better protect the confidentiality of inmates.
SUMMARY (continued)

receiving ART. Jails and prisons perceived as unsafe are not conducive to the treatment of HIV because inmates often believe an HIV-positive status raises their chances of being subjected to violence. This more immediate concern overrides concern about HIV. For ART to be accepted by inmates, healthy choices also should appear to be reasonable choices.
I. ACCESSING ANTIRETROVIRAL THERAPY AFTER ARREST: BARRIERS AND STRATEGIES IDENTIFIED BY MEN LIVING WITH HIV

A. Introduction

This cross-sectional, descriptive study comprises in depth interviews conducted with HIV positive men and transgendered persons [n=42] recently released from correctional facilities in Illinois. The purpose of these interviews was to determine whether and how these men retained access to life-saving medical treatments as they migrated through the criminal justice system.

B. Background

Despite ground-breaking advances in HIV treatment and prevention, including the discovery that treating HIV positive adults with antiretroviral therapy (ART) can prevent transmission of HIV to their sexual partners (Cohen et al., 2011), the majority of adults living with HIV in the U.S. are not yet receiving the full benefits promised by these scientific advances. As shown in Figure 1, engagement in HIV care is a continuum. At one end is the 20% of the nearly 1.2 million Americans living with HIV who have not yet been diagnosed (CDC, 2011). At the other end is the estimated 28% of all persons living with HIV in the U.S. who are virally suppressed, that is, receiving the full physiologic benefits of combination drug therapy. In the middle are the quarter of those who have been diagnosed that delay entry into care and the nearly half (49%) of those diagnosed that are not retained in care. At present, there is solid evidence that treating HIV positive adults and keeping them in care could eventually halt the spread of HIV (Granich et al., 2010). It is more important than ever, therefore, to ensure strong, responsive, and client-centered health systems through which these interventions can be scaled-up to reach affected populations. Today, one of the most significant barriers standing between these achievements and the groups they are most likely to benefit is the lack of care continuity for men who become incarcerated.
Approximately 20% of all men living with HIV in the U.S. pass through a correctional facility each year (Spaulding et al., 2009a). Although incarceration can provide important opportunities for detection and treatment of HIV, many of these opportunities are missed (Duffus et al., 2009). As these men pass through jails and prisons, their healthcare access is disrupted and non-adherence to prescribed treatments often occurs, placing them at greater risk for disease progression and transmission. To increase the number of HIV-infected persons in the U.S. benefitting from treatment, correctional facilities should prioritize activities that link HIV positive men to care and keep them connected to care as they enter and exit correctional facilities. Indeed, unprecedented resources are currently being directed at efforts to find and treat HIV among incarcerated populations (NIH, 2010).

**Figure 1.** Engagement in HIV Care

I have argued elsewhere that the passage of HIV positive men through the criminal justice system represents a series of strategic opportunities to initiate and establish a process of care (Culbert, 2011). Keeping HIV positive men connected to care as they traverse the criminal justice system requires us to organize and deliver health services that are congruent with men’s
perceived health needs and expectations. This study fills a significant gap in the scientific literature by describing what makes health services accessible and acceptable to HIV positive men who find themselves in trouble with the law.

C. Methods

1. Setting

Funded through a grant from Sigma Theta Tau Nursing Honor Society, this project was conducted at six community clinics located in Chicago communities with the highest HIV prevalence rates and greatest concentration of returning ex-offenders (IDPH, 2011, LaVigne & Mamalian, 2003). These particular settings were chosen based on participant observation carried out over a two-year period as part of the author’s doctoral training in public health nursing. Located in underserved neighborhoods, five of these clinics were operated by the University of Illinois at Chicago, HIV Community Clinic Network (HCCN), located in the field stations of the (UIC) Community Outreach Intervention Projects. The sixth clinic was operated by the Ruth M. Rothstein CORE Center, a Corrections Continuity Clinic that provides HIV primary care to men and women leaving Cook County Jail, the Illinois Department of Corrections, and the Federal Bureau of Prisons.

2. Conceptual Framework

The conceptual framework for this study is strongly influenced by the theoretical and methodological traditions of symbolic interactionism and ethnography. These approaches to the study of human behavior are premised upon the fundamental assumption that humans create personal and shared meanings through social interaction and that these meanings influence how they think and act (Mead, 1934; Whorf, 1941). For humans, meaning is causal. Moreover, distinct communities are assumed over time to develop their own unique patterns of thinking and
behaving or cultures (Handwerker. 2009). The task of ethnography is to represent the perspective of the group member who is an insider to this culture (Geertz, 1974, Spradley, 1979).

This study uses a qualitative and naturalistic approach that borrows heavily from the methodological traditions of ethnography. Since the beginning of the AIDS epidemic, ethnography has been valued for “its exploratory and descriptive capabilities to enlighten emergent trends and explain phenomena within the natural social context” (Weibel, 1996, p. 187). Ethnographic methods are also considered indispensable for elucidating the diverse social connections between prisons and communities (Wacquant, 2002). Building on principles of cross-cultural communication and techniques of ethnographic interviewing (Spradley, 1979; Heyl, 2001), the researcher used flexible and open-ended questions and encouraged informants to talk about the facets of their experiences that they found most relevant and meaningful.

3. Recruitment Strategy

The researcher used purposive sampling to generate a sample that would include men with diverse kinds of criminal justice system (CJS) involvement. With purposive sampling, the researcher deliberately selects units to include in a sample (Shadish, Cook & Campbell, 2002, p. 511). The ‘power’ or logic of purposive sampling lies in “the quality of the information that is gathered from each sampling unit” (Sandelowski, 1995, p. 179). Samples should be large enough to support claims of theoretical saturation but small enough that a detailed analysis of the data is reasonably permitted (Sandelowski, 1995). The sample size for this study was well within the recommended sampling range for ethnographic studies (Sandelowski, 1995, p. 182).

Sampling decisions were driven by the researcher’s interest in showing the depth, breadth, and intensity of the cultural knowledge possessed by informants. The researcher collaborated with nurses, physicians, social workers, and case managers at each of the sites to
identify men who had reported recent CJS involvement. Clinicians then introduced the study to these men individually during their routine clinic visits. In addition, the study was introduced to groups that met weekly for counseling, and palm cards with information about the study were distributed to case managers at the field stations. To make the study more inclusive of men who were not yet firmly established in community-based HIV care, the researcher collaborated with a corrections case manager to introduce the study to men who were returning to the community from prison.

The researcher also attempted to recruit men who had a history of CJS involvement but may not have disclosed this to their providers. Because each clinic was only open one day a week, the researcher was available at each of the sites during normal clinic hours to introduce the study to patients. Any patient coming into the clinic was able to learn about the study and be interviewed if he was eligible and gave informed consent (Appendix A). Each person who responded to the recruitment materials was offered the chance to participate. Nearly a quarter of the participants [n=10] were recruited directly from the Ruth M. Rothstein Core Center. The remaining participants [n=32] were recruited from HCCN clinics.

4. Participant Population

Like other major urban centers in the U.S., Chicago is disproportionately affected by HIV and incarceration. The HIV prevalence rate for Chicago (756.5/100,000) is about three times the national average (276.5/100,000). In 2010, 20,391 people were known to be living with HIV infection in Chicago (CDPH, 2011), of whom almost 80% of these were men. In the same year, Chicago (Cook County) received over half (54%) of all male prison parolees released in the State of Illinois (IDOC, 2010). Most of these men returned to community areas of Chicago with elevated rates of HIV and other measures of social inequality (LaVigne & Mamalian, 2003).
Men sampled for this study \[n = 42\] included a cross section of HIV positive men leaving jails and prisons and returning to the Chicago metropolitan area. Table 1 shows characteristics of men in the sample. Men were eligible to participate if they were 18 years of age or older, self-reported a previous HIV diagnosis, self-reported significant criminal justice system involvement in the last three (3) years, spoke English, and were willing to discuss their experiences with a researcher in a voice recorded interview.

Men were between the ages of 19 and 55 years (mean = 38 years), and most identified as Black or African American. About one in five men never completed high school, while nearly a quarter finished at least some college. More than 60% of men identified their sexual orientation as ‘straight’. About 40% of men identified their sexual orientation as gay, bisexual, or transgender.

The sample included men from each major transmission risk category including men who had sex with men, men whose only risk factor was heterosexual sexual contact, men who were exposed through injection drug use, one man who was infected perinatally, and another who was infected through a blood transfusion. More than a third of men in the sample received their initial HIV diagnosis in a correctional facility. The average age at diagnosis was 27.8 years (range: birth-47 years). Men in the sample had been living with HIV for 10 years on average.

Table 1. Descriptive statistics for recently incarcerated men living with HIV \[n = 42\]

<table>
<thead>
<tr>
<th>Measure and variable</th>
<th>N</th>
<th>Mean (SD)</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>42</td>
<td>38.5 (10.7)</td>
<td>19</td>
<td>55</td>
</tr>
<tr>
<td>Years living with HIV</td>
<td></td>
<td>10.6 (7.1)</td>
<td>1</td>
<td>27</td>
</tr>
<tr>
<td>Age at diagnosis (years)</td>
<td></td>
<td>27.8 (8.7)</td>
<td>0</td>
<td>47</td>
</tr>
</tbody>
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Table 1. Descriptive statistics for recently incarcerated men living with HIV (continued)

<table>
<thead>
<tr>
<th>Measure and variable</th>
<th>N</th>
<th>(%)</th>
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</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>37</td>
<td>88%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Biracial</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Education(^1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;HS</td>
<td>9</td>
<td>21%</td>
</tr>
<tr>
<td>HS</td>
<td>16</td>
<td>37%</td>
</tr>
<tr>
<td>Some College</td>
<td>10</td>
<td>24%</td>
</tr>
<tr>
<td>Gender/Sexual orientation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Straight</td>
<td>26</td>
<td>62%</td>
</tr>
<tr>
<td>Gay</td>
<td>8</td>
<td>19%</td>
</tr>
<tr>
<td>Bisexual</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>Transgender</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>AIDS diagnosis(^1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>38%</td>
</tr>
<tr>
<td>No</td>
<td>21</td>
<td>50%</td>
</tr>
<tr>
<td>Mode of Infection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>15</td>
<td>36%</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>21</td>
<td>50%</td>
</tr>
<tr>
<td>Injection drug use</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>Mother-to-child</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>History of gang affiliation(^1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>31%</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>54%</td>
</tr>
<tr>
<td>Diagnosed in a correctional facility(^2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>38%</td>
</tr>
<tr>
<td>No</td>
<td>25</td>
<td>59%</td>
</tr>
<tr>
<td>Initiated antiretroviral therapy (ART) in jail or prison(^2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18</td>
<td>43%</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>55%</td>
</tr>
<tr>
<td>Missed doses of HIV medication during any incarceration(^1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27</td>
<td>64%</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>16%</td>
</tr>
<tr>
<td>Not applicable</td>
<td>5</td>
<td>12%</td>
</tr>
</tbody>
</table>

\(^1\) Missing data: Education (16%), AIDS (11%), Gang affiliation (14%), Missed doses (7%). \(^2\) < 2% data missing.
5. **Interviews and Analysis**

The researcher conducted semi-structured interviews with participants in private rooms located at the community clinics and hospital where participants were recruited. Following Spradley (1979), the researcher used techniques of ethnographic interviewing to encourage participants to respond using the particular words, concepts, and frames of reference that they used, to experience, interpret and shape social reality. Every participant completed at least one face-to-face interview. The researcher continued sampling and interviewing subjects until he reached data saturation, that is, until topical and thematic redundancy had been achieved. After preliminary analysis, the researcher conducted follow-up interviews with 19 participants, some by phone, to clarify information that was shared during the first interview and to gather additional information about the participant’s background. All face-to-face interviews were digitally recorded. Results are based on more than 33 hours of tape-recorded interviews, each interview averaging 42 minutes.

The interview guide (Appendix B) was developed based on prior fieldwork, a review of the existing literature, and through collaboration with academic researchers. An expert informant with extensive personal and professional connections to the topics and target populations provided critical input that was used to further refine the interview guide. All interviews were transcribed completely by the researcher. The researcher completed a contact summary after each interview, transcribed the digital recordings, and maintained fieldnotes. In vivo and topical codes were applied to each interview transcript during initial transcription (Lofland et al., 2006). During a second round of coding, thematic codes were applied. Third round coding consisted of further refining of thematic codes and composing analytic memos regarding topics, themes, or other patterns that emerged from the interviews.
6. **Protection of Human Subjects**

All research sites used a common study protocol that was approved by an Institutional Review Board (IRB) at the University of Illinois at Chicago and the Cook County Bureau of Health Services (Appendix C). To protect participant confidentiality, the Department of Health and Human Services (DHHS) issued a Certificate of Confidentiality (Appendix D). To further protect the privacy of participants, the researcher collected all identifying information outside the audio-recorded interviews. The interviews were deleted from recording devices after being downloaded to prevent the data from being compromised or lost in the field. All identifying information was expunged from the transcripts. Audio-recorded interviews and transcripts were encrypted and stored on a password protected laptop computer. Each participant was assigned a unique random three-letter code at enrollment. The master code sheet was kept on the same computer and secured with an encrypted password. Data were regularly backed-up on a portable hard drive that was locked with the consent forms in a file cabinet inside the researcher’s office.

D. **Results**

1. **HIV Testing & Diagnosis**

   Approximately one fifth of all persons living with HIV in the U.S. are unaware that they are infected with HIV (CDC, 2011). For these men and women, HIV testing represents a critical and necessary step in accessing treatment. HIV testing in jails and prisons has been shown to be both feasible and acceptable to inmates (Beckwith et al., 2007). For men who were not reached by HIV testing services in the community, prisons and jails may represent their gateway to HIV primary care.

   More than a third (38%) of the men in the sample \([n=16]\) were diagnosed with HIV in a correctional facility. Half of these diagnoses \([n=8]\) were made since 2001, suggesting that for the
45% of men in the sample who were diagnosed during that last decade, prisons and jails remained integral to their entry into care. Men who were diagnosed in prison or jail were only slightly older than men who were diagnosed in the community (mean = 39.5 years and 37.7 years, respectively). Neither was the mean age at diagnosis very different for men who were diagnosed in a correctional facility (28.8 years, SD = 7.8) compared to men who received their initial diagnosis in the community (27.2 years, SD = 9.4). There were some noteworthy differences between men who were diagnosed in correctional facilities and those who were diagnosed in the community. Not surprisingly, men who were first diagnosed in a correctional facility usually had spent the most time behind bars. Half of the men who were diagnosed in a correctional facility [n = 8] had been incarcerated for at least ten years of their life. A quarter [n=4] had spent at least 20 years behind bars.

Among men with less than a high school education, twice as many were diagnosed in prison or jail (66.7%) compared to the community (33.3%). Conversely, among men who reported completing at least some college, only 30% were diagnosed in a correctional facility. Of the men whose only known HIV transmission risk factor was male-to-male sexual contact (MSM), only 21% was diagnosed in a correctional facility, compared to 57% of men whose only reported transmission risk factor was heterosexual contact. Similarly, nearly half (46%) of self-identified ‘straight’ men in the sample were tested and diagnosed in a correctional facility, compared to roughly a quarter of men who identified as gay, bisexual, or transgender. This finding is consistent with the results of other studies showing that correctional facilities are important case identification sites for men whose only identifiable risk factor is heterosexual contact (Sabin, Frey, Horsley, & Greby, 2011).
Of the men who reported affiliation with a gang or street organization, almost half (46%) had received their initial HIV diagnosis in a correctional facility, compared to less than a third (30%) of men who said they had never belonged to a gang. Men who reported receiving an AIDS diagnosis in their lifetime [n=16] were less likely to have been diagnosed in a correctional facility (37%) than in the community (62%), suggesting that correctional facilities may have played an important role in timely diagnosis and treatment for some of these men.

A majority of the men who were diagnosed in a correctional facility said that they had not routinely participated in HIV testing outside of a prison or jail. Some men said they got their first HIV test in jail or prison. Community-based HIV testing and counseling services had failed to connect with these men. Some of the men who were diagnosed in a prison or jail characterized their participation in corrections-based HIV testing as passive or coerced. Although HIV testing had marked a turning point in their entry into care, some men said they were not fully aware that they were being tested for HIV.

_They tested me. I don’t know if it was for HIV. They didn’t say. But they done a lot of stuff to me. So it must have been…it might have been...They get all the inmates to line up._

_‘This is where you got to go. This what you got to do today.’ Took us downstairs. [NBP: 4/18/11, p. 9]_

Some men said that they had requested an HIV test in prison or jail because they became gradually aware of their HIV risk while they were incarcerated. One participant said that a conversation he had with his female sexual partner while he was incarcerated led him to seek HIV testing.

_Yeah, my ex-wife...she was coming to see me in Cook County Jail and I had noticed a knot on her neck. And she went and got...And I told her...I asked her what was the knot._
She went and got tested. And told me that it was HIV. That made me go and get tested.

[APW: 9/13/11, p. 7]

Another participant talked about coming to terms with his HIV risk after learning that his sexual partner died from complications of HIV infection.

The last time I was in (prison), I called home one day and my mother told me the girl I was seeing died. And I’m like, ‘Died?’ And she says, ‘Yeah. Yeah. She had AIDS.’ And I said, ‘What?’ She looked normal. She didn’t look like she was sick or nothing. She lost a lot of weight. And I was like, ‘What’s going on?’ And she told me she had cancer. She lied to me. But then my brother was dating her sister at the time. That’s how they…that’s how he found out. And he told me. He says, ‘Go get yourself tested.’ [844: 4/27/11, p. 1]

Men were sometimes motivated to participate in HIV testing because they were beginning a new and significant relationship.

I didn’t get tested until nineteen ninety-five. I was incarcerated and I was getting ready to get married so I said, ‘Well, I was gonna get all these tests done.’ I wasn’t even thinking about it. [U8P: 8/8/11, p. 4]

Men who were confined to stifling cells twenty-three hours a day generally took advantage of any opportunity for movement. Some men said they had participated in HIV testing just to get out of their cell.

[Int.] What made you decide to get tested that day?

[Res.] Shit, ‘cause I ain’t never been tested for it. I just said, ‘Fuck it.’ Plus we was on lockdown. I was fixing to get out of my cell. [APW: 8/22/11, p. 1]
A participant who had recently screened positive in the community but failed to disclose his HIV status at intake was similarly seeking some relief from the conditions of his confinement when he asked for an HIV test.

_I chose to ask for an HIV test. I was bored. And I said, ‘I ain’t getting no movement. So I’m gonna ask for an HIV test to get some movement._ [ABK: 12/14/11, p. 5]

For at least some men, having access to information about symptoms of HIV infection played a role in realizing that they might be acutely infected and seeking an HIV test.

_And for some reason I had picked up this HIV/AIDS pamphlet. And it was saying something about night sweats. Like if you are going to sleep and waking up sweaty then it’s a possibility that you can be HIV positive. So when I saw that, I tried to get a test, ‘cause I had these for eight…nine days already. So I’m like, ‘Let me get a test and see what’s going on._ [FHG: 8/29/22, p. 3]

Very few of the participants who were diagnosed in a correctional facility said they had received the kind of client-centered post-test counseling that is considered the standard of care in the community. Rather, men felt that their attempts to learn about their diagnosis were rebuffed and that healthcare providers had been aloof and skeptical.

_He (the physician) just told me that my test came back positive. He asked, ‘Are you familiar with HIV?’ I said, ‘Yeah. I seen it on commercials.’ Then he said, ‘How long you known you been positive for HIV?’ I told him ‘I didn’t know I was positive for HIV.’ He just looked at me and gave me a prescription paper and told me I can go._ [EVA: 9/7/11, p.1]

Like men who are diagnosed in the community, men who received an HIV diagnosis in prison or jail often responded with shock and dismay. The grief that men experienced was compounded by
their relative isolation and the perception that they could not talk about their diagnosis with anyone. Drug withdrawal, uncertainty about the disposition of their legal case, and loss of meaningful contact with family members added to men’s suffering and sense of hopelessness after getting an initial HIV diagnosis. To some men, an HIV diagnosis given in prison or jail felt like an additional punishment placed upon them. Besides the sadness and anger that some men expressed after an HIV diagnosis, some men discussed having thoughts of suicide and planning to harm themselves.

_It just made me very depressed. I just like shut down. I didn’t want to deal with it. At that time in my life I was like, ‘Well fuck, my life is over. I might as well just kill myself. I just wanted to die. I really didn’t give a shit about life anymore. I was like, ‘Well, fuck it.’ If I figure out a way to kill myself, I’m gonna._ [844: 4/27/11, p. 2-3]

Two men said they had attempted suicide after they were diagnosed. A participant who was diagnosed in a state facility midway through an eighteen-year sentence talked about eroded gang ties and suicidal intentions as he returned to the general inmate population after his diagnosis.

_You know how you can lay there and get some rank in your gang. Well, I was Vice Lord. I was Ebony Vice Lord. At that time, I didn’t want to be nothing. I had talked about killing myself. I remember when I had went down to Shawnee and I was locked up in segregation. I had tried to hang myself. If my cellie hadn’t been there at the time I had tried to do it, it would have been all over for me._ [WDN: 5/16/11, p. 4]

HIV testing guidelines published by the Centers for Disease Control (CDC) recommend screening all inmates for HIV unless the inmate declines (opt-out screening) and do away with the requirement to provide HIV prevention counseling (CDC, 2009). Although these policies are aimed at boosting detection rates and improving access to clinical care, they deprive men of
important opportunities for risk reduction counseling and may contribute to eroding men’s autonomy. HIV testing without prevention counseling misses a crucial opportunity to help men recognize HIV risk behaviors, and could be viewed by men as part of the coercive apparatus of the institution.

2. Disclosure

As HIV positive men enter the criminal justice system, they must decide whether to disclose their HIV diagnosis or conceal it from healthcare workers. Men generally recognized that in order to receive prompt medical attention and access antiretroviral therapy (ART), they needed to disclose their HIV diagnosis. Most correctional facilities offer at least a brief medical screening as part of their procedures for intake and processing. Many men chose this time to disclose their HIV status and identify their health needs. However, some men reject this opportunity, choosing instead to conceal their diagnosis from custodial and healthcare staff. In this section, I will examine whether, how, and why men disclosed their HIV diagnosis while they were incarcerated.

About half the men in the sample [n=20] said they had notified a nurse, physician, phlebotomist, or correctional officer of their HIV related health needs shortly after their arrest or transfer. (Another four men had not been rearrested since learning that they were HIV positive and so were not included in this portion of the analysis.) These men felt strongly that disclosure was an important initial step in accessing ART. These men viewed disclosure as straightforward and necessary and said they were able to disclose without compromising their confidentiality. “If you go in there and tell ‘em you have HIV, they keep it under the table…the staff. And they provide your medicine” [TPB], said one participant. Another participant explained, “I told them I have HIV. I told the police and everybody” [WDN]. Other participants affirmed matter-of-
factly, “I told the doctor, I'm HIV positive’. So it's not like I went in to hide my condition” and
“I just told them I was HIV positive...that I needed to see a nurse immediately.” Some men,
however, said that healthcare providers treated their disclosure with skepticism. “They did the
blood work to see if I was actually telling the truth” [BHR], said one participant. Explaining how
he had to prove his HIV diagnosis, another participant stated,

They wanted me to see a doctor in order to be given the medication because quote,
unquote, so many people come in saying they have a medical condition or HIV or AIDS
when they really don’t...which they assume will help them get on disability. So I let them
know I had nothing to lie about and I gave them the information to the clinic I was
actually going through. [4BH: 9/6/11, p. 1]

Most often, men disclosed because they wanted to access antiretroviral therapy and avoid
treatment interruption. One participant explained, “I wanted my med’s and I couldn’t get them
without letting them know” [T2Q]. A participant who disclosed his HIV status to correctional
officers after being transferred to prison said, “I didn’t have a choice at the time. Because they
was trying to take my medication when I got there” [AAQ].

Men agreed that it had been important to remember the names of the HIV medications
that they were taking prior to arrest. Not being able to recall their regimen sometimes led to
delays in prescribing. “All you got to do is remember the medicine that you take. And I always
try to remember. I always keep a paper in my pocket” [TPB]. Men who disclosed immediately
after arrest tended to be older (mean age = 41.9 years) than men who said they had concealed
their diagnosis at some point in the past (mean = 34.8 years) and were generally older when they
were diagnosed with HIV (mean age at diagnosis = 30.5, versus 23.9). Men who had completed
at least some college and men who said that they were infected through injection drug use were also more likely to report that they had disclosed during intake and processing than not.

Other men handled disclosure more passively, believing that healthcare providers at the jail or prison were already aware of the HIV status from a prior incarceration and that they didn’t need to tell anyone in order to get medical attention. One participant explained, “I didn’t disclose at that time. But (the physician) knew I was there. Because he sent for me, as always, and just did a random check-up…it was already on file” [JK5].

3. Non-Disclosure

Roughly forty percent of the men in the sample [n = 18] said that they had deliberately withheld their diagnosis from healthcare providers at some point while they were incarcerated. About two thirds of these men [n =12] were taking ART prior to their last arrest. Some waited days or weeks before sharing their diagnosis with a custodial or healthcare staff worker. Others chose not to disclose their diagnosis at all. Men who did not disclose were not remarkably different from men who did disclose in terms of education, gender identity, gang affiliation, or whether the participant was diagnosed in prison or jail. However, taking ART prior to arrest did seem to be an important motivational factor in disclosure. Only one of the seven participants who were not taking ART prior to their last arrest disclosed his HIV status at intake.

Of the men who initially concealed their diagnosis, almost half [n = 8] said that they eventually disclosed their HIV status to a healthcare worker. Some of these men disclosed only after being transferred to an infirmary or mental health unit. Some men waited to disclose until their case had been adjudicated and it became clear that they were going to be transferred to a downstate prison. “I didn’t share it with nobody until I got shipped to Stateville” [TXE], said one participant. Another said, “I just told ‘em, ‘No’. Because I didn’t think I would be there that
long to be processed and sent to another jail” [BGB]. Other times, men opened up only after developing trust and rapport with a particular healthcare worker. One participant, who began to suspect that he might be infected, struggled to find a caring person in the prison to open up to.

But then one of the nurses, she’s like, ‘Is there something wrong with you?’ She was really nice and stuff. I said, ‘Well, I don’t really know how to say it. Yeah. There is something wrong with me.’ And finally she says, ‘Well, do you want to see a psychologist?’ And I went in there and I didn’t feel comfortable with the guy so I didn’t say nothing. But I got to know the nurse a little better and then finally she was coming... ’cause they lock you up...you’re locked up 23 hours a day...coming down the tier and...I got to know her a little bit. And then finally I said, ‘I think I’m HIV positive.’ And she says, ‘Well, why didn’t you tell us when you first got here?’ you know. ‘Cause I was actually there for almost a month before I told anybody. [844: 4/27/11, p. 2]

Others disclosed only after their health deteriorated. Opportunistic illness was often the impetus for men disclosing their HIV status and seeking medical attention. One participant stated, “I didn’t inform them about my health problems or nothing...I was in perfect health until ninety-nine, until my neck swelled up. I sat in the hospital or about a week until the swelling went down. Then they gave me (HIV) medication” [KDD]. Shame and lack of acceptance contributed to some men’s decision not to disclose. When these men disclosed, they sometimes did so indirectly by requesting an HIV test. Explaining why he waited to disclose until he was hospitalized with symptoms of opportunistic infection, another participant stated, I was ashamed. I didn’t want to accept it. I always kept it to myself. ‘No way’, I used to tell all the health people. Because I knew my body was deteriorating. And I actually
called the paramedics and told them I was dying. That’s when I started to care for myself. I wanted to live. [U7Q: 7/13/11, p. 5-6]

A desire to manage physical appearance, control body weight, and avoid muscle-wasting conditions motivated some men to seek HIV treatment during incarceration. Maintaining body weight may be especially important in prison where men with lower body mass index may be more likely to be sexually victimized. A study of HIV transmission among male inmates in the Georgia Department of Corrections (GDC) found that having a body mass index (BMI) less than or equal to 25.5kg/m² was one of only four covariates significantly associated with HIV seroconversion in prison (CDC, 2006). One participant who waited for almost a year after his sentencing to disclose his HIV status said that symptoms of disease progression, including difficulty swallowing, motivated him to disclose.

Because I got sick. What happened was I got sick about that time. I lost a lot of weight. My mouth...even my tonsils turned snow white. I opened my mouth and it was just like a snowball back there. I went and looked in the mirror, and I was having bad reactions. So I went over to the doctor. And that’s when I told him about my HIV. [QGV: 10/31/11, p. 13-14]

A few men [n=5] resisted disclosing altogether. These men were usually incarcerated for shorter periods of time, but some waited as long as two years before revealing their HIV-related health needs to a correctional healthcare provider. Some feared that if they disclosed they might be isolated, “I don’t want to be isolated in no room over here...with all these people in the infirmary that got HIV or AIDS” [4BH]. Other worried that revealing their HIV status could lead to the wrong kind of attention, “In the County I was thirty days, and I was trying to be as isolated as possible” [FHG]. These men felt that the costs associated with loss of privacy and
confidentiality outweighed the potential health risks involved in treatment interruption. “I took my chances with my health” [HFD], said one gay man. Explaining why some men hide their HIV diagnosis during intake, another participant summarized a sentiment that was widely shared by men in the sample.

So many times while people are incarcerated they don’t want to divulge that information. They don’t want to disclose that information. Primarily because of the way information travels through that system. Because of the stigma that still lingers over HIV, they don’t want to readily disclose that information. Especially in that kind of setting...the incarceration setting. [E5B: 11/11/11, p. 1]

A participant who concealed his diagnosis throughout multiple arrests and transfers explains why he rejected opportunities to disclose his HIV status and seek medical attention.

When I go in there I avoid the health issues with them because it’s so...it’s not enough confidentiality...Because you tryin’...you want to be accepted, and you wanna have people to associate with when you are in jail. So you tend not to tell nobody. Especially if you look healthy. They don’t assume anything. That’s the way you leave it. You just leave it that way. [HFD, 4/27/11, p. 5]

Disclosure was often just the first step in getting timely and appropriate HIV primary care. After intake and processing, men usually were transferred immediately to a tier or cell unit where they sometimes languished for days and weeks, waiting to be seen by a physician before their medications could be prescribed.

4. Getting Medical Attention

Men perceived a number of situational and institutional barriers to getting medical attention in correctional facilities. Perceived barriers to accessing health services included
intense physical isolation, interpersonal violence, procedures for controlling violence, a
correctional officer’s apathy or unwillingness, and fees for health services. Some men felt that
even if they did have urgent health problems, they might not get prompt medical attention. Many
participants perceived the inaccessibility of health services as a more pressing problem than lack
of privacy and confidentiality. One participant talked about what he had to do to get medical
attention in the county jail.

>You had to put in grievances to see the doctor. It was specific times you could see them.
>Like from seven in the morning to three in the afternoon. And no one would be on call
>after that. A couple of times I got sick in the middle of the night. So I had to stay in my
>cell until the next morning. And then if I wasn’t on sick call...and there wasn’t no way for
>me to sign up for sick call in the County. You had to wait and tell the officer that you
>were sick. So now you have to wait for the paramedics to come. And if it really wasn’t an
>emergency, they wouldn’t come. You literally had to...really had to pass out for a nurse
to come see you. [TS9: 10/5/11, p. 1]

Participants agreed that correctional officers had significantly mediated their access to health
services, describing some correctional officers as helpful, supportive, and caring, and others as
inert and abusive. Because of this, men felt that they had to carefully manage relations with
correctional officers (CO’s). Managing relations with CO’s involved knowing the chain of
command, getting close to certain officers and calling them by name, and being careful not to
provoke guards with repeated requests for care. Said one participant, “You got to bug ‘em. The
doctor told me to bug ‘em. But you don’t want to take it too far, ‘cause they’ll beat your ass”
[PV3]. One participant talked about how he tried to get medical attention when he developed
symptoms of cryptococcal meningitis, a life-threatening opportunistic infection associated with HIV infection.

I was sick but I wasn’t taking my medicine. I was sick and would tell the officer to tell the nurse. I had a couple of guys, couple of inmates, they was trying to tell the doctor...well, tell the officer. See you have to go through the officer to get any kind of medical treatment. So some officers will say, ‘You faking it. You not sick.’ But my cellie, he knew I was sick, ‘cause I wasn’t eating and I wasn’t coming out. I was just constantly in bed. And for them to really get me some medical attention, I literally passed out in the day room. [TS9: 10/5/11, p. 3-4]

Minimal interaction with healthcare providers added to men’s sense of vulnerability and contributed to delayed medical attention. The perceived inaccessibility and poor quality of medical care was one of the foremost concerns of men who were diagnosed in a correctional facility. One participant shared his reaction to being diagnosed in prison.

The thing that scared me the most about finding out that I was HIV positive wasn’t the fact that I couldn’t deal with knowing. It was the fact that I was locked up and wondering will I receive adequate health care in here or am I just going to have to figure out a way to care for myself. [74U: 9/22/11, p. 1]

Another participant said that physical isolation and limited means of communication contributed to his sense of insecurity after being diagnosed with HIV.

Now at night made me nervous, ‘cause all you got is your intercom button. But see, they can’t hear the intercom button on the outside. Your intercom button only goes to the front desk that’s outside the pod. If they’re in another pod, they won’t hear it ‘till they do their round. Say for instance you got one pod and you’re feeling bad, and you’re locked in a
cell. He probably won’t come back to your pod for twenty minutes. It makes you nervous when you can’t get proper assistance if you need it. [FHG: 8/29/11, p. 5]

One man who had been living with HIV for nearly 27 years at the time of the interview explained what he had to do to get medication.

*I went through a lot of red tape getting my medication for at least two weeks. I went two weeks without getting my medication. So excuse the way I’m saying...I bitched and went off on them about it. And I said, ‘Do you know that after being without medication for so long that you body will not have...will not take effect to it. It will not want to acknowledge the medicine no more.* [4BH: 9/6/11, p. 1]

Another institutional barrier to care were co-pays for doctor visits. Men said that they had spent as much as half their monthly disposable income on each visit. One participant said that fees for health services had discouraged him from seeking medical attention.

*They give you ‘State pay’ as they call it. The average guy down there gets ten dollars a month. That’s really for you to buy your soap, deodorant, maybe a little food or something...but mostly for your hygiene. But if you’re a sick guy and say you go to sick call two times that month, your ten dollars gone if you don’t have nobody on the outside taking care of you...They won’t deny you (medical care). They’ll let you go. But you always owe. If your people send you money, they’ll take their five dollars out. But they’re gonna get their five dollars. I had a toothache for about two weeks. That was hard for about two weeks until I broke down and paid the five dollars to get my tooth pulled.* [TS9: 10/5/11, p. 15-16]

One participant that had recently been hospitalized with an acute illness in the community and suspected he might have HIV, talked about his attempts to initiate further testing.
So I started filling out these medical request forms. And I assumed that they would answer my request form because I’m letting them know that there’s a possibility from what the doctor had told me that I might have leukemia. So it took them about two months to reply to the request. So when they replied to the request they replied that there was nothing they could do about it. So I filled out another request and told them that I wanted to be tested for HIV. [74U: 9/22/11, p. 1]

When filling out request slips did not achieve the desired effect, patients tried other ways to communicate their needs. Some men reluctantly recruited family members to intervene on their behalf while they were locked up. One participant who went without HIV medication for two weeks after being locked up in a county jail described how he enlisted family members to help while deflecting their questions.

I finally got in touch with my brother out in Arizona. ‘Cause I didn’t...I really didn’t want to call him. And I told him to call the girl I was staying with and have her get in touch with my doctor. And my brother’s like, ‘What about?’ I said, ‘She will know. Just tell her to take care of it.’ [844: 4/27/11, p. 8]

Although some men felt that health services in prisons and jails were generally more accessible that health services in the community, they believed those services were intended primarily for inmates with apparent injuries or life-threatening emergencies. One participant observed, “What do you have to do to get medical attention when you’re in there? Be busted up. Busted head. Nose bleeding” [T2F]. Another participant reflected, “They’re not really concerned about your medical history unless you’re falling out on the floor or something like that, or having seizures” [TNF]. Men said that correctional officers and healthcare workers were unlikely to respond to HIV infection as an urgent medical problem. Men were aware that disclosing an HIV diagnosis
did not automatically qualify them for expedited medical attention. Because of this perception, some men felt that they had to undertake extraordinary measures, threatening legal action, “I advised them that I am going to speak to a lawyer about this, ‘cause I’m being denied treatment” [TNF], claiming a more serious diagnosis, faking mental illness, or refusing HIV medication in order to get medical attention.

Not all men agreed that disclosure was the quickest route to medical care. HIV positive men who perceived their medical needs as especially urgent, for example, men who were infected with a drug-resistant strain of HIV, were sometimes more likely to say they had pursued other strategies for getting medical attention. Rather than disclose their HIV status during intake and processing, these men disclosed other medical conditions that they expected would trigger their transfer to an infirmary or medical unit – a key access point for utilizing health services and a place that men generally perceived as safer, cleaner, and more conducive to disclosure and treatment. One participant explained why he decided to reveal a potentially life-threatening coagulopathy in order to secure access to the infirmary.

If I had told them that I was HIV positive, they would have put me out in population, in a regular prison ward. But they say a blood clot is more serious than HIV. Because if I get bruised or injured, I might bleed to death. And then it’d be on their hands. The only reason I got medicine was because I was in the infirmary. And by me being in the infirmary, they had to give me my medication. So that’s what kept me safe really. Because population in the County you had to fight just about every day or get everything taken away from you. And by me not being in the gang, by me not being in no organization, I would have been getting jumped on, fighting every day. And if I would have been getting into a fight, a major fight, and I would have got cut, it would have been hard or me to
stop bleeding. That's why they put me in the infirmary. But other than that...just being HIV positive, they would have put me in population. Because they really don’t care about people with HIV. They say you just another human being. Go on out there and do what you need to do. [LVW: 4/25/11, p. 4]

To get medical attention for their HIV disease, a few men [n=3] said they had faked or exaggerated symptoms of mental illness. Believing that complaints of psychiatric illness could lead to priority housing and more timely and efficient interventions, these men said that they had claimed a psychiatric diagnosis or magnified symptoms of mental illness in order to achieve the kinds of interactions with healthcare providers that were likely to get them the medical attention they felt they needed. Importantly, these men said that they had already been unsuccessful in their attempts to get treatment for their HIV by simply disclosing their HIV diagnosis. They expected to be able to negotiate healthcare access more effectively if they came across as riskier or more vulnerable to correctional officers, nurses, and physicians. One man said he had claimed to experience psychoses and threatened suicide in order to get treatment for HIV infection.

So the fifth day came and I asked for my medication. They said, ‘Well, you don’t have any medication. The doctor hasn’t issued it yet.’ They said, ‘We don’t have nothing with your name on it. I said, ‘Okay.’ I said, ‘I’m gonna commit suicide.’ They said, ‘Are you sure?’ I said, ‘I’m bipolar. I’m seeing dead people anyway.’ I said, ‘They’re telling me to hang myself.’ So they started watching me. They took me to the psych ward. They asked me if I was on medication. I said, ‘Yeah’, I was on lithium. So lithium is supposed to be in your system. So when they took my lab, they said, ‘You’re not on lithium.’ They said, ‘Why did you say you were on lithium?’ I said, ‘Because I tried to explain it to them in receiving but wasn’t nobody listening to me.’ So I said, ‘If I have to play another game to get my
medication, that is what I’m gonna do.’ I said, ‘Each time I come into jail and you people don’t give me my (HIV) medication, y’all gonna have me on a mental ward until you take my lab work and see what medicine is in my body. [4BH: 9/6/11, p. 7]

Not all men viewed their claims of mental illness as chicanery. Because men experienced jails and prisons as places that induce altered mental states and because mental illness in jails and prisons was generally seen as unexceptional, men did not express embarrassment or shame when they discussed their attempts to circumvent the system by exaggerating symptoms of mental illness. Rather, men’s descriptions of these strategies suggest that they viewed mental health as circumstantial. Men agreed that they had been fighting for their survival, and that they did what they had to do in those situations.

Men’s deceptive behaviors were also shaped by their concrete experiences of being denied health services in the community. Some men who faked mental illness in jail or prison said that they also had used community-based mental health services to gain temporary relief when substance abuse and homelessness had made life unbearable. One young man talked about being turned away from a community hospital when he presented with signs of a life-threatening opportunistic illness days after being discharged from prison.

*When I got out (of prison) I couldn’t eat. I couldn’t do nothing. I had to literally take myself to the hospital. I went to (a hospital). They turned me around. And I went to (another hospital) and they treated me. But it’s so messed up. I think medical care is so messed up for guys like us. If you have no medical card...because I was dehydrated. They had to put me on a water bag and all that stuff. Then they tried to discharge me. I know the mental health like the back of my hand. Yeah, I use it to my benefit at times, but I hear voices. I really do need mental health. But at the same time, I know how to use it to my
ability if I really need the help. ‘Cause there were plenty of times that I was on crack cocaine and I put myself into mental hospitals ‘cause I was tired of staying on the street. But I was hearing voices due to the drug abuse, and seeing things. I was hearing voices since I was young. It would be the voice of my mom or an evil voice calling my name. So they tried to discharge me. So I told ‘em, ‘If you let me go, I’m going to kill myself. ‘Cause I’m dying anyway.’ [U7Q: 7/13/11, p. 1-2]

Besides men who said that they had exaggerated claims of mental illness to get medical attention, nearly a quarter of the men in the sample said they had been diagnosed with an actual major psychiatric illness and were taking psychiatric medication in addition to their HIV medicine. These men did not feel that their mental illness had helped them leverage health resources while they were incarcerated. Neither did men with a history of mental illness seem any more likely to have successfully avoided treatment interruption. More often, mental illness including mood disorders, depression, and substance abuse disorders interfered with their ability to influence providers to address their health needs.

Some bids for medical attention involved taking health risks. Some men found themselves in situations where they felt the only way to get medical attention was to show guards and nurses that they were willing to risk harming themselves to get the care they felt they needed. Two participants described refusing HIV medication and going on a medication strike because they believed they were receiving inadequate medical care. Both accounts suggest that some men are willing to risk their health when other means to negotiate healthcare access have failed. One participant talked about refusing his medications because he could not tolerate the side effects and his physician was unwilling to switch him to a different medication.
Being in prison, they don’t want to change your medication. If you go to ‘em and tell ‘em, ‘Look, I’m having problems with this medication. All these pills is stressing me out, giving me nausea and diarrhea.’ They act like they don’t want to change it. You have to go through a lot to get it changed. It got so bad that I just stopped taking my medication. And my t-cell count dropped all the way to thirty-one. And my viral load was up real high. And they started telling me I got to take my medication. And I got to the point, I said, ‘I can’t take my medication.’ The only way they changed me over was because my t-cell count had got so low. And they said, ‘If we change you to Atripla, will you take it?’ I said, ‘Yeah. That’s what I want.’ And so they said, ‘Okay. We gonna give you Atripla.’ And they changed it. That was the only way they changed it. [U8P: 8/8/11, p. 3]

Another participant talked about refusing HIV medicine after he was assaulted by correctional officers and subsequently denied evaluation or treatment for his injuries.

I wasn’t getting medical attention for my assault so I went on a medication strike and a hunger strike. And I told them, ‘I’m not taking no medication. I’m not eating until I get medical attention...I gave them the medication the first day. And I told them, ‘I ain’t taking no medication no more.’ And they said, ‘Why?’ And I told them why. And they went and they documented it down in my file. Because they was failing to document my complaints. They did not want to document them down. [ABK: 12/14/11, p. 13-14]

Men’s attempts to have their injuries evaluated, treated, and documented were continuous with their efforts to preserve their dignity and personhood. Requesting medical attention was one way that men found to resist attacks on their autonomy. Becoming a patient while in jail or prison was seen as a way of establishing an alternate identity that conferred certain rights and privileges.

“I’m an inmate. But if I’m in a medical ward...anybody in a medical dorm is a patient. You’re a
patient first” [ECC]. Though men attached special importance to their status as patients and seemingly went to great lengths to secure access to medical care while they were incarcerated, more than a few said they had delayed HIV treatment in the community, sometimes to the extent of repressing awareness of symptomatic infection.

5. Delaying Treatment in the Community Before Incarceration

Some men talked about postponing medical treatment, ignoring symptoms, and delaying entry into care before they became incarcerated. These men believed incarceration catalyzed their health-seeking behaviors. One recently diagnosed participant reflected, “And I believe too, in a way, that me going to jail was a way to get introduced back into being healthy and checking up on myself” [T2F]. Some men readily admitted to ignoring acute health problems, missing medical appointments, or failing to follow-up with healthcare providers in the community for routine medical care. Some of these men said they had needed emergency care or hospitalization shortly after their arrest. One participant said that he put off seeking medical attention for symptoms of a facial infection that he knew could be life threatening until after he was arrested.

[INT] So how long before you got locked up were you having these symptoms?

[RES] I’d say about...about a month before.

[INT] Did you go see a doctor that month?

[RES] Prior to that? No. Because I was out running the street. I was out trying to make money and, you know, I felt...I figured, ‘Hey, I’m not going to get locked up. So if it gets worse, I’ll just run over to the hospital, sit down, they can keep me a few days, pump some antibiotics, and I’ll be fine.

[INT] So this is a condition that you had before?
Yeah, I’ve had this before on my leg...where they had to...this one that was here on my leg was so bad...my whole calf had swollen, and they actually had to go in there and dig it out to the bone.

So you kind of knew what was happening to you?

I knew what was happening. [JK5: 10/12/11, p. 6]

Although this participant admitted postponing treatment in the community, he sought medical attention soon after his last arrest, saying that his face became so painfully swollen that he could not eat or talk before he received appropriate medical treatment. Participants said that life circumstances interfered with their ability to access care in the community. “When you don’t have money. And it’s tight. No bus fare. Yeah, it (medical care) was difficult to keep up with” [YHS]. Men said they had to relearn how to access care in the community. Some of the clinics that had served these men had been shut down while they were incarcerated. “I used to go to the county hospital. They closed down. I wouldn’t even know which way to go” [QGV], said one participant. Another concluded that it was easier to get medical care in prison than in the community. “It’s more complicated out here (in the community) than it is in there (in prison)” [QGV]. Poverty and unemployment interfered with medical care and also led some men to commit criminal acts, such as forgery, that caused them to be sent back to prison.

6. Initiating HIV Treatment in a Correctional Facility

The decision to begin treatment for HIV infection is an important one with life-long consequences. Though many factors influence the decision when to start, in the U.S., antiretroviral therapy is usually indicated in patients whose CD4 lymphocytes are measured at 350 cells/mm³ or fewer (DHHS, 2012). Overall, more than 40% of men in the sample initiated antiretroviral therapy in a correctional facility. Among the men who were diagnosed in a
correctional facility, 81% initiated antiretroviral therapy in a correctional facility, suggesting that many of these men already met the criteria for initiation of treatment. Initiating ART in a correctional facility was more common among men who had not completed high school (77.8%) than among men who had finished high school (50%) or some college (20%). Only 20% of MSM started taking HIV medicine in a correctional facility compared to 66% of men who said they had been infected with HIV through heterosexual contact. Likewise, among men who initiated ART in a correctional facility, 77% identified their sexual orientation as straight. For these men, incarceration was their gateway to HIV treatment. However, these men also said they had to overcome numerous obstacles in order to adhere to a daily pill-taking regimen, manage side effects, and protect their privacy in a jail or prison.

Men described a number of barriers to starting medication in a correctional facility. Many of these obstacles were related to their perceptions of stigma and violence among inmates and their beliefs about the inadequacy of health services. Several participants said that taking medicine in a prison or jail made them feel vulnerable and insecure. Men were concerned about managing side effects and maintaining their privacy while quartered closely with other inmates. Some hesitated to start treatment, believing that HIV medicine could reduce their mental alertness, making them less vigilant and more susceptible to exploitation.

You’re in there with murderers, killers, and rapists. There’s so many people doing different things, in different frames of mind. And I was like, I don’t know if I want to be on this medication. Does it make you drowsy or sleepy? Or where you’re not focused on your environment? And I was skeptical what it does. Does it make you sleep? I really didn’t want to sleep. I mean you’re around people that don’t care about hurting you.
They could hurt you. They might come in your cell and do something to you while you’re asleep because your door is open. [AAQ: 11/17/11, p. 12]

Initiating treatment for HIV brought men in closer contact with the correctional health services. Some men valued the opportunity for more frequent interaction with healthcare providers. “I said, ‘I’ll start treatment’ ‘Cause in [jail], it was hard to see a nurse. So if the nurse come and bring your medication, I could always tell her my medical problems when she come up” [ABK].

However, not all men agreed that closer contact with correctional medicine was a good thing. Some men felt that initiating treatment could expose them to the hazards of substandard healthcare. One man said that doctors in prison are not real doctors, but physicians that are subject to disciplinary measures or practicing under a restricted license. One participant described a previous experience with a medication error and expressed his concern that initiating treatment for HIV infection in a prison meant that he might be given the wrong medication again.

They really don’t care what type of medicine they give you. They don’t care. If they gave you the wrong medicine and you died in the cell, they don’t care. The nurses got attitudes. If you piss them off, they will do anything to you. They will just throw a bag of medication through the door just to set you off. [EVA: 9/7/11, p. 6]

Men often said that they felt disengaged from important choices about their treatment. Because treatment decisions in prison were sometimes made without explanation, men were left to supply the reasons. Some men felt that information about medications, their indications, precautions, and side effects was withheld in order to reinforce submission. Others said that they were subjected to unorthodox and suboptimal regimens while they were incarcerated. Two men used the word ‘experimentation’ to describe their clinical care in prison. One participant explained the
rationale for a treatment decision that he believed had caused bone marrow suppression and nearly cost him his life.

And she (the physician) said, ‘Ok. I’m gonna switch your medicine.’ She figured that my t-cell count was high. I’m gonna tell you what (the physician) was really doing...trying to save money at my expense. That’s what they was doing. They was giving me generic med’s. The med’s I take now, one bottle costs over a thousand dollars. That’s what I think they were doing. Trying to save money. [T2Q: 6/30/11, p. 16-17]

The belief that treatment decisions in prison were not guided by the patient’s best interest hardened after men were released and their community providers changed them to another medication, explaining to them that the medication they had been taking prison was harmful. Men said they had wanted more interaction with healthcare providers in prison so that they could fully understand their choices. Since correctional officers usually accompanied men to clinic visits, some men felt that officers were eavesdropping on their conversations with healthcare providers and that their interactions with healthcare providers were cut short.

For many participants, their foremost concern when initiating antiretroviral therapy in prison was the fear that taking HIV medication would result in loss of confidentiality and expose them to humiliation, threats, and loss of supportive relationships. A participant who had already been taking medicine for hypertension talked about his decision to initiate HIV treatment in a prison almost 11 years after he was diagnosed.

It was scary because that was my secret. I didn’t want it to get out. As long as this nurse keep coming to my door every morning, I can play it off that it’s my blood pressure. But then this guys working the hallway, he seen what kind of medication she was giving me. So that really got scary. And in prison, you don’t want nobody to know you got the
After making a calculated decision to start treatment, men next had to overcome barriers to taking the medication the way it was prescribed.

7. Taking HIV Medication

The treatment of HIV in U.S correctional facilities has improved greatly over the past decade because of advances in HIV treatment, progress in correctional health policy, and advocacy for prisoners living with HIV. AIDS-related deaths in prisons have fallen dramatically since the introduction of highly active anti-retroviral therapy (HAART). In the U.S., the number of male inmates who died from AIDS-related causes has declined rapidly in recent years (Maruschak, 2009). In 2002, 9.1% of all deaths in State prison were AIDS-related. By 2007, only 3.5% of all deaths in State prison were related to AIDS. For some men, prison provides a structured setting that contributes to improved medication adherence (Roberson, White, & Fogel, 2009; Whol et al., 2003) and slowing disease progression (Springer et al., 2004). For others, arrest and detention can interrupt treatment, and expose them to substandard healthcare, infectious diseases, and environmental stressors.

A majority of the men in the sample (80%) were taking HIV medication during their last incarceration. Compared to men who were not taking medication, men who took medication tended to be older and had been living with HIV longer. Those who did not take HIV medication during their last incarceration had either not yet begun treatment or refused treatment. Although men said it had been beneficial to take HIV medicine in a correctional facility, they agreed that the experience did not necessarily improve their access to other health services, and sometimes made them feel powerless and dehumanized. One participant said, “Got my med’s like you would...
feed a dog. You know? Just, ‘Here!’ ‘Here they are!’ No interaction with the doctor about the medication. None of that” [3XR]. Another participant stated, “I saw them take the med’s and just throw them. See when you at a county jail, they figure you ain’t even human. They feel like you ain’t a man or nothing. So they don’t treat you that way” [PV3]. Men often complained that HIV medication was dispensed with little regard for patient privacy. “Everybody knew what medicine she [the nurse] was giving you anyway. There was no privacy to that at all. She was doing it right in front of everybody” [TNF]. Men did not feel any less exposed when healthcare providers used discrete packaging. “People know you have HIV, because they give you medicine in a brown paper bag” [HFD]. The lack of privacy that men experienced while taking their medication was a major reason that men did not disclose their HIV status or stopped taking their HIV medication.

Institutional inefficiencies were also to blame for treatment interruption. Although nearly all of the men who asked for ART during their last incarceration eventually received treatment, prescribing was often delayed, medications were sometimes out-of-stock, and some men received their doses intermittently. Almost a quarter of the men in the sample [n=10] said they had experienced delayed prescribing of their HIV medicine after they were arrested or transferred to another facility. Three participants said they missed doses because medication was not in supply or had been misplaced during transfer. One participant explained, “I think I had to wait a whole month. Because they kept telling me pharmacy didn’t get it yet. Pharmacy didn’t have it yet” [QFW]. Another participant described the supply chain problem that led to his treatment interruption. “They had to get in contact with my doctors so they could have my med’s shipped down there” [TXE]. A few men who had medication delivered to their cell each day by a nurse reported intermittent dosing. Intermittent dosing is arguably more dangerous that taking
no medicine since it provides he virus with opportunities to become resistant to the medications. One participant stated, “If they do bring you the medicine, they’ll bring it to you one day, then miss three days, then bring it, then miss some days, and then bring it. They bring it off and on” [QFW]. Men sometimes had no choice about when to take their medication. At least one participant who was supposed to take his medicine before he went to sleep in order to minimize neurologic side effects was given his medication in the morning when the nurse delivered medicine to all the inmates. Other facets of the institution impinged on men’s adherence and readiness to accept treatment. One participant was so demoralized by his physical isolation that he developed acute depression and stopped taking his HIV medication.

Division Ten is strictly behind doors. So you’re only out for three hours a day. And that wasn’t what I signed up for. I was getting so depressed that... that was one reason why I didn’t take my medication too. Because I was behind that door. I was like, ‘Man, forget it. I ain’t fixin’ to take the medicine. I ain’t fixin’ to do nothing. [TS9: 10/5/11, p. 24]

These men agreed that accessing ART was just the first step in a more complicated process of taking HIV medicine discretely behind bars. In order to protect their confidentiality and take HIV medicine the way it was prescribed, men had to manage side effects, hide medication, and nurture rapport with healthcare workers. Men who were unsuccessful usually quit treatment.

Managing relationships with cellmates or ‘cellies’ was a major source of concern for men who were taking HIV medicine in jail or prison. HIV positive men were mistrustful of cellies and viewed them suspiciously and as a source of stress. Men were particularly concerned that a cellmate might look through their personal items and discover that they were HIV positive.
The medication was kind of hard for me to take because I was sharing a cell no bigger than this room with someone. You constantly have someone in your business trying to figure out what it is you’re taking it and why you’re taking it. [3XR: 8/17/11, p. 1]

Another participant talked about the difficulty he experienced taking HIV medicine in front of his cellie and how he protected his privacy.

It’s harder to deal with it, because you’re enclosed. They give you your medication so you gotta take it in front of your cellie. And they ask you, ‘What’s that?’ And you wanna get it. And that’s when I shut them down. I… I completely throw a wall up. I tell them I got Parkinson’s disease, ‘cause I shake. That’s as far is it goes. They don’t ask no questions. I work out. I don’t do nothing. I don’t ask for nothing. We eat. Simple as that. [KDD: 5/5/11, p. 3]

Men typically saw cellies as the person most likely to breach their confidentiality, exposing them to insults, threats, and the scorn of the rest of the inmate population. In order to take their medicine the way it was prescribed, men would distract and lie to cellmates. One participant describes the ‘shell game’.

I would take my pillbox and put my little doses in this little envelope. I would take the envelope and stick it under my pillow so that when I would wake up in the middle of the night knowing he was asleep...I would take it right on out, pop my pills, drink my water and hide the rest of ‘em. But that’s what I mean by ‘shell game’. More or less just hiding them...hiding what was going on with me. [3XR: 8/17/11, p. 6]

For one man, the fear that his cellmate might find out he was taking HIV medicine was so great that he decided to stop his treatment altogether.
I ended up getting placed in a cell with this one person. He was alright. Didn't have any problems with him. But I got scared. I didn’t want to take my medicine. I came off my Atripla for almost two and a half months. I was shit-scared as to being off the medicine. I was shit-scared of being in a cell with this person. I was just scared of being back in population. [74U: 9/22/11, p. 5]

Nurses sometimes coached HIV positive inmates on the best ways to ward off prying questions from other inmates.

I asked the nurse, ‘If people ask me what I’m taking medicine for, what do you think I should say?’ She asked me a couple of questions like, ‘How’d you catch it?’ I’m like, ‘I caught it from birth.’ And she said, ‘Well, if I was you, I would just tell those who do ask and you get cool with that you have a lymphoma. I asked her to explain that to me a little more. She explained it to me and that’s what I told them. [TXE: 5/17/11, p. 5]

Hiding medication from other inmates was common among men who chose to take HIV medication while they were incarcerated. Some men expressed the concern that other inmates might steal their medication in order to sell it; “They fucking be trying to trying to sell your medicine” [APW], use it recreationally, or as pre-exposure prophylaxis.

I’ve seen a guy…he was on med’s. His cellie went into the cell and wanted to get high. He took the man’s last dose. Oh, they’ll steal any medicine. They’ll take the medicine and mix it with hooch. Just to make the hooch stronger. That’s how they roll. [74U: 9/22/11, p. 26]

This fear of theft meant that some men preferred to take their medicine in a pill line while others felt that they had to closely monitor HIV medications that were kept in their cell.
In some of the correctional facilities, people see you with medication, they’re figuring that it’s something that they can take that might make them...have them feeling good. Because a lot of guys that was getting medication there was selling it and not taking the medication that was prescribed for them. And I’m talking...this was real strong stuff. They was selling the stuff. And I was scared to leave the medication in there and somebody go through my stuff and find it. [AAQ: 11/17/11, p. 11]

HIV medication needs to be taken every day. An HIV treatment regimen may consist of two or three pills that have to be taken twice daily. Men who kept HIV medicine in their cells or in their personal locked box were often handling large amount of medication that was difficult to conceal. One participant said he was able to get a work assignment within the prison that afforded him more discrete access to the prison dispensary.

I could pick up my med’s whenever I wanted. I didn’t have to stand in no line to do it. So basically I had more privacy than other people. I would sneak them back to the dorm when they were out in the yard. Then I’d go and put it in my box. When I was ready to take it...I would take it out like an hour before when I seen it was a good advantage. And I kept it all together instead of having to go through each jar. That way nobody heard me rattling the things, wondering why I’m taking so much med’s. [5DM: 7/14/11, p. 1-2]

While some men worried that taking HIV medicine could threaten their privacy, others worried that not doing so could result in additional sanctions. Four men talked about compulsory treatment of HIV. These men said that they believed that would be placed in solitary confinement if they did not take their HIV medication. One man, who twice experienced treatment interruptions after transferring to another facility, talked about his perception that he could be placed in segregation if he did not take his medication.
If you got med’s and the nurse come and you’re not in the med line you get an eight-hour lockdown. You have to stay in your cell for eight hours, which is actually one day. ‘Cause the times they let you out...they let you out four different times a day but they average up to eight hours. [FHG: 8/29/11, p. 4]

These men saw HIV treatment as part of the coercive apparatus of prisons and an additional layer of social control and punishment. Others, however, saw advantages to compulsory treatment. And you can actually go to segregation for not taking it, you know. That was like a good thing, I guess...you could say. [TXE]. Because some men found it difficult to take HIV medicine in jail or prison, they could justify compulsory treatment as a reasonable way for the institution to guarantee access. However, punishing men for not taking their medicine did not do away with other threats to men’s treatment continuity.

8. **Retaining Access to Health Services**

As men migrate through the criminal justice system, they contend with ongoing threats to the continuity of treatment. Several of these have been the focus of discussion thus far including non-disclosure, delayed prescribing, out-of-stock medications, intermittent dosing, medication strike and theft of medications. Besides these, men described three other threats to treatment continuity: medication confiscation, no discharge medications, and failure to renew a prescription while participating in a work release program or while under house arrest. In this section, I will briefly discuss each of these scenarios described by men that had threatened to interrupt or actually interrupted their HIV treatment.

a. **Medication Confiscation**

Four men reported that they had experienced a treatment interruption because a correctional officer had seized their medications. The medications that were confiscated from
three of these men had been prescribed and issued to them by a correctional healthcare provider. Two men had their jail-issued medications seized when they transferred from Cook County Jail to the Northern Receiving Center (NRC) for Illinois, Stateville Penitentiary. One man had medications seized that he brought with him when he turned himself in at Cook County Jail. Although men recognized that any medication could potentially be contraband in a prison or jail and that inspecting medication was important for safety, men had difficulty explaining away confiscation of prison-issued medications as simple inefficiencies in the system. Men felt that correctional officers had ignored information that could have prevented treatment interruption. In at least one instance, the confiscation of HIV medication was believed to be deliberately punitive and pre-meditated. When a participant was extradited from California by plane, escorted by two U.S. air marshals who were tasked with dispensing his medication to him en route, he did not expect to have his HIV medications taken away from him for four days when he got to the County Jail.

_I came from the airport with my medication. The federal marshals brought me to the jail._

_I was like, ‘Those are my med’s, man. I gotta have them. Y’all see my file. Here go all my paperwork. My log.’ I had my own medical file, the one I sent them. I always carry it with me. They was like, ‘We don’t care. You got to see the doctor.’ I said, ‘Man you see the doses right there.’ The marshal even told ‘em, ‘There’s the doses. I’ve been giving them to him.’ They was like, ‘We don’t care. We ain’t giving it to him. We can’t administer them to him.’ And I’m looking at the nurse that sees people when they first come in intake at the County Jail...they didn’t come over and do anything. I was like, ‘Come here. Can I speak to you?’ ‘No. Wait ‘till I see you.’ I was like, ‘Aw, man I got to deal with this.’ So I wait._ [ECC: 8/24/11, p. 1-2]
Men whose medications were seized said they were left with few choices. Behind bars, men can either refuse food or refuse housing. When men did attempt to resist the conditions of their treatment and confinement by refusing to eat or return to their cells, healthcare workers were sometimes recruited to mollify men.

*When they finally processed me, they took me upstairs where they put you if you have tuberculosis. What we call ‘segregated’. And they feed you through a chuck hole. I’m like, ‘Man, this is how they do people? Where I’m from in California, you don’t get isolated. You HIV positive, as long as you can make your med call, you’re good. It’s not a stigma. You don’t have open sores, you don’t have to be in a medical facility. I was like, ‘Oh man, this is what I was afraid of.’ So I cried. I prayed and I cried. And it was cold up there, man. It was cold. Cold food. I didn’t eat for three days ’cause the food was cold. They fed me through a chuck hole. I was like, ‘Man, what the…’ Just the stigma this has…this illness got. So when they finally did come let me out for a shower, I was like, ‘Man, I’m not going back in. Fuck y’all! I’m not going back in. Call the Sergeant or somebody. Fuck you! ’Cause I know this is unethical. I know this is unethical for you! You took an oath, man!’ She was like, ‘You need to talk to an officer.’ I’m like, ‘What?’* Then this one older nurse came and she sat with me. She said, *Please go back in your cell. Please don’t make this hard on the rest of ‘em. I know what it’s like up there.’ I said, ‘No you don’t. You’re not in that cell with no contact…no nothing…dark all day. She said, ‘Please go back in the cell. Don’t make this hard.’ And I looked at everybody else in there, they standing in their window. I was like, ‘Alright’. I went back. She said, ‘I promise you somebody will be up here and we’ll move you.’ So I waited the next day nobody came.* [ECC: 8/24/11, p. 1-2]
The punishments alleged by this participant including segregation from other inmates, denial of medicine for HIV infection, and insufficient protection against the cold may have infringed his Eighth Amendment rights under the U.S. Constitution and also violated international human rights standards and treaties for the treatment of prisoners (Lines, 2008). The participant’s biological vulnerability (i.e. HIV infection) was arguably exploited to render ‘penal harm’ or injury and suffering that went beyond mere deprivation of liberty (Vaughn & Smith, 1999). If true, instances of deliberate indifference to the medical needs of an inmate represent the gravest threats to establishing and maintaining a process of care for HIV positive inmates.

b. **Discharge Medications**

The risk of treatment interruption looms for men who have recently been discharged from a correctional facility. Although taking HIV medicine at the time of release has been associated with retention in care (Harzke, Ross, & Scott, 2006), poor rates of medication uptake in the post-release period have been documented (Baillargeon et al., 2009) as well as concomitant loss of virologic control (Springer et al., 2004, Stephenson et al., 2005). Accessing HIV treatment in the community means applying for benefits, making appointments, and arranging transportation. Despite numerous legal precedents that make clear the intention to hold states responsible for comprehensive discharge planning (Mellow & Greifinger, 2008), men agreed that post-release planning had been woefully inadequate and generally felt unprepared to access care in the community. Several men had achieved undetectable viral loads in prison and wanted to remain undetectable. For these men, losing access to medication after release was a paramount concern. “Shit…I’ll run out of med’s. ADAP won’t pay for ‘em no more. That’s my biggest concern” [APW].
The effects of incarceration on men’s health seeking behaviors are most evident in the post-release period. Even patients who were committed to making certain adjustments to remain in care did not seem to grasp the many steps involved in accessing care before their supply of discharge medications would be exhausted. The men leaving prisons who were interviewed for this study were sometimes given a 30-day supply of medication. Some were given a 90-day supply. At least two men got no medication on the day of their release, and experienced immediate cessation of treatment. One participant who went off medication for two weeks after he was released explains what happened when he got to the prison gate on the day of his release.

*When we got to the gate there was no med’s there. I didn’t have no bag, no nothing. I asked them, ‘Is there any med’s up here for me?’ They’re like, ‘No.’ And IDOC, they real lazy about a lot of stuff they do. It ain’t like they was gonna go back and call healthcare. They just wanted to get us out of there. And that’s what happened. No med’s. Come on, let’s go.* [EQM: 8/29/11, p. 11]

Some men said that it became harder to access medical treatment after release. Although most men had an appointment scheduled for them at a community clinic after discharge, men reported a number of barriers to keeping that first appointment. Some men were unable to attend their first clinic visit because they could not arrange transportation. Healthcare providers had turned one man away because his insurance information could not be verified. Most men had not met with their case manager prior to their first clinic visit. So the first clinic visit was spent completing benefit application forms that were needed to pay for medical care and medications.

After release, many men were receiving medication through the AIDS Drugs Assistance Program (ADAP), a federally funded program that provides ‘last-resort’ medication insurance coverage to adults living with HIV. The ADAP application process was not being initiated while
the men were still in prison. Men were not aware of any attempts to verify their eligibility for programs before they left prison. Although some of these men had been locked away in an Illinois correctional facility for more than a decade, they had to show proof that they were Illinois residents before they could receive coverage. Further, the client applying for ADAP needs to submit a recent CD4 and viral load. Although these labs had been drawn while the men were in prison, they did not have records of the results and so these labs had to be drawn again at their first clinic visit in the community. Assuming that the supporting materials are complete and verified, it still takes about 4 to 6 weeks for the ADAP application to be reviewed and approved. 

Even men who were discharged with a standard 30-day supply of medication were unlikely to avoid treatment interruption because of the challenges they faced applying for benefits. The groundwork for their failure was established before they walked out the prison gate. Critical information that could have prevented them from losing access to life-saving treatments was overlooked or ignored. Providers were reaching out to these men. Men were coming to their appointments and asking for services. But bureaucratic obstacles that stood in the middle sometimes prevented these connections from happening. To make matters worse, many of these men talked about lacking the social and psychological resources to overcome institutional and environmental barriers to care. Other studies have shown that the perception of being assigned to an indigent system of care contributes to parolee’s sense of futility and the belief that their health problems will never be resolved (Marlow, White, & Chelsa, 2010).

According to men, lack of social stability during the post-release period, especially homelessness, interfered with their ability to take their medication every day. One participant who was panhandling and living on trains said that he stashed HIV medicine at locations throughout the city so that he would always have access to his medication. Men explained their
own struggles to find stability in the context of wider patterns of family and community instability. A few participants said that even the people they depended on were living in precarious social and financial circumstances. Men did not want to trouble or burden family and friends with their own hardships. After prison, men usually moved to halfway house with other men or moved in with family members. While men described halfway houses as supportive, they had difficulty finding employment in surrounding neighborhoods because they were full of men looking for work and jobs were scarce.

Men often talked about problems renewing relationships. After an initial homecoming during which family members accepted and embraced them, men eventually felt estranged, unwelcome and both forced and wanting to become self-reliant. Some men felt that they suffered symptoms of post-traumatic stress disorder (PTSD). Years of being caged and fighting for their survival had left men mistrustful, hyper-vigilant, and unable to admit vulnerability or ask for help. One participant reflected,

Now, when I deal with people, I got to walk on eggshells. ‘Cause they’re not as they used to be before. And I don’t want to say nothing that may come out as wrong, ‘cause I’ve been incarcerated for so long. My dealings with people and things...it’s not as...as normal. Now that I’ve been out six months, I’m learning. But back then I was more aggressive. I would look at somebody with that suspicious look. [KDD: 5/5/11, p. 8]

A few men said they had returned to substance abuse as a way of escaping or coping with the traumas they had experienced during incarceration. Because of the difficulties that men experienced with housing, employment, family, and medical treatment, some men speculated that life would be easier if they just went back to prison. “Sometimes I think I’d rather just be
back in prison. And it’s a shame. It sucks to have to say that” [KDD]. They acknowledged the futility of that view but felt that they sometimes had no other choice.

I don’t care if I get locked up. When it’s really cold outside and I got nowhere to go. I don’t care if they lock me up for the winter. ‘Cause it means I got a room. I got heat. And I got three meals a day. [844: 4/27/11, p. 13]

Adding to men’s frustration and sense that they would be unable to resume their lives in the community were the responsibilities, restrictions and penalties they encountered from parole and probation officers.

c. Community Supervision

Community supervision, including probation or parole, raised other potential barriers to HIV primary care and successful community reintegration. More than forty percent of the men in the sample [n=18] were participating in some form of community supervision at the time of the interview. Fourteen men were on parole. Three men were on electronic monitoring. Two were participating in a work release program and one was a registered sex offender. Community supervision meant maintaining contact with a parole or probation officer, paying probation fees, and submitting to drug testing. Three men said that they had been punished when their HIV medicine had caused a false positive result on a urine toxicology test. In this way, HIV treatment indirectly threatened one man with parole violation and resulted in two men being sent to ‘the hole’ or solitary confinement, one for six months. In order to clear themselves and avoid additional punishment, these men had to petition physicians and forensic experts and disclose their HIV status to parole officers and prison administrators. One man said he was rearrested and sent back to prison because he could not keep up with his probation fees.
Men who had participated in a supervised work release program said that it was difficult to refill a prescription while ensuring their privacy. One participant had stopped taking his HIV medicine for three months while he was in a work release program because he did not want to explain to the program supervisor why he needed to leave for a few hours to renew his prescription.

*It’s really nothing that’s supposed to get in you way of wanting to live. It shouldn’t matter. But I was so…I don’t want to say ashamed. But I didn’t want nobody in my business. I was there. If I leave and come back…and then a lot of us slept in one room. It wasn’t no cells or nothing like that. It was basically about privacy. I felt I would have no privacy. So I was going to wait until I got out.* [EQM: 8/29/11, p. 6]

Although jails and prisons are compelled to provide health services to inmates (Rold, 2008), no such right exists for men who face punitive restrictions in the community. A participant in a work release program said that the quality of medical care available to him there was no better than that which he could expect in prison, saying, “*They don’t have no type of healthcare in there. Say you ask somebody to take you to the doctor ‘cause you don’t feel well. They’ll just give you a hundred questions before you even leave out the door*” [EVA]. One participant complained that he had missed doses of his medication because he was placed under house arrest at the home of a family member where he did not have access to his medication. Men who were supervised in the community had to fend for themselves medically while meeting the commitments of parole or monitoring. While these men were still considered wards of the state and their freedom was conditional, they sometimes felt that they did not exercise substantial self-determination over their use of health services.
E. Conclusions & Recommendations

Much of the literature on HIV and incarceration in the U.S. recognizes that although incarceration is regrettable, it nonetheless represents a significant public health opportunity (Beckwith et al., 2010). While it is important to retain a sense of optimism about the possibilities for treating HIV in jails and prisons, we should consider why this should be in the first place. That is, incarceration has become a healthcare alternative for some men because frontline community-based testing and treatment programs missed them.

This study shows that while incarceration was an important gateway to healthcare for many men with a history of recent CJS involvement, incarceration also jeopardized their health through inadequate and sometimes negligent healthcare, eroded their autonomy and personal choice. Men’s prior experiences with correctional health services, both positive and negative, weighed heavily in their decisions to pursue HIV treatment after arrest. The kinds of treatment that men described were often inadequate and failed to meet the standard of care for persons living with HIV. Even when equivalent standards were achieved, health interventions may still have fallen short of what is needed to realize comparable outcomes (Lines, 2006). Healthcare tended to be viewed as least confidential and most fragmented in jails, where a majority of men are awaiting adjudication and presumed innocent. In prison, routines became more established and access to medication more predictable. However, mass punishments could disrupt treatment and some men still did not have access to an HIV specialty provider.

Very few men received any kind of risk reduction counseling while they were incarcerated. Even fewer men said they had received counseling before being tested for HIV. Some men said they did not even know they were being tested for HIV. Post-test counseling was said to be perfunctory or absent. After receiving their diagnosis, some men did not even get the
minimum counseling that might assure them that their death was not imminent. The information that providers gave to men sometimes created unrealistic expectations and fears. One participant, for example, thought that if he was infected with drug-resistant HIV, he might need emergency care. “I hear people say it just different strains and some is worse than other ones - super-virus. So it makes you nervous when you can’t get the proper assistance if you really need it” [FHG].

Medication adherence drops sharply after release from prison (Baillargeon et al., 2010). To be adherent to medications after release, men will have to navigate complex health systems, establish their own routines, and cultivate social support (Spaulding, et al., 2009b). Men who actively abstain from alcohol and drugs (Harzke et al., 2006) and seek treatment for depression and other mental illness (Scheyett et al., 2010) are likely to get the most out of community-based HIV care. However, few of the men interviewed for this study reported having opportunities in prison to practice the skills that they would need to survive when they returned to the community. Paradoxically, in prison we take away men’s autonomy but then expect them to be resourceful and self-reliant when they reenter the community.

Furthermore, men felt that HIV treatment was sometimes rationed simply to create an additional layer of social control. Some of the situations described by men including compulsory treatment, denial of medical care, paying fees for health services, and having correctional officers assess their health needs or seize their medications may represent violations of international human rights standards (Lines, 2008; WHO, 2007). Assuming these accounts are accurate, they represent instances where the goals of HIV primary care and preventive medicine are severely undermined. Before jails or prisons can serve as entry points for the healthcare system, we need to guarantee the accountability and oversight necessary to ensure that correctional facilities are promoting human rights and public health.
The results of this study show that incarcerated men do not passively use health services. Neither do they see themselves as hapless victims of institutional inefficiencies. Rather these men are active consumers of health services, balancing their treatment needs with safety concerns while maximizing opportunities for therapeutic interactions with healthcare providers. Men are making calculated and rational choices about their health and attempting to minimize their risk exposure in an environment that is potentially very dangerous. The strategies that men use for confronting perceived health obstacles, including exaggeration and deception, suggest that men have health needs that these institutions as a whole are failing to meet. This problem is evidenced by the serious health risks that some men took in order to get medical attention.

Men’s decisions to undergo HIV testing, to disclose their HIV status, or to take HIV medication are also strongly influenced by factors not specifically related to correctional health services but more tied to their perceptions of violence and lack of safety in jails and prisons. These perceptions begin to take shape before men ever enter a correctional facility. “Every man in my family that been to prison would talk about, ‘If you go to jail, them niggas is gonna be after you.’ So I was scared.” We need interventions that counteract these perceptions. Cases detected in jails and prisons may often be people who already knew or should have known their HIV status. For these men, accessing care is a conscious choice. Men who feel unsafe in a correctional facility are less likely to disclose their HIV status or seek medical attention. Jails and prisons that are perceived as unsafe are not conducive to treatment of HIV. Therefore, all parts of correctional facilities have to be configured to make people feel safe, to facilitate disclosure, and to maximize opportunities for treatment. We need solutions that make certain health behaviors appear rational - that make healthy choices seem like reasonable choices.
F. Strengths and Limitations

This study used an innovative conceptual and methodological approach to the problem of understanding the secondary prevention needs of HIV positive former inmates. Many earlier studies in this area have focused on organizational factors that influence healthcare access, and given less attention to inmates’ beliefs and attitudes toward those systems and services. The results of these studies usually indicate only whether an inmate received a health service but not how or why he did. By using an ethnographic approach, this study provided preliminary answers to the urgent question raised by these earlier studies, namely, why do some previously incarcerated HIV positive men not receive the health services that are planned for them.

The lack of evidence to substantiate these men’s stories was arguably an important potential limitation of this approach. However, the purpose of this study was to understand men’s perceptions more completely. The author therefore made no attempts to substantiate these men’s stories. In the future, it would be foremost to validate these accounts, since these alleged situational factors (e.g. medication confiscation or medication strike) had played a pivotal role in shaping men’s perceptions.

The researcher sampled for maximum variation (Sandelowski, 1995) in order to include men with diverse incarceration and HIV treatment histories. To ensure the broadest possible access to potentially eligible men, the researcher used multiple recruitment methods and collaborated with clinicians, case managers, and outreach workers at each of the sites. These recruitment strategies also helped to address one of the most important threats to validity: the use of community clinics as recruitment sites. Patients at these sites presumably already showed a commitment to receiving care and the ability to overcome barriers to accessing community health services. To include men who had not yet accessed community-based health services or
demonstrated success at making the transition from prison back into the community, the
interviewer collaborated with a Department of Corrections case manager to identify men as they
were being released from prison. A limitation of this approach was that a number of these men
failed to attend their initial clinic visit and were not contacted by the researcher. These men
represent a population that is of particular public health concern and future research should
endeavor to include their voices and perspectives.

By having nurses and physicians introduce the study to patients, the interviewer built
upon the trust and rapport that patients had with their providers. Generally, participants felt
assured that the project was safe because they learned about it from a clinician. A limitation of
this approach is that some participants may have withheld information or changed their
responses to make them congruent with the perceived expectations of their healthcare providers.

Interviews were timed to support the credibility of this study. By interviewing men soon
after their release from prison or jail, the researcher expected to avoid distortions in the
information that could be rendered by the stressful and coercive environment of jails/prisons,
while still retaining the freshness and ease of recall that is essential for capturing ethnographic
detail. However, unlike orthodox approaches to ethnographic interviewing (Heyl, 2001) these
interviews were comparatively brief, and did not occur in close spatial proximity to the events
that they covered. Therefore the researcher was unable to compare what men said to what they
did or to see how men’s explanations may have changed across time or settings.

This study did not examine how men’s perceptions of correctional health services may
have changed over time. Differences between how correctional facilities were 10 years ago and
how they are now were sometimes blurred in men’s narratives and consequently this research did
not take these differences into account. As an example of how quickly men’s perceptions of
conditions within the jail can change, one young participant reflected,

I was locked up in 2008 for something totally different. I would say though...I know it’s
all bad, but it’s kinda changed differently, I guess, for the homosexuals, as far as the
clinics, the jail system period. [T2F, 5/4/11, p. 1]

Neither did this study examine differences between different correctional facilities and did not
differentiate between jails and prisons. This is a significant limitation because there can be large
and important differences in the availability and quality of health services depending on how a
particular facility is administered (Glaser and Greifinger, 1993).

However, men’s direct and indirect experiences with correctional medicine in various
settings over the last two decades have influenced how they utilize health services today. Among
HIV-infected persons, negative experiences with and distrust of healthcare providers and
government institutions can play a major role in subsequent decisions to access HIV medical
care (Beer et al., 2009). The control that certain negative experiences exerted on men’s choices
was evident in the way men told their stories. Men often mingled favorable and unfavorable
impressions, obscuring some of the changes that may have occurred over time.
II. INTERRUPTION OF ANTIRETROVIRAL THERAPY AMONG RECENTLY INCARCERATED MEN: CULTURAL AND SITUATIONAL FACTORS INFLUENCING ACCESS AND ADHERENCE TO TREATMENT

A. Introduction

Using data obtained from qualitative interviews with recently incarcerated HIV positive men and transgendered persons [n=42], this paper describes some of the cultural and situational factors that contribute to interruption of antiretroviral therapy (ART) and discontinuity of HIV primary care.

B. Background

Nearly 20% of all American men living with HIV are incarcerated each year (Spaulding et al., 2009a). Although incarceration can provide important opportunities for testing and treatment, many of these opportunities are missed (Duffus et al., 2009; Grinstead et al., 2003). As these men enter and exit the criminal justice system, discontinuation of healthcare access and non-adherence to prescribed treatments often occur (Fontana & Beckerman, 2007; Baillargeon et al., 2009). Men who do not access healthcare during or after incarceration are at risk for treatment interruption and, in turn, accelerated disease progression. They also become more infectious to others (Cohen et al., 2011).

Keeping HIV positive men healthy and connected to care as they pass through the criminal justice system is complex and challenging. When HIV positive men become incarcerated, decisions to disclose their HIV status, to participate in HIV testing, to request medical attention, or to postpone treatment may be mediated by a shared set of culturally based and situationally-relevant assumptions about what to expect during incarceration.
Unique cultural and situational norms develop during captivity based on expectations for healthcare, mistrust of authority, fear of discrimination and an overriding preoccupation with safety, meeting basic survival needs and avoiding exploitation. These norms influence how some HIV positive men perceive and respond to health services in correctional facilities (Braithwaite & Arriola, 2003; Belenko, Shedlin & Chaple, 2005; Patterson & Greifinger, 2004; Kacanek et al., 2007).

Policies aimed at helping incarcerated HIV positive men receive the treatment and care they need should therefore be guided by an understanding of the cultural and situational factors that guide these men’s decisions, motivate their behaviors, and structure treatment opportunities during incarceration. For this study, culture is defined as a “coherent set of patterned and coordinated activities rationalized by a shared set of norms, which are rationalized by a shared set of assumptions about the world of experience” (Handwerker, 2009). Situational factors refer to external events or environmental stimuli that happen within a specific context like incarceration that may alter a person’s motivational state and, over time and through human interaction with that environment, give rise to particular cognitive and behavioral norms.

For recent cohorts of American men, incarceration has evolved unnaturally into a common detour on the pathway to adulthood (Pettit & Western, 2004). The growth of prisons and the virtual invisibility of the groups that migrate through them demand that scientists give voice to these populations by generating culturally sensitive and locally inscribed accounts of the everyday worlds inhabited by people who experience incarceration (Wacquant, 2002).

Incarceration influences how many largely minority and disadvantaged adults living with HIV survive their disease, seek medical attention, establish health goals, and develop expectations of health care providers. Understanding how these men selectively attend to multiple threats to their
physical, mental, and social well-being may help providers make the most of limited opportunities to detect and treat HIV in corrections and after release from incarceration.

C. Methods

1. Setting

Funded through a grant from Sigma Theta Tau Nursing Honor Society, this project was conducted at six community clinics located in Chicago communities with the highest HIV prevalence rates and greatest concentration of returning ex-offenders (IDPH, 2011, LaVigne & Mamalian, 2003). These particular settings were chosen based on participant observation carried out over a two-year period as part of the author’s doctoral training in public health nursing. Located in underserved neighborhoods, five of these clinics were operated by the University of Illinois at Chicago, HIV Community Clinic Network (HCCN), located in the field stations of the (UIC) Community Outreach Intervention Projects. The sixth clinic was operated by the Ruth M. Rothstein CORE Center, a Corrections Continuity Clinic that provides HIV primary care to men and women leaving Cook County Jail, the Illinois Department of Corrections, and the Federal Bureau of Prisons.

2. Conceptual Framework

The conceptual framework for this study is strongly influenced by the theoretical and methodological traditions of symbolic interactionism and ethnography. These approaches to the study of human behavior are premised upon the fundamental assumption that humans create personal and shared meanings through social interaction and that these meanings influence how they think and act (Mead, 1934; Whorf, 1941). For humans, meaning is causal. Moreover, distinct communities are assumed over time to develop their own unique patterns of thinking and
behaving or cultures (Handwerker. 2009). The task of ethnography is to represent the perspective of the group member who is an insider to this culture (Geertz, 1974, Spradley, 1979).

This study uses a qualitative and naturalistic approach that borrows heavily from the methodological traditions of ethnography. Since the beginning of the AIDS epidemic, ethnography has been valued for “its exploratory and descriptive capabilities to enlighten emergent trends and explain phenomena within the natural social context” (Weibel, 1996, p. 187). Ethnographic methods are also considered indispensable for elucidating the diverse social connections between prisons and communities (Wacquant, 2002). Building on principles of cross-cultural communication and techniques of ethnographic interviewing (Spradley, 1979; Heyl, 2001), the researcher used flexible and open-ended questions and encouraged informants to talk about the facets of their experiences that they found most relevant and meaningful.

3. Recruitment Strategy

The researcher used purposive sampling to generate a sample that would include men with diverse kinds of criminal justice system (CJS) involvement. With purposive sampling, the researcher deliberately selects units to include in a sample (Shadish, Cook & Campbell, 2002, p. 511). The ‘power’ or logic of purposive sampling lies in “the quality of the information that is gathered from each sampling unit” (Sandelowski, 1995, p. 179). Samples should be large enough to support claims of theoretical saturation but small enough that a detailed analysis of the data is reasonably permitted (Sandelowski, 1995). The sample size for this study was well within the recommended sampling range for ethnographic studies (Sandelowski, 1995, p. 182).

Sampling decisions were driven by the researcher’s interest in showing the depth, breadth, and intensity of the cultural knowledge possessed by informants. The researcher collaborated with nurses, physicians, social workers, and case managers at each of the sites to
identify men who had reported recent CJS involvement. Clinicians then introduced the study to these men individually during their routine clinic visits. In addition, the study was introduced to groups that met weekly for counseling, and palm cards with information about the study were distributed to case managers at the field stations. To make the study more inclusive of men who were not yet firmly established in community-based HIV care, the researcher collaborated with a corrections case manager to introduce the study to men who were returning to the community from prison.

The researcher also attempted to recruit men who had a history of CJS involvement but may not have disclosed this to their providers. Because each clinic was only open one day a week, the researcher was available at each of the sites during normal clinic hours to introduce the study to patients. Any patient coming into the clinic was able to learn about the study and be interviewed if he was eligible and gave informed consent (Appendix A). Each person who responded to the recruitment materials was offered the chance to participate. Nearly a quarter of the participants [n=10] were recruited directly from the Ruth M. Rothstein Core Center. The remaining participants [n=32] were recruited from HCCN clinics.

4. **Participant Population**

Like other major urban centers in the U.S., Chicago is disproportionately affected by HIV and incarceration. The HIV prevalence rate for Chicago (756.5/100,000) is about three times the national average (276.5/100,000). In 2010, 20,391 people were known to be living with HIV infection in Chicago (CDPH, 2011), of whom almost 80% of these were men. In the same year, Chicago (Cook County) received over half (54%) of all male prison parolees released in the State of Illinois (IDOC, 2010). Most of these men returned to community areas of Chicago with elevated rates of HIV and other measures of social inequality (LaVigne & Mamalian, 2003).
Men sampled for this study [n = 42] included a cross section of HIV positive men leaving jails and prisons and returning to the Chicago metropolitan area. Table 2 shows characteristics of men in the sample. Men were eligible to participate if they were 18 years of age or older, self-reported a previous HIV diagnosis, self-reported significant criminal justice system involvement in the last three (3) years, spoke English, and were willing to discuss their experiences with a researcher in a voice recorded interview.

Men were between the ages of 19 and 55 years (mean = 38 years), and most identified as Black or African American. About one in five men never completed high school, while nearly a quarter finished at least some college. More than 60% of men identified their sexual orientation as ‘straight’. About 40% of men identified their sexual orientation as gay, bisexual, or transgender.

The sample included men from each major transmission risk category including men who had sex with men, men whose only risk factor was heterosexual sexual contact, men who were exposed through injection drug use, one man who was infected perinatally, and another who was infected through a blood transfusion. More than a third of men in the sample received their initial HIV diagnosis in a correctional facility. The average age at diagnosis was 27.8 years (range: birth-47 years). Men in the sample had been living with HIV for 10 years on average.

**Table 2.** Descriptive statistics for recently incarcerated men living with HIV [n = 42]

<table>
<thead>
<tr>
<th>Measure and variable</th>
<th>N</th>
<th>Mean (SD)</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>42</td>
<td>38.5 (10.7)</td>
<td>19</td>
<td>55</td>
</tr>
<tr>
<td>Years living with HIV</td>
<td></td>
<td>10.6 (7.1)</td>
<td>1</td>
<td>27</td>
</tr>
<tr>
<td>Age at diagnosis (years)</td>
<td></td>
<td>27.8 (8.7)</td>
<td>0</td>
<td>47</td>
</tr>
</tbody>
</table>
Table 2. Descriptive statistics for recently incarcerated men living with HIV (continued)

<table>
<thead>
<tr>
<th>Measure and variable</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>37</td>
<td>88%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Biracial</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;HS</td>
<td>9</td>
<td>21%</td>
</tr>
<tr>
<td>HS</td>
<td>16</td>
<td>37%</td>
</tr>
<tr>
<td>Some College</td>
<td>10</td>
<td>24%</td>
</tr>
<tr>
<td><strong>Gender/Sexual orientation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Straight</td>
<td>26</td>
<td>62%</td>
</tr>
<tr>
<td>Gay</td>
<td>8</td>
<td>19%</td>
</tr>
<tr>
<td>Bisexual</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>Transgender</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td><strong>AIDS diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>38%</td>
</tr>
<tr>
<td>No</td>
<td>21</td>
<td>50%</td>
</tr>
<tr>
<td><strong>Mode of Infection</strong></td>
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<td></td>
</tr>
<tr>
<td>MSM</td>
<td>15</td>
<td>36%</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>21</td>
<td>50%</td>
</tr>
<tr>
<td>Injection drug use</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>Mother-to-child</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td><strong>History of gang affiliation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>31%</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>54%</td>
</tr>
<tr>
<td><strong>Diagnosed in a correctional facility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>38%</td>
</tr>
<tr>
<td>No</td>
<td>25</td>
<td>59%</td>
</tr>
<tr>
<td><strong>Initiated antiretroviral therapy (ART) in jail or prison</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18</td>
<td>43%</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>55%</td>
</tr>
<tr>
<td><strong>Missed doses of HIV medication during any incarceration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27</td>
<td>64%</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>16%</td>
</tr>
<tr>
<td>Not applicable</td>
<td>5</td>
<td>12%</td>
</tr>
</tbody>
</table>

1 Missing data: Education (16%), AIDS (11%), Gang affiliation (14%), Missed doses (7%). 2 < 2% data missing.
5. Interviews and Analysis

The researcher conducted semi-structured interviews with participants in private rooms located at the community clinics and hospital where participants were recruited. Following Spradley (1979), the researcher used techniques of ethnographic interviewing to encourage participants to respond using the particular words, concepts, and frames of reference that they use, to experience, interpret and shape social reality. Every participant completed at least one face-to-face interview. The researcher continued sampling and interviewing subjects until he reached data saturation, that is, until topical and thematic redundancy had been achieved. After preliminary analysis, the researcher conducted follow-up interviews with 19 participants, some by phone, to clarify information that was shared during the first interview and to gather additional information about the participant’s social background. All face-to-face interviews were digitally recorded. Results are based on more than 33 hours of tape-recorded interviews, each interview averaging 42 minutes.

The interview guide (Appendix B) was developed based on prior fieldwork, a review of the existing literature, and through collaboration with academic researchers. An expert informant with extensive personal and professional connections to the topics and target populations provided critical input that was used to further refine the interview guide. All interviews were transcribed entirely by the researcher. The researcher completed a contact summary after each interview, transcribed the digital recordings, and maintained fieldnotes. In vivo and topical codes were applied to each interview transcript during initial transcription (Lofland et al., 2006). During a second round of coding, thematic codes were applied. Third round coding consisted of further refining of thematic codes and composing analytic memos regarding topics, themes, or other patterns that emerged from the interviews.
6. Protection of Human Subjects

All research sites used a common study protocol that was approved by an Institutional Review Board (IRB) at the University of Illinois at Chicago and the Cook County Bureau of Health Services (Appendix C). To protect participant confidentiality, the Department of Health and Human Services (DHHS) issued a Certificate of Confidentiality (Appendix D). To further protect the privacy of participants, the researcher collected all identifying information outside the audio-recorded interviews. The interviews were deleted from recording devices after being downloaded to prevent the data from being compromised or lost in the field. All identifying information was expunged from the transcripts. Audio-recorded interviews and transcripts were encrypted and stored on a password protected laptop computer. Each participant was assigned a unique random three-letter code at enrollment. The master code sheet was kept on the same computer and secured with an encrypted password. Data were regularly backed-up on a portable hard drive that was locked with the consent forms in a file cabinet inside the researcher’s office.

D. Results

Three major themes emerged from the interviews that have direct relevance for understanding the cultural dynamics of treatment interruption in jails and prisons. These three interrelated themes help to explain why some men do not disclose their HIV status after they became incarcerated and why others had trouble taking their medication the way that it was prescribed. These three cultural themes include (1) violence and perceptions of violence, (2) fear of stigma and alienation, and (3) wanting to achieve protection, mutual support, or intimacy from other inmates. The interview guide did not specifically include questions about men’s perceptions of violence, stigma, or social support. Nevertheless, men brought up these issues
repeatedly as they explained why they withheld their diagnosis from healthcare providers or missed doses of their HIV medication while they were incarcerated.

Overall, more than sixty percent of men in the sample experienced a treatment interruption as a consequence of criminal justice system (CJS) involvement and more than forty percent deliberately withheld their diagnosis from healthcare providers at some point during their incarceration. Men described several situations that had resulted in both brief and sustained interruption of antiretroviral therapy after their arrest, including non-disclosure, delayed prescribing, medication confiscation, medication strike, having no discharge medications, and intermittent dosing. These causes of treatment interruption have been described in another paper. Not all of these causes of treatment interruption can be explained by reference to these cultural themes. However, understanding how violence, stigma, and the pursuit of social support influence men’s health-seeking behaviors, provides insight into why some HIV positive men reject or fail to receive the health services that are planned for them.

Treatment interruptions were as brief as two missed doses and as long as five months, though typically, treatment interruptions lasted for a period of days to weeks. Although some men had difficulty remembering the exact length of time that they had gone without medication, most men recalled with startling precision the dates and circumstances around which they had missed doses of their medication, perhaps reflecting the significance of bodily habits, like movement, meals, and taking medication, in marking the passage of time in jails and prisons.

1. **Perceptions of Violence**

Men characterized the threat of violence in jails and prisons as omnipresent. Violence ranged from verbal assaults to brutal physical attacks that emanated mainly from other inmates.
In this context, men viewed mere survival as an accomplishment. As a gang leader who had been living with HIV for more than 23 years behind bars explained,

*Believe me when I tell you man, muthafuckas was getting beat the fuck up every day.*

*Every day somebody was getting, man...I’m talking about beat to a pulp. Beat damn near dead or making ’em wish they was dead. Every day.* [APW: 12/8/11, p. 19]

Violence was perceived as so endemic to correctional facilities that some men said they had expected to die in prison.

*I didn’t think I would make it back home. Because they got where they start hiding weapons all over the place. People getting stabbed...getting cut up...this is what we’re seeing and hearing everyday.* [AAQ: 11/17/11, p. 22]

More than 40% of the men in the sample [n=18] talked about violence as they discussed their HIV treatment experiences behind bars. Violence and men’s perceptions of violence interfered directly and indirectly with the detection and treatment of HIV in several important ways. First, actual violence and procedures for preventing and controlling violence directly interfered with men getting the opportunity to share their diagnosis with a healthcare provider. Correctional officers forcefully countered explosive violence among inmates with repressive tactical control measures.

*I was denied that [medical care] because they (inmates) actually started a fight in the bullpen. So the police officers that were there, they were really trying to keep everything under control. But they didn’t really care about anything else...about the fact that that I had an asthma condition or that I was really trying to get to speak with one of the physicians there so I could tell him that I was trying to take my (HIV) medicine.* [K9B: 9/7/11, p. 6]
Procedures for controlling violence also directly interfered with inmates getting their medication. Outbursts of violence in jails and prisons, especially those that involved rival gangs could result in punishments like ‘lockdowns’ that affected all inmates regardless of their affiliations. Some participants stated that during lockdowns they would miss doses of their medication.

Sometimes they had like statewide lockdowns when you didn’t get your medication sufficient...your medicine wasn’t sufficient. Because they have to bring medicine to you...And you got 2600 people...and you got three nurses passing out med’s. Come on.

You know it’s gonna be some screw up. [T2Q: 6/30/11, p. 10]

The perception of violence contributed indirectly to treatment interruption by influencing men’s decisions to disclose or conceal their HIV diagnosis and to seek protection from staff or other inmates. Specifically, some men did not disclose their HIV diagnosis because they perceived that controlling violence and managing injuries associated with violence were higher priorities than treating HIV infection and associated symptoms of opportunistic illness. One participant talked about why he decided not to seek treatment for a painful outbreak of herpes zoster.

I don’t know. Because it didn’t come across to me as that urgent. Because in jail, of course, people fight all the time. People fight for just differences that they may have about whatever. Again, that comes across to them as being more urgent than somebody with cold or flu symptoms or something like that. That stuff takes precedence over...you know. [E5B: 11/11/11, p. 16]

Although the threat of violence was perceived to emanate primarily from other inmates, correctional officers were felt at times to contribute to that threat through their inability or unwillingness to intervene to stop violence if or when it occurred. One participant explains why he chose not to disclose his HIV status during intake.
You had one correctional officer there. A fight broke out. She said, ‘Oh, I don’t do fights. I’ll just call it in.’ So she called it in on her radio. And then when we go out to the rec. yard, you see people fighting. So it’s kinda rough. So I didn’t feel comfortable talking to nobody there. [FHG: 8/29/11, p. 13]

Another participant talked about the vulnerability he experienced in prison as a consequence of his being in close proximity to men who had nothing to lose and feeling that correctional officers would not aid him or protect him.

A lot of guys down there had a lot of time to do and they don’t care what they have to do to survive. And the police barely…the police wasn’t hardly doing anything to help you. That’s the hardest part. The police. They the ones supposed to be protecting you, ‘cause they’re…the officers that’s assigned to your housing unit. You can hardly get them to help you. [AAQ: 11/17/11, p. 22]

The threat of interpersonal violence was felt to be especially present by men who identified as gay or transgender. These participants said they had often been ridiculed and harassed by inmates and that correctional officers used the mere threat of interpersonal violence as a form of control or punishment.

There’s three CO’s (correctional officers) and a hundred mother fucking dudes. Anything is possible. And some of the time, if not most of the time, they’re not cuffed or they have one cuff on them, or not cuffed at all…totally. Yes, it’s very scary. Especially me being gay and being out…It’s like anytime…I don’t care if you’re on deck or in the cell with just one person. You could be in one-on-one with a cellie and he could just flip the fuck out. You don’t know who’s hiding a shank. [T2F: 5/4/11, p. 8]
Another transgendered participant who stopped taking antiretroviral medication for forty-five days after her last arrest talked about how her safety was threatened as she arrived at her assigned housing unit in prison.

_They put me in a cell with a gang-banger. And when I walked up to the cell, I had my basket. And he was like, ‘Oh no! You can’t come in here.’ And I said, ‘Well, this is where they sent me. You have a problem with it, you go talk to them.’ He was like, ‘I don’t give a fuck what you say. You got to get your shit. You ain’t coming in here.’ And the other guys, they heard him…the other gang bangers, they heard him. So now I’m getting scared, ‘cause I don’t know what they’re gonna do. And I’m looking around. I don’t see an officer nowhere. So I’m petrified now. But I had to show that I’m tough, that I’m not no weakling even though I was scared._ [69K: 6/16/11, p. 3]

Adding to the apparent lack of personal safety during incarceration are threats issued by correctional officers. One participant who identified as a gay man and chose to conceal his diagnosis from healthcare providers during intake and processing at the jail gave his impression of the threats issued by a correctional officer.

_It [the jail] scared me from booking. One of the guards was talking about people who’s being gay and so on. He was like, ‘Well this is your check in…I don’t like people who’s gay. So if you’re gay, don’t tell me you’re gay or I’m gonna have your ass whooped…because I don’t like gay people.’ So if you’re gay, you keep it on the DL._ [FHG: 8/29/11, p. 12]

Some participants described being sexually assaulted by correctional officers.

_When I went to jail it was kinda hard, because my breasts was real big. I was taking hormones, and my breasts was real big. And the officers…when they…they wasn’t
supposed to check me. I'm leaving from one room to the other one...and they put
me...they would squeeze on my breasts. And they would feel on me and stuff. And I told
them...I said, 'What y'all doing? You better stop that.' But I was hurt. Because you're
violating me. No matter what, I still have my morals. [69K: 6/16/11, p. 13]

Men’s sense of vulnerability was exacerbated further by their participation in mass strip
searches. Three participants talked about having been strip searched at Cook County Jail and
receiving legal settlements from class action suits that led to ending this practice. Although strip
searches are no longer carried out on inmates who enter the jail, they mark out a significant
domain of shared experience that has consciously and unconsciously assumed form in men’s
health-seeking behaviors. Men acknowledged that strip searches were performed to prevent
importation of contraband and protect inmates and staff. However, they also understood the
potential for these mass strip searches to humiliate, weaken, and depersonalize inmates. A 25
year-old participant who was waiting to be escorted to a medical evaluation, at which he
intended to disclose his HIV status, describes the procedures that were used to search him after a
fight erupted.

They proceeded piece-by-piece...issue-by-issue...piece of clothing in the strip search. All
the way down ‘till we were naked. And then they told us to put our hands on the wall and
then face each other. Having us repeatedly cough. Then they told us to squat
down...facing the wall or facing each other with our hands on the wall or our hands on
the ground and told us to cough again. Or if there’s anything we were hiding in our
areas...our rectal areas...under our...I guess...penis or scrotum. They wanted to get
everything you could possibly try to bring in like drugs...money...anything. And send us
on our way. They didn’t even care if we put our clothes back on. [K9B: 9/7/11, p. 9]
Men did their best to avoid conflicts with other inmates. Avoiding conflict was important for minimizing risk of injury or death. For some men, the threat of violence was so intense that segregation or solitary confinement was seen as a desirable alternative.

You’re by yourself. So you can pretty much take care of yourself. You’re safer there when you’re going through this illness. You’re safer there. You don’t have to worry about explaining to people what’ going on. [BHR: 12/5/11, p. 5]

Some men felt that it was impossible and therefore unrealistic to avoid violence. Instead, they did what they could to prepare for it. One man who had survived more than two decades in prison, living with HIV for fifteen of those years, explained how he responded to the violence that had nearly engulfed him.

You carry a big knife. You hope your knife bigger than his. That’s all. I carried two of them muthafuckas. Two big ones. Made holsters for ‘em and everything. I made sure I kept both of ‘em with me. I went everywhere with them muthafuckas. I even laid in bed with that muthafucka. ‘Cause if you come up in there I’m gonna butcher your ass. Simple as that. I’m counting on you to get the goddamn worst of it. Doc, it’s just like out here. It’s survival. It’s survival of the fittest. Only…in there…man, I’ll say a thousand times tougher…a thousand times rougher than it is out here. [APW: 12/8/11, p. 20]

Threats of physical violence and sexual violence were foreshadowed by and seamless with another kind of violence that was integral and essential to the first: being ostracized and being transformed into an outcast.

2. **Fear of Stigma and Alienation**

Adding to the nearly universal perception of violence in jails and prisons, men discussed two especially virulent strains of discrimination: entrenched antipathy toward homosexuals
compounded by stigma against men living with HIV. More than two thirds [n=29] of the men interviewed for this study expressed some degree of fear about being singled out for their HIV status. Although the kinds of concerns that men expressed about being labeled HIV positive by other inmates were strikingly similar across subgroups, there were some important differences.

Men who identified as gay or male-to-female transgendered persons said that although they had experienced a degree of acceptance behind bars and had found ways to openly express their gender, they nonetheless felt that having their HIV diagnosis widely known among other inmates would represent a kind of social death. “That’s how they feel gay is, like you’re dead, you’re dying” [T2F]. Discrimination against homosexual men was felt to be so painful that some gay men and transsexual women believed that they could not bear the added stigma that would come from being labeled HIV positive. One gay participant opined,

*I would have become a pariah. I’m sure they would have been like, ‘That’s the guy in 208. That’s the guy. He got AIDS. That’s the guy there.’ I probably would have been called ‘fag’. I probably would have been called every name there was in the book. But it just would have been the stigma of me having HIV...AIDS. It would have been the stigma attached to me that...there would have been nothing I could do to live that down. Even though I was there for a very short period of time, I saw and heard how when other medical information got out about other inmates, I saw how they were treated.* [3XR: 8/17/11, p. 5]

Another stated succinctly,

*When you’re in jail and you’re positive, you’re pretty much treated as a second-class inmate.* [TNF: 6/8/11, p. 11]
When men talked about HIV behind bars it was usually for the purpose of branding certain inmates with stigmatizing labels. Because cells were arranged so that inmates could not see one another, inmates shouted back and forth in order to communicate. Insults directed at one inmate echoed along the tier for all men to hear. HIV positive men who were exposed to this kind of demeaning talk began to feel isolated and afraid. One participant, reflecting on his inability to be open about his illness while he was incarcerated, said,

*This ain’t something that you...because that’s all you hear in prison. ‘Man, you don’t want to catch that backpack.’ That makes people with HIV feel bad. ‘Cause everybody knows you are referring to HIV/AIDS when you say, ‘You don’t want to catch the backpack.’* [ABK: 12/14/11, p. 22]

Another participant talked about the kinds of things he overheard.

*They talk a lot about catching AIDS and stuff. I always felt uncomfortable when they’d talk about it. You know, ‘This girl got AIDS’ or ‘You’ll catch AIDS from her.’ If a gay guy came in, they talk about, ‘You’ll catch AIDS.’ Just hearing the word ‘AIDS’ made me feel uncomfortable.* [5DM: 7/14/11, p. 6]

In the context of widespread interpersonal violence, intense homophobia, and HIV contagion fear, gay men and transgendered persons believed that if they sought treatment for their HIV, they would be exposed to sudden stigmatizing attacks from other inmates. Explaining why he did not seek treatment for his HIV infection while he was incarcerated, one participant recalled how the stigma of HIV infection places additional demoralizing restrictions on social acceptance.

*You got to worry about being stigmatized. You’re gonna have to worry if people wanna deal with it...if people are going to try to hurt you. It’s scary. ‘Cause you already have this, ‘You’re in a gang, we’re not allowed to talk to you...blah, blah, blah...’ You already
have to deal with that. So if I’m gay and I tell you I’m positive, they gonna say, ‘Oh, he a fag. He got that shit. Don’t talk to him.’ There’s just so much going on that you…sometimes you feel so down about it and you feel like you have nobody to turn to. So you just don’t even get involved with dealing with the HIV issue anymore. [HFD: 4/27/11, p. 10]

One transgendered participant talks about why, after living with HIV for nearly 11 years, she did not disclose her HIV status when she entered the County Jail.

I didn’t want it to get out. ‘Cause it was still relatively new to me. I’m still dealing with…it didn’t bother me, but I still know that I have this condition. I’m not going to say this ‘condition’, this ‘plague’. Everybody think this is…is a plague. We can’t stand and talk. We can’t touch. We can’t do nothing without me getting it. So at that point in time, I didn’t want nobody to know. I would have been shunned. And I don’t have no problem with the guys in the prison. They don’t bother me or say nothing. [69K: 6/16/11, p. 8]

Transgendered persons felt especially vulnerable to being singled out for harassment by correctional officers. Gay men and transgendered persons said that correctional officers were more likely to harass them or punish them because they were assumed to be violating prohibitions on contact between inmates.

I’m gonna tell you this one incident in prison that really shook me to the core. Me being gay…It was a gentleman. Me and him was talking. And I put my arms around him. And they gave me a ticket. And they was trying to give me an extra year for just putting my arms around the guy. Saying that I was touching him inappropriately. ‘Cause I say, that’s a double standard. The only reason you’re charging me is because I’m gay. I say,
these heterosexual men touch each other all the time. There’s no problem. [HFD: 4/27/11, p. 21]

A transgendered participant talked about being subjected to harassment when correctional officers discovered HIV medications among her belongings as she was being discharged.

Officers was standing around me, and they pick up. ‘What’s this for? Is this for HIV? If this is for HIV we’re gonna have to hold you here and see have you had sex with anybody else. [69K: 6/16/11, p. 21]

Because gay men and trans women felt more discriminated against, they would sometimes conceal their gender identity or perform the identity of heterosexual men.

Men who identified as straight or heterosexual, on the other hand, feared that being labeled HIV positive would automatically expose them to the abuses reserved for homosexuals. As one straight man put it,

Eighty percent of the prison population is gay. And 60 percent of them are HIV positive or AIDS-infected, know? So you stay away from them and keep your health to yourself. [KDD: 5/5/11, p. 2]

Another heterosexual participant talked about his fear that he would suffer discrimination aimed at homosexuals and would be assigned to housing with homosexuals if he shared his HIV diagnosis. Straight men felt strongly that their gender identity had been threatened by disclosing their HIV status. Mistaken gender identity potentially undermined not only their sense of self, but their safety, and opportunities for socialization as well. One participant was disturbed that correctional officers had mistaken him for a gay man when he disclosed his HIV status during intake at the jail.
The only bad thing about it is when you tell ‘em that you’re HIV positive, they automatically think you’re gay. And so they go and they tell the officer that maybe you should be placed where the rest of the gay people are at. So they want to separate you from the general population. And I had to tell them. I said, ‘I’m not gay.’ I got this through heterosexual sex. I don’t want to go on the gay tier. [U8P: 8/8/11, p. 1]

Procedures for sorting and classifying inmates contributed to men’s perception that homosexuals and men living with HIV are somehow all members of the same universe of prison outcasts.

“Your universe is not connected to our universe” [T2F]. An older straight man talked about how, in the process of getting medical attention, he became worried that he would be assimilated with gay or transgender men.

They divided me over with a lot of transvestites...homosexuals, transgender...I mean, I don’t have no problem with them, I’m just saying, you know, people who quote unquote got HIV look at it and say, ‘Well, either he’s gay or he got the package.’ That’s how they think in prison. That’s exactly how it is. And they wasn’t discrete about dividing us up and showing us that we had to go to a different room to get blood tested...and get blood tested and all this stuff...right in the open. That’s how it is. [T2Q: 6/30/11, p. 2]

Some men felt that the degree of fear or acceptance of other HIV positive inmates depended on race. One participant explained to me why he isolated himself while he was incarcerated.

Me dealing with it, as being open and being Latino, and being positive is a lot different than being Black and being positive and being incarcerated. Because for some reason, it seems like it’s more acceptable to a Black inmate who’s incarcerated as opposed to Hispanic. A Hispanic in Florida would be ridiculed, they be talking shit about them, ‘Get you sick ass outta here.’ [KDD: 5/5/11, p. 2]
Because men viewed violence and stigma as ever-present threats, men often sought to insulate themselves against these twin perils by nurturing amicable and mutually fulfilling relationships with other inmates.

3. **Achieving Mutual Support, Protection & Intimacy from Other Inmates**

Incarceration severely constrains some options for self-preservation, including the ability to flee dangerous situations. “Out here (in the community) you can run and hide and avoid a muthafucka. In there, ain’t no avoiding nobody. Ain’t no runnin’. Ain’t no hiding” [APW]. At the same time, incarceration fails to stifle - and perhaps amplifies - the impulse to achieve survival aims by socializing and cooperating with others. About forty percent of the men discussed social support in relation to their health management in jails and prisons.

Men attached special importance to their relationships with other inmates because these were viewed as a source of protection, a defense against boredom and loneliness, and sometimes a route to intimacy. Finding another inmate to ‘do time’ with helped men maintain their physical health and mental well-being. These men indicated that ties to other inmates were crucial to maintaining safety, dignity, sanity, and personhood through years of confinement. Forming and sustaining supportive, meaningful, and fulfilling relationships with other inmates also helped these men to manage difficult periods of illness. One participant who had been living with HIV behind bars for more than 11 years summarized the importance of mutual support.

*In prison everybody’s so-called, ‘hardcore’. But there’s always someone looking for someone to keep ‘em so they can do time together. Not…not as in a relationship way but in an understanding way. Because you get close to somebody. You guys share food together. You guys go to the store, ya know…so forth and so one. There’s no…there’s no*
Men wanted to blend in and get along with other inmates while also managing their illness. They wanted to avoid the stigma that comes from being labeled HIV positive, but they also wanted healthcare providers to understand and promptly address their HIV-related health needs. To balance these conflicting interests, men went to great lengths to conceal their diagnosis from other inmates.

Human contact had been important to most participants but not without social costs and personal risks. Men who stayed socially connected to other inmates through gang affiliation acknowledged greater exposure to violence. Gay men who pursued intimacy with other inmates recognized that they risked longer sentences for violating prison regulations prohibiting such behavior. Because of the risks involved in socialization, men who expected to serve shorter sentences or were fatigued by defending their position or ‘spot’ within the gang, chose to isolate themselves from other inmates.

About a third of the men \( n=13 \) in the sample reported a history of affiliation with a Chicago street gang. These men belonged to a ‘set’ or ‘clique’ connected to one of Chicago’s street gangs including the Vice Lords, Gangster Disciples, and Blackstone Rangers. For some men, gang affiliation in prison was automatic and provided continuity with life outside of prison. Men who were ‘plugged’ or ‘on the team’ felt somewhat more insulated against violence and exploitation but acknowledged that being a member also exposed them to violence from rivals as well as men within their own gang. Men who belonged to a street gang or organization were concerned that if their HIV diagnosis were revealed that they would forfeit the mutual support
and protection that they had come to expect as a gang member and that loss of confidentiality could be life threatening.

*It means you’re on your own. No protection. You just fucked. You get into fight, you out there by yourself. Nobody to come aid you. None of that. It’s the same way like out here (in the community). Only in there they rougher than out here. A hell of a lot rougher.*  
[APW: 8/22/11, p. 2]

This same participant reflected further on what this loss of confidentiality might have meant not only for his safety but also for his social support.

*It’s not only about protection. It’s about losing friends and muthafuckas that have been behind you since day one. They won’t fuck with you after they find out you got AIDS. I couldn’t blame ‘em. I’d probably be the same way.*  
[APW: 8/22/11, p. 2]

Another participant who belonged to a gang said,

*It was scary, ‘cause I was wondering if people would find out, ‘cause I didn’t want anybody to know. I was scared that I would be excluded from society out there. ‘Cause it’s hard, you know, being in prison by yourself…with this.*  
[BHR: 5/18/11, p. 3]

Men who were in a gang also worried that being identified as HIV positive in prison could have a disastrous impact on their social standing and financial opportunities when they returned to the street. “*What if somebody found out that I’m taking HIV medicines? Go back and tell the guys I run with? Tell the people I’m affiliating with?*”  
[JK5] Some of these men had achieved status within their organization and directed activity within the gang, enforcing the laws, and issuing penalties or ‘violations’ when members stepped out of line. One of the men interviewed had become a legal expert during the two decades he spent in prison, writing petitions and filing appeals on behalf of other gang members. Gang members who had rank within their organization
were better able to mobilize resources through their connections with other inmates and correctional officers. Being in a gang also provided a certain level of privacy that helped men to be adherent.

_Due to the fact that I was in a gang and they didn’t bother me about certain things. They just thought it was regular medicine so they didn’t inquire about what I’m taking or why._

_so I didn’t have that problem._ [BHR: 12/5/11, p. 6]

Gang ties were dynamic. Men talked about trying to ascend within the gang, being ‘sold out’ by their gang, or betrayed and forgotten. Some men felt that their aspirations for status within the gang had been thwarted by their HIV diagnosis. Others felt that their diagnosis did not alter their social standing. A few men said that their HIV diagnosis was something they simply did not discuss with other gang members. Doing so could be dangerous for both men involved. One participant explained how this ‘code of silence’ worked.

_If I tell on you, I tell on myself. It’s just like me and you do a crime and you get caught...If you tell, you’re telling on yourself. You’re gonna get just as much time as I am if they catch up with me. So why should I tell you something if it ain’t your business first of all. So if another person come and tell you, ‘He got AIDS’ or ‘He ain’t lookin’ so good.’ You’ll get a whooping for that. Spreading a word around on a person like that._

_Because he’ll send the mob at you._ [TPB: 5/4/11, p. 12]

With few exceptions, gangs provided the only organized outlet for social contact with other inmates. A few inmates talked about participating in Bible study but rarely did men achieve mutual support through organized peer education programs with other HIV positive inmates. In fact, when it came to opportunities for education or developing life skills, men agreed that there is very little available to men in correctional facilities in Illinois.
Although there is ample evidence that HIV peer education is feasible and acceptable, only one participant was involved with any kind of HIV health education and peer support while he was incarcerated. This participant was at a facility where he met with other HIV positive inmates each week to discuss topics related to healthy living with HIV including medication adherence, substance abuse, and disclosure. This participant said that his participation in the weekly discussion groups helped him understand the benefits of HIV treatment, clarify misconceptions about HIV, and feel less isolated.

*As I went through prison, I found out there was a lot more people who had the same thing. So that’s how I dealt with it…It was comfortable to deal with it. Because they had the same diagnosis as me so it was easier to deal with and take my medicine…to do that.*

*It made me feel good, ‘cause I wasn’t alone.* [BHR: 5/18/11, p. 3]

Men who neither belonged to a gang nor benefitted from the companionship and support provided by peer health education programs turned to cellmates, family members, drug use partners, or other members of their gender community for meaningful social contact.

Staying socially connected to other inmates was important for many men. For three transgendered participants, social cohesion during incarceration meant finding emotional and sexual intimacy with another inmate. For at least one participant, the desire for mutually supportive relationships was so strong that he resisted disclosing his diagnosis to healthcare providers and refused treatments and other routine care that might threaten his privacy. For him, the need for camaraderie outweighed the need for HIV treatment. One participant described his decision not to disclose his diagnosis to healthcare providers in the prison because he believed that doing so could erode opportunities to pursue intimacy with other inmates.
When I go in there I avoid the health issues with them because it’s so...it’s not enough confidentiality. So I never...I never tell them when I got to the County. Because you tryin’...you want to be accepted, and you wanna have people to associate with when you are in jail. So you tend not to tell nobody. And then for a lot of the gays, they kind of don’t tell because a lot of...sometimes we go...we look for intimacy. Because we get that attention in the jail with the men. So in order for us not to disclose, or don’t nobody know...Especially if you look healthy, they don’t assume anything. That’s the way you leave it. You just leave it that way. [HFD: 4/27/11, p. 5]

This participant went on to explain his preference for being housed with other heterosexual men.

I like being in housing with men because I like straight men...heterosexual men, ya know.

I like dominant men. So being housed with the men, it’s comfortable for me. Because it’s like being a woman inside of a prison. ‘Cause you’re the closest thing to a woman. So you know you’re gonna get all this attention. And that’s usually what happens. [HFD: 4/27/11, p. 8]

These men described networks of intimate partners built up around the exchange of food, cigarettes, commissary goods, services, and sexual favors. Within these networks, there was a special value attributed to ‘husbands’ or primary male partners. One participant describes contracting with another inmate to exchange favors and mutual support.

And we had formed a relationship. And he told me, he said, ‘Look, these guys...you the only one down here with titties, baby. You’re the only one. These niggas gonna be on you. Make them pay. Don’t do nothin’ for free. And if you want to give me something, you can. But if not, I’m good. I’m your man.’ I was like, ‘baby, I got you. You ain’t got to say another word. I got you.’ And every time I braid somebody hair, I did somebody
homework, I got paid for it. And I made sure my husband...he was my husband at this point. 'Cause we had made this bond that we was gonna be together. [69K: 6/16/11, p. 7]

The prohibition on sexual contact in prisons and jails did not deter some participants. A few of these men talked about having multiple oral and anal sexual partners while they were incarcerated. These same men said they had refused treatment while they were incarcerated. Men who pursued intimate relations with other inmates also said they had exposed themselves to other sexually transmitted infections and possibly risked being re-exposed to HIV. In the context of these intimate partnerships, men had no access to the HIV prevention tools including condom and lubrication that persons outside of jail or prison can typically access. None of these men said that they had access to condoms. However they said that they had improvised protection using rubber gloves or sandwich bags, and remained conscious of the health risks they had taken in order to pursue intimacy.

Although the pursuit of mutual support and intimacy interfered with treatment and adherence for some men, for others, having an accepting and supportive cellie seemed to encourage medication adherence. “He’s the only person I told. ‘Cause he was the only person I could trust being around me. He just told me to be careful and continue to take my medicine and make me stronger” [Q7H]. For at least one participant, sharing a cell with an intimate partner meant having privacy and companionship that supported his adherence to HIV treatment. This participant talked about what it meant for him to share a cell with his intimate partner.

We were cellies for over a year. And he was...he is a blessing in so many ways. I hadn’t cried when I found out [that I was HIV positive]. I wanted to be hugged when I found out. That night I admitted to the man I love that I was HIV positive. From that day up until now, that man writes me every day. Every day that we were together he would ask, ‘Did
you take your pills?’ There were days when I didn’t feel like doing anything. [He’d say], ‘Take that pill.’ He would ask me questions about things I did not know. So when it came time for labs, I asked...And he hugged me. I hadn’t...When I told my mom [that I was HIV positive], I told my mom through the glass at Cook County. So the hug I needed from her I ended up getting from him. [74U: 9/22/11, p. 5-6]

More than one man said the hardest part about being HIV positive behind bars was having to keep quiet about his illness. “Not being able to talk about it. That’s the hardest part. Because only you know. And to have that bottled up...” [JK5] The silence and secrecy that envelop HIV in prison seem to have interfered with men’s ability to grieve, cope with, or accept their diagnosis while incarcerated. Men felt that the social support and emotional outlets available to them in jail or prison were insufficient for complex bereavement. Although some aspects of human grieving appear universal, the grief experience seems to be quite malleable (Rosenblat, 2001) and subject to cultural and environment constraints (Rosaldo, 2004). Without an opportunity to sort through feelings in culturally sanctioned ways, many of these men left prison with raw and unprocessed emotions, or even in denial about their HIV. These men, in turn, may have been less likely to adhere to medication or to take precautions to prevent re-infection or passing the virus to others. As one participant stated,

A person who’s bent on revenge will constantly tell you, ‘I don’t have it.' And he’ll mess around and infect almost everybody. Instead of a person that comes out and says he’s got it and he’s looking for some help. [WDN: 8/15/11, p. 2]

As correctional facilities adopt more aggressive HIV testing policies such as ‘opt-out’ testing aimed at improving case identification, they should also ensure that men who are diagnosed with HIV are offered mental health services and peer support as well as risk-reduction counseling, and
HIV primary care. Some evidence suggests that risk reduction counseling added to HIV testing may not significantly reduce sexual risk taking compared to HIV testing alone (Metsch et al., 2012). However, being in HIV care is associated with reductions in sexual risk behaviors among HIV–infected adults (Metsch et al., 2008). As policy makers attempt to balance resources and services, they should emphasize continuity of care for men leaving jails and prisons. Now that scientists are confident about the direct therapeutic benefits of ART and its important role in preventing future transmission of HIV, the question is how to keep these men connected to HIV care as they return to their communities. In a recent national survey, HIV-infected patients more often reported emotional barriers as reasons why people living with HIV were not receiving care or treatment (Mayer, 2011). Developing interventions that focus on the social and emotional needs of men who are leaving prisons and jails are likely to strengthen men’s commitment to treatment and perhaps contribute to reducing recidivism.

E. Conclusion & Recommendations

The personal and shared meanings that form the basis for culture compel us to think and act in certain ways and not others (Handwerker, 2009). This exploratory study aimed to find out what kinds of meanings circulated in jails and prisons that had implications for HIV treatment. The study provides only partial answers to the questions that it originally posed and raises other new and important questions. For example, why did some men’s perceptions of violence and stigma deter them from seeking treatment while those of others did not? As Thomas (1993) has written, the job of ethnography is to find out what kinds of questions exist in the first place. As we begin to confront the challenges of finding and treating HIV positive men within the criminal justice system, the ‘insider’s’ or ‘natives’ point-of-view (Geertz, 1974) becomes indispensable. Too often, the scientific literature treats these men as passive recipients of health services and
fails to include their voices in debates about the future of correctional medicine. This study shows that men have a lot to tell us about what makes health services accessible and acceptable.

The results of this study show that violence, stigma and the pursuit of mutual support frequently interfere with HIV treatment in jails and prisons and contribute to loss of healthcare access, poor adherence, and ineffective coping. Some HIV positive men respond to incarceration in ways that curtail their health care access, while others take advantage of the opportunities that are available to them. Moreover, men’s decisional frameworks are multi-dimensional and they may consider many factors simultaneously when deciding whether to disclose their HIV status or to accept treatment. By understanding the factors that influence men’s choices in all their complexity, we can plan interventions that make healthy choices into reasonable choices.

Peer-to-peer support and HIV risk-reduction and mental health counseling are vastly underutilized and could provide an important alternative to the prevailing culture of shame and silence. Interventions designed and led by peer health educators could weaken the control that certain meanings exercise on men’s choices and strengthen the positive impetus that other give. Incarceration and parole represent ‘reachable’ and possibly transformative moments – turning points in the lives of men when they assess their lives up to the present and become oriented to other structures, institutions, opportunities, and choices.

Violence is part of the culture of jails and prisons – so much so that jails and prisons have virtually come to symbolize violence in our own culture. There, the threat of violence operates like a second layer of social control. It causes mental anguish and impedes the utilization of health services. The solution has been to impose additional punishments; that is, isolate men from one another, and radically restrict their movement inside of prisons. These ‘reforms’ have created a new set of problems that include self-injury and post-traumatic stress (Rhodes, 2004).
In this study, men who felt most defenseless took the most circuitous route to care. For HIV positive men charged with non-violent offenses, alternatives to incarceration that integrate holistic HIV primary care may be a more sensible approach. Given what we now know about the impact of HIV treatment on preventing transmission, it is important that we seize opportunities to connect community supervision with community-based treatment and care.

Recognizing and responding to gender in jails and prisons is a crucial strategy for promoting human rights, ensuring safety, and making health services available to all inmates. Cook County Jail has recently started to test housing protocols that allow transgender participants to be assigned to special housing units. These programs may promote greater security, lead to more timely health service utilization, and optimize use of resources. Using gender-based violence to control inmates is never acceptable (Lines, 2008). Men in this study often reported that correctional officers had contributed to their sense of helplessness by expressing prejudicial attitudes and inciting discriminatory behavior. Correctional facilities should recruit officers who understand the populations they protect and serve and train them to deliver cultural messages that are congruent with the aims of safety and rehabilitation. Small acts that affirm individual self-worth can begin to change culture. Reflecting on the discrimination aimed at transgendered persons in prison, one participant remembered,

_The prejudice against transsexuals down there is awful. Except for one guard. She was real nice. When I was in segregation, I was in the yard and I was standing close to the fence. She could see my breasts. She came down and she said, ‘Oh, I’m so sorry but would you like a bra? Would you like me to see if they have a bra for you? Because I know you feel uncomfortable.’ I was like, ‘Ma’am, you know I really, really do.’_ [69K: 6/16/11, p. 22]
Adjusting institutional policies so that inmates have access to the same evidence-based HIV prevention tools that are available to them in the community is key to changing the current culture of sexual risk-taking in correctional facilities. A few of the men in this study reported engaging in oral and anal sexual intercourse with other inmates. Making condoms accessible to these men could help control intra-prison transmission of HIV, and give them the opportunity to practice negotiating safer sex. Universally accessible mental health counseling and peer-to-peer support should supplement these prevention tools. At present, the pursuit of social support in prison often involves unacceptable forms of risk-taking. Replacing these kinds of social connections with ones that encourage healthy communication and behaviors should be a priority. The fact that some correctional facilities are doing this shows that it is possible to deliver tailored HIV prevention messages to incarcerated men and that this should be the norm.

In our culture, we punish people whose behavior is judged to be fundamentally antisocial by removing them from society and dissolving their social ties. Moreover, many of the practices of modern penology, for example, the widespread use of psychotropic medications and solitary confinement, are aimed at dissociating the inmate’s mind from his body. In fact, some have argued that it is the mind, not the body, that is the object of modern correctional control (Foucault, 1977). Conversely, we often think of HIV treatment as something we do to the body (e.g. reduce viral load, preserve immune function), without considering adequately how medication adherence and disease transmission depend on certain states of social and emotional awareness and the myriad connections between the mind and the body. Perhaps what we need are holistic interventions that build up the connections between self and society and repair the bonds between the mind and body.


APPENDICES

Appendix A

Informed Consent

“Understanding the Secondary Prevention Needs of Recently Released Men Living with HIV/AIDS”

What is this study about?
You are being asked to take part in a research study to learn more about the health needs of adult men living with HIV/AIDS who have experienced arrest or involuntary detention in the past. This research study is being conducted by Gabriel Culbert, a doctoral candidate in the College of Nursing at the University of Illinois at Chicago (UIC). You have been asked to take part in this research because you are a male over the age of 18, and have reported a diagnosis of HIV/AIDS, and prior significant criminal justice system involvement. The following information is meant to help you decide whether you want to be in the study or not.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Illinois at Chicago or The Ruth M. Rothstein CORE Center. Your decision whether or not to participate will not affect your relations with clinical staff members at any of the clinics operated by the University of Illinois HIV/AIDS Project (UICHP) or the Core Center and will not affect your ability to participate in treatment and care now or in the future. If you choose to participate, you are free to withdraw at any time without affecting your relationship with UICHP or the CORE Center.

What is the purpose of this research?
The purpose of this research is to find out more about what men living with HIV/AIDS need in order to stay healthy if they ever find themselves in trouble with the law. I would like to understand why some men are more likely than others to remain in treatment and care as they enter and exit the criminal justice system. One aim is to understand what changes must be made in order for men to feel comfortable and ready to participate in HIV treatment if they are ever detained. I am not interested in the reasons why you were arrested. I will not ask you to share with me any information about charges that may have been brought against you. I will not ask about the disposition of those charges or how those charges were resolved. The purpose of this research is to understand how being involved with the criminal justice system affected your health.

How could knowledge gained from this study benefit society or others?
This study is expected to improve scientific understanding of the treatment needs of previously incarcerated HIV-positive men. The information gathered during this study is expected to help healthcare providers to make the most of limited opportunities to detect and treat HIV in corrections and the community. The results of this project are expected to aid in the development of a community-based prevention intervention for HIV-positive men with a history of criminal justice system involvement.

What procedures are involved?
If you agree to be in this research, I will ask you to do the following things:

1) I will ask you to participate in two (2) interviews, lasting approximately forty-five (45) minutes, each. The interviews will be done separately. Each interview will be scheduled at a time that is convenient for you. Each interview will happen in a private room here at this clinic. I will digitally record each interview.

2) During the first interview, I will ask you to tell me a little about yourself including your overall health, your history of HIV treatment, and questions about your previous experiences within the criminal justice system. I will ask you to tell me whether or not you tried to use health services after you were last arrested and what it was like to try to access those health services.

3) During the second interview, I will ask you questions about issues and concerns that you raised during the first interview.

About 60 adult men over the age of 18 in the Chicago area will participate in this study.
Appendix A (continued)

What are the potential risks and discomforts?

1. You may find some questions unpleasant or difficult to answer. Some of the questions are highly personal and could cause you to feel emotional or psychological distress. Although the information is confidential, some of the issues could make you feel uneasy or embarrassed. If there are questions you don’t want to answer, you may choose not to answer them. You can also stop answering questions at any time. A case manager will be available to talk about anything that comes up during or after the interview.

2. There is a possible risk that your privacy could be violated and other persons may find out information about your health or HIV status. The researcher is trained about Federal and University of Illinois guidelines concerning privacy protection for people who participate in research studies. The researcher will use a study code number, not your name, on all forms that record information gathered during the interviews. All study information will be stored in a locked cabinet inside a locked office at the UIC College of Nursing.

3. There is a possible risk that your confidentiality could be violated. The researcher and clinical staff members who are helping to identify potential participants are trained regarding issues of confidentiality. To further protect your confidentiality, the research will use a study code number, not your name, on each of the study forms. All study information will be kept in a locked cabinet inside a locked office at the UIC College of Nursing. Only the researcher and members of his dissertation committee will have access to the data. This study is also covered by a Certificate of Confidentiality (see below).

4. Because healthcare providers at this clinic may have told you about this study, you may feel pressured or coerced to join the study or worry that your healthcare will be jeopardized if you do not join. The researcher will not tell clinical staff members whether or not you decide to participate. However, the clinic is compact, and the room that is used for interviewing is near the examination rooms. The researcher can not eliminate the possibility that your participation in this study may be guessed at by some clinical staff members or other patients.

Are there benefits to taking part in this research?

There are no direct benefits from participating. However, your participation in this research may help other adult men, and you may benefit from sharing your experiences and knowing that you have assisted others.

What about privacy and confidentiality?

The only people that will know you are a research subject are the researcher, members of his dissertation advisory committee, and UIC auditors. Transcripts of the interviews will be record only a study code number, not your name. The researcher will not tell any employees, volunteers, or patients at this clinic which men decide to participate in this study and which men do not. Further, the researcher has not provided any incentives or rewards to clinical staff members for sharing information about the study with potential participants. All information generated from the study, including this consent form, will be kept in a locked file cabinet or stored on a password protected computer in a locked office at the UIC College of Nursing. Three years after the completion of the study, all information generated from this study that could be used to identify you as a research subject will be destroyed.

To help the researcher to protect you and the information he will be collecting from you, this study has been given a Certificate of Confidentiality by The U.S. Department of Health and Human Services. This Certificate means that the researchers cannot be forced, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, to disclose any information that may identify you. The researchers will use the Certificate to resist any demands of information that would identify you, except as explained below. The Certificate cannot be used to resist a request for information from United States government employees if the request is for auditing or evaluation of federally funded projects. The Certificate does not stop you or a member of our family from voluntarily disclosing to any person information about yourself or your involvement in the study. If you give your written consent to release study information to an insurer, employer or other person, the Certificate cannot be used to withhold this information. If the researchers become aware of possible child abuse or elder abuse, or that you may cause serious harm to yourself or others, the researchers may report this to the appropriate authorities without your consent.
Appendix A (continued)

**What are the costs for participating in the research?**
Other than your time, there are no costs for participating in this research.

**Will I be reimbursed for any of the expenses or paid for my participation in this research?**
You will receive $10 at the end of each interview as a way of saying Thank you for your time.

**Can I withdraw or be removed from the study?**
You can choose whether to be in this study or not. If you volunteer to be in this study, you may stop participating at any time without consequences of any kind. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The researcher may remove you from this study at any time at his discretion. Some of the reasons that he may do this are if you are later found to be ineligible.

**Who should I contact if I have questions?**
The researcher conducting the study is Gabriel Culbert. You may ask any questions that you have now. If you have any questions later, you may contact Mr. Culbert by phone at 312.996.2270 or by email at gculte1@uic.edu. You may also contact the researcher’s faculty advisor, Dr. Colleen Corte, at 312.996.7025 or by email at ccorte@uic.edu.

**What are my rights as a research subject?**
If you feel that you have not been treated according to the descriptions set forth in this form, or if you have any questions about your rights as a research subject, you may call the UIC Office for the Protection of Human Subjects (OPRS) at 312.996.1711 (local) or 1.866.789.6215 (toll-free) or email OPRS at uicirb@uic.edu.

**Remember**
Your participation in this study is voluntary. You are free to join the study or stop being in the study at any time. Your decisions whether or not to participate will not affect you current or future relations with UIC, UICHP or the CORE Center. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

I have talked to Mr. Gabriel Culbert about this study. I have been allowed to ask questions and all of my questions have been answered. I have been given a copy of this consent form to keep. I understand that if I sign the form, there will be a written record linking my name to the study. I understand that signed consent forms will be kept in a locked file cabinet to protect my confidentiality.

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<tr>
<th>Date</th>
<th>Signature of study participant</th>
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<th>Date</th>
<th>Signature of person obtaining consent</th>
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Appendix B

Interview Guide

I. Introduction

Thank you for agreeing to speak with me. My name is Gabe Culbert. I am a nurse and a researcher at the University of Illinois. I’m here to interview men to find out what kinds of things help them to stay healthy when they find themselves in trouble with the law.

I’d like to learn more about what happens after patients get arrested and what they are doing to stay healthy after they get arrested. So while I know a little about treatment of people living with HIV, I don’t know anything about what it is like for someone living with HIV to be arrested or put in prison. I’d like to learn more about what happens to men living with HIV after they are arrested, what kinds of problems they have and how these problems affect their health and safety.

II. HIV treatment history

First, I want to get to know you a little better and ask you a few questions about living with HIV. I’m interested in what was happening around the time that you were diagnosed. This is so that later, when I start asking you about the times that you were arrested or sent to jail or prison, I will have a frame of reference for understanding what was already going on with your physical and mental health.

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<thead>
<tr>
<th>Questions</th>
<th>Probes</th>
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<tr>
<td>Tell me about when you were first diagnosed with HIV?</td>
<td>What was happening around the time of your diagnosis?</td>
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<td>What were your thoughts about medical care?</td>
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<td>What had to happen for you to get medical care?</td>
<td>When did you start treatment?</td>
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<td>What has changed since you began treatment?</td>
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<td>How would you say your overall health is today?</td>
<td>What concerns do you have for your health today?</td>
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III. Incarceration history

Now, I want to ask you a few questions about your prior involvement with the criminal justice system. First, I want to learn more about how often and how seriously you have been involved with the criminal justice system. You said earlier that you have been involved with the criminal justice system sometime during the previous 3 years.

How many times in the last three years have you been arrested or taken into custody?  ________

How many times have you been arrested or taken into custody ever or in your lifetime?  ________

How old were you the first time that you were arrested?  ________
### Appendix B (continued)

#### III. Incarceration history (cont.)

When was your most recent arrest? ___/___/___ Just so I’m clear, was your most recent arrest before or after you learned that you were HIV-positive? Now, I want you to think back to your most recent arrest.

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<th>Category</th>
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<tr>
<td>Vulnerability</td>
<td>What were your biggest concerns after you were arrested?</td>
<td>What did you think was going to happen to you?</td>
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<td>How did you expect to be treated by other inmates?</td>
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<td>How did you expect to be treated by staff?</td>
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<td>What are the most important things an HIV-positive man should do after he is arrested?</td>
<td>When would _____ be an important thing to do?</td>
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<td>Disclosure</td>
<td>What were your thoughts about telling other inmates or staff that you were HIV-positive?</td>
<td>What opportunities did you have to disclose?</td>
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<td>What needed to happen for you to tell that person?</td>
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<td>How did you expect him/her to respond?</td>
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<td>What are the circumstances that might lead an inmate to reveal that he was HIV-positive?</td>
<td>What would you say to let another inmate know that you were HIV-positive?</td>
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<td>Did you expect that information to remain confidential?</td>
<td>What terms would you use?</td>
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<td>How did you learn these terms?</td>
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<td>Testing</td>
<td>What kinds of medical tests or exams were performed on you after you were arrested?</td>
<td>How would you describe HIV testing to another inmate? How was the test administered?</td>
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<td>Do you recall being offered an HIV test?</td>
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<td>Did you take an HIV test?</td>
<td>Why did you believe you were being tested?</td>
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<td>Yes</td>
<td>What did you think would happen if you refused to be tested?</td>
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<td>No</td>
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<td>Can you walk me through how that HIV test was offered to you?</td>
<td>What things influenced your decision to be tested?</td>
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<td>What concerns did you have about being tested there at that time?</td>
<td>What did you think that test was for?</td>
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<td>How were you given your result?</td>
<td>What did that result mean to you?</td>
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<td>What things helped you understand the meaning of that result?</td>
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<td>What happened after you got your results?</td>
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<td>What were your expectations after this?</td>
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## Appendix B (continued)

### III. Incarceration history *(cont.)*

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<th>Category</th>
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<tr>
<td>Treatment</td>
<td>After you were arrested, what were your expectations regarding treatment?</td>
<td>Were you taking ART prior to this arrest?</td>
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<td>Was ART stopped after this arrest?</td>
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<td>When was ART stopped?</td>
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<td>What needed to happen for you to begin taking HIV medicine again after you were arrested?</td>
<td>What did you say to let that person know that you wanted to start taking HIV medicine?</td>
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<td>Did you receive medication?</td>
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<td>What needed to happen for you to take your medicine exactly as it was being prescribed?</td>
<td>Tell me about how you took your medicine while you were incarcerated.</td>
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<td>Were there days that you didn’t get your medicine?</td>
<td>What concerns did you have about how you were taking your medicine?</td>
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<td>What was happening on those days?</td>
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I’d like to know more about the things you did during a typical day to try to stay healthy. I’m interested in how you modified your surroundings to suit your needs. I want you to think back and remember a place where you spent a lot of time while you were in jail or prison – it could be your cell. I want you to describe what it looked like, what kinds of things were in it, and what it felt like to be there.

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<tr>
<th>Category</th>
<th>Question</th>
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<td>Health behaviors</td>
<td>What kinds of things can an HIV-positive inmate do on a typical day to stay healthy?</td>
<td>How does _____ help a person to stay healthy?</td>
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<td>What needs to happen for a person to be able to do that?</td>
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<td>What kinds of health concerns did you have while you were incarcerated?</td>
<td>What kinds of effects does _____ have on someone living with HIV/AIDS?</td>
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<td>Can you describe any illness or injury that occurred while you were in custody?</td>
<td>How did this affect your health?</td>
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<td>What were you able to do about it?</td>
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<td>Who can you count on to help you if you need medical attention?</td>
<td>What are some of the ways an inmate could get medical attention if he thought he needed it?</td>
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<td>What is the best time for an inmate to identify his health needs to ______?</td>
<td>What could have been done differently to make it easier to take care of yourself?</td>
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</tbody>
</table>
Now, I want to ask you some questions about things that you or someone else might have done while you were incarcerated that could put you at risk for becoming re-infected with HIV. If you prefer not to answer any of these questions we can skip ahead. I’m asking, though, because people who already have HIV can get infected with HIV again if they are exposed to semen or blood or body fluids from another person who is infected with HIV. Sometimes this can make their HIV harder to treat or progress more quickly.

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
<th>Probe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk behaviors</td>
<td>What kinds of things happen to men while they are incarcerated that might put them at risk for catching a disease, like HIV?</td>
<td>How do you feel that _____ might put someone at risk? How do you know that? What makes you say that?</td>
</tr>
<tr>
<td></td>
<td>What kinds of things can someone do to try to reduce his risk of becoming infected with HIV while he is incarcerated?</td>
<td>How would you describe that risk reduction step to another inmate? How did you learn about that form of protection?</td>
</tr>
</tbody>
</table>

Finally, I want to ask you some questions about what it was like to leave jail or prison and return to the community. I would like to know what that transition was like and what kinds of things happened in order for you to access medical care once you were back in the community.

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
<th>Probe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge and Reentry</td>
<td>Tell me about the day that you were released. What happened that day?</td>
<td>What time were you discharged or released? Was there someone there to meet you?</td>
</tr>
<tr>
<td></td>
<td>What was you biggest concern on the day that you were released?</td>
<td>What did you plan to do about that?</td>
</tr>
<tr>
<td></td>
<td>What did you plan to do about your medical care after you were released?</td>
<td>Were you released with ART medication? Did you start taking medication right away?</td>
</tr>
<tr>
<td></td>
<td>What were your discharge plans?</td>
<td>Were those plans clear to you?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
<th>Probe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview experience</td>
<td>How did this interview make you feel?</td>
<td>Were there questions that you felt uncomfortable answering?</td>
</tr>
<tr>
<td></td>
<td>Were there questions that I should have asked but didn’t?</td>
<td>What were they?</td>
</tr>
</tbody>
</table>

Appendix B (continued)
Appendix B (continued)

Contact Summary

Interview date: ____/____/____ □ □  Time of interview ____ : ____  Interview #:____

Site: __________________________  Participant identification No. ____________

Month/Year of diagnosis: _________  Number of years living with HIV/AIDS: _________

Number of arrests: ____  Number of times incarcerated: ____  Age at first arrest: ______

Incarceration # ____

Type: ____________  Date: ___/___/___

Location: __________________________  Duration: _________________ days

Circumstances: ________________________________________________________________________________

1. □ Pre-diagnosis □ or □ Post-diagnosis □ or □ diagnosed while incarcerated □
   1a. While you were in custody did you reveal to anyone that you had HIV?  Yes □ or  No □
   1b. Who did you tell: ______________________________________________________________

2. Was offered an HIV test  Yes □ or  No □
   4. Was tested for HIV  Yes □ or  No □
   5. Was given diagnosis:  Yes □ or  No □
   6. Started on ARV:  Yes □ or  No □
   7. Were you taking ART prior to this arrest?  Yes □ or  No □
   8. Was ART stopped after this arrest?  Yes □ or  No □
   9. What date was ART stopped: ___/___/___ and what date was ART re-started: ___/___/___
   10. Length of treatment interruption: _________ days/weeks
   11. Did you experience any other illness?  Yes □ or  No □
   12. Describe any illness or injury that you experienced while in custody: ______________________________
   13. What date was your release? ___/___/_____  
   14. Were you released with ART?  Yes □ or  No □
   14. Were you given a medical appointment after release?  Yes □ or  No □
   15. After release, did you stop taking ART for > 2 weeks?  Yes □ or  No □

Major topics addressed during the interview:
____________________________________________________________________________________________
____________________________________________________________________________________________
____________________________________________________________________________________________
____________________________________________________________________________________________
Appendix B (continued)

Eligibility Screening Checklist

Name: ______________________________  Age: _______  Screening date: ___/___/___

In order to be eligible to enroll in this study, each person must meet the following criteria:

- 18 years of age or older (verified by state issued ID)
- Self-reports a previous diagnosis of HIV or AIDS
- Self-reports prior significant criminal justice system involvement during the last three (3) years, including but not limited to: arrest, detention, incarceration in a city or county jail or state or federal prison in any U.S. jurisdiction, community supervision, probation, parole, home detention, or electronic monitoring
- Speaks English
- Is willing to discuss his experiences with the researcher in a voice recorded interview

Is the person eligible?  Yes  No (circle one)  Date:___/___/___  PI initial:___

Enrollment Form & Contact Information

- Informed consent signed: Date: ___/___/___  PI initials: _____
- Questions asked during consent: _____________________________________________________
- Given copy of signed consent for to keep for himself
- Declines to retain copy of signed informed consent for himself
- Assigned participant ID Date: ___/___/___  PI initials: _____
- Participant ID __________________________________
- Scheduled 1st interview  1st interview date ___/___/___

CONFIDENTIAL

Name: _________________________________  Emergency contact: ______________________ (first, last) (name, relationship) Telephone: _____________________________  Telephone: _____________________________

- Completes 1st interview Date: ___/___/___  PI initials: _____
- Reimbursed $10 for 1st interview Date: ___/___/___  PI initials: _____
- Scheduled 2nd interview yes no Date: ___/___/___  PI initials: _____
- 2nd interview date: ___/___/___ Date: ___/___/___  PI initials: _____
- Completed 2nd interview Date: ___/___/___  PI initials: _____
- Reimbursed $10 for 2nd interview Date: ___/___/___  PI initials: _____
Appendix C

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response to Modifications)

January 14, 2011

Gabriel Culbert
Health Systems Science
845 S. Damen Ave., Room #1144
Chicago, IL 60612
Phone: (312) 375-8601

RE: Protocol # 2010-1002
“Using ethnography to understand the secondary prevention needs of previously incarcerated men living with HIV/AIDS”

Dear Mr. Culbert:

Your Initial Review (Response to Modifications) was reviewed and approved by the Expedited review process on January 14, 2011. You may now begin your research

Please note the following information about your approved research protocol:

**Protocol Approval Period:** January 14, 2011 - January 13, 2012

**Approved Subject Enrollment #:** 65

**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.

**Performance Sites:** UIC

**Sponsor:** None

**PAF#:** Not Applicable

**Research Protocol(s):**

a) Using ethnography to understand the secondary prevention needs of previously incarcerated men living with HIV/AIDS; Version 1.0; 11/08/2010

**Recruitment Material(s):**

a) Eligibility Screening Checklist, Secondary prevention; Version 1.0 10/17/2010

b) Recruitment Flyer; Version 1.0

**Informed Consent(s):**

a) Waiver of Signed Consent Document granted under 45 CFR 46.117 for eligibility screening

b) Consent: Health Experiences of Men; Version 3.0
Appendix C (continued)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:
(6) Collection of data from voice, video, digital, or image recordings made for research purposes.
(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

<table>
<thead>
<tr>
<th>Receipt Date</th>
<th>Submission Type</th>
<th>Review Process</th>
<th>Review Date</th>
<th>Review Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>11/12/2010</td>
<td>Initial Review</td>
<td>Expedited</td>
<td>11/16/2010</td>
<td>Modifications Required</td>
</tr>
<tr>
<td>12/02/2010</td>
<td>Response To Modifications</td>
<td>Expedited</td>
<td>12/08/2010</td>
<td>Modifications Required</td>
</tr>
<tr>
<td>01/04/2011</td>
<td>Response To Modifications</td>
<td>Expedited</td>
<td>01/14/2011</td>
<td>Approved</td>
</tr>
</tbody>
</table>

Please remember to:
→ Use your research protocol number (2010-1002) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Marissa Benni-Weis, M.S.
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s):

1. UIC Investigator Responsibilities, Protection of Human Research Subjects
2. Informed Consent Document(s):
   a) Consent: Health Experiences of Men; Version 3.0
3. Recruiting Material(s):
   a) Eligibility Screening Checklist, Secondary prevention; Version 1.0; 10/17/2010
   b) Recruitment Flyer; Version 1.0

cc: Arlene Miller, PhD, RN, Health Systems Science, M/C 802
    Colleen Corte, PhD, Health Systems Science, M/C 802
Appendix C (continued)

TO: Gabriel Culbert, RN, BSN, AB
    Doctoral Candidate
    UIC College of Nursing

From: Karen Kroc
    Associate Director of Research

DATE: November 17, 2010

SUBJ: CORE Research Committee Study Approval

I am pleased to inform you that the CORE Center Research Committee approved your study, *Using Ethnography to Understand the Secondary Prevention Needs of Previously Incarcerated Men Living with HIV/AIDS*, at the November 4, 2010 meeting.

Please do not hesitate to contact me if I can be of further assistance. Congratulations and good luck with your study.

cc: Audrey French, M.D., Director of Research
    Chad Zawitz, M.D., CORE Principal Investigator
Appendix D

DEPARTMENT OF HEALTH & HUMAN SERVICES

National Institutes of Health
National Institute of Nursing Research
31 Center Drive MSC 2178
Building 31, Room 5B05
Bethesda, MD 20892-2178
Tel: (301) 496-3230
Fax: (301) 594-3405

4/5/2011

University of Illinois at Chicago
Dr. Colleen Corte
College of Nursing
Department of Health Systems Science
845 S. Damen Ave.
Chicago, IL 60612

Dear Dr. Corte,

Enclosed is the Confidentiality Certificate protecting the identity of research subjects in your project entitled, 'Understanding the Health Needs of Previously Incarcerated Men Living with HIV/AIDS'. Please note that the Certificate expires on 09/01/2012.

Please be sure that the consent form given to research participants accurately states the intended uses of personally identifiable information (including matters subject to reporting) and the confidentiality protections, including the protection provided by the Certificate of Confidentiality with its limits and exceptions.

If you determine that the research project will not be completed by the expiration date, 09/01/2012, you must submit a written request for an extension of the Certificate three months prior to the expiration date. If you make any changes to the protocol for this study, you should contact me regarding modification of this Certificate. Any requests for modifications of this Certificate must include the reason for the request, documentation of the most recent IRB approval, and the expected date for completion of the research project.

Please advise me of any situation in which the Certificate is employed to resist disclosure of information in legal proceedings. Should attorneys for the project wish to discuss the use of the Certificate, they may contact the Office of NIH Legal Advisor, National Institutes of Health, at (301) 496-6043.

Correspondence should be sent to:

Donna Jones
CoC Coordinator
National Institute of Nursing Research
6701 Rockledge Dr.
Suite 8018J
Bethesda, MD 20817
Telephone: (301) 594-4734
Fax: (301) 480-2858

Sincerely,

[Signature]

Donna Jones
Appendix D (continued)

CERTIFICATE OF CONFIDENTIALITY
CC-NR-11-04
issued to
University of Illinois at Chicago
conducting research known as
Understanding the Health Needs of Previously Incarcerated Men Living with HIV/AIDS

In accordance with the provisions of section 301(d) of the Public Health Service Act 42 U.S.C. 241(d), this Certificate is issued in response to the request of the Principal Investigator, Dr. Colleen Corte, to protect the privacy of research subjects by withholding their identities from all persons not connected with this research. Dr. Corte is primarily responsible for the conduct of this research.

Under the authority vested in the Secretary of Health and Human Services by section 301(d), all persons who:
1. are enrolled in, employed by, or associated with the University of Illinois at Chicago and their contractors or cooperating agencies and
2. have in the course of their employment or association access to information that would identify individuals who are the subjects of the research pertaining to the project known as Understanding the Health Needs of Previously Incarcerated Men Living with HIV/AIDS

are hereby authorized to protect the privacy of the individuals who are the subjects of that research by withholding their names and other identifying characteristics from all persons not connected with the conduct of that research.

This descriptive study will use ethnographic interviewing, a qualitative method, to study the secondary prevention needs of a group of HIV-positive men who report significant previous criminal justice system (CJS) involvement.

A Certificate of Confidentiality is needed because sensitive information will be collected during the course of the study. The certificate will help researchers avoid involuntary disclosure that could expose subjects or their families to adverse economic, legal, psychological and social consequences.

All subjects will be assigned a code number and identifying information and records will be kept in locked files at the Institution.

This research is currently underway and is expected to end on 09/01/2012.

As provided in section 301 (d) of the Public Health Service Act 42 U.S.C. 241(d):

'Persons so authorized to protect the privacy of such individuals may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals.'

This Certificate does not protect you from being compelled to make disclosures that: (1) have been consented to in writing by the research subject or the subject’s legally authorized representative; (2) are required by the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 301 et seq.) or regulations issued under that Act; or (3) have been requested from a research project funded by the National Institutes of Health (NIH) or the Department of Health and Human Services (DHHS) by authorized representatives of those agencies for the purpose of audit or program review.

This Certificate does not represent an endorsement of the research project by the DHHS. This Certificate is now in effect and will expire on 09/01/2012. The protection afforded by this Confidentiality Certificate is permanent with respect to subjects who participate in the research during the time the Certificate is in effect.

Date: 4/5/2011

Cheryl Stevens
Executive Officer
National Institute of Nursing Research
VITA

Gabriel J. Culbert

Education
2012 Ph.D., College of Nursing, University of Illinois at Chicago (UIC)
2004 B.S.N., University of Illinois at Chicago (Nursing)
1998 B.A., University of Chicago (Anthropology)
1994 Deep Springs College

Professional Experience
2012 Research Coordinator, DAIDS Clinical Trials Unit (CTU), College of Medicine, UIC
- Research responsibilities: Supervise clinic operations and research staff; oversee implementation of experimental HIV vaccine research protocols; ensure data integrity; coordinate staff training; act as Principal Investigator designee for clinical research including health assessment, safety monitoring, adverse event reporting, and compliance with local IRB, state, and federal regulations
- Clinical duties: Perform physical examination; collect blood and mucosal specimens; obtain medical history; detect and treat common sexually transmitted infections; administer experimental and therapeutic agents; counsel newly diagnosed HIV positive adults and link to care; collaborate with healthcare team to provide HIV primary care

2010-12 Clinical Researcher, College of Medicine, UIC, Chicago, IL
- Coordinated the START Study, a large, federally funded research study examining health outcomes associated with earlier initiation of antiretroviral therapy.

2009 Intern, World Health Organization (WHO), Western Pacific Regional Office, Manila
- Provided technical research support to the Regional Advisor (RA) for Nursing for 3 months; researched and developed teaching materials for nurses working in rural and remote areas of the Western Pacific; analyzed and presented data on the prevention and control of Hepatitis B at 3-day workshop in Shandong Province, China; Presented findings from research with Chinese nurse educators to stakeholders and China Ministry of Health members in Hong Kong.

2005-07 Staff Nurse, University of Illinois Medical Center, Neurological Intensive Care Unit
- Provided evidence-based critical care nursing and medical interventions to high acuity patients on 22-bed hemorrhagic stroke/neurological unit.

2005-05 Staff Nurse, Rush University Medical Center, Medical –Surgical Unit, Chicago, IL

2003-05 Program Coordinator, University of Illinois at Chicago, MIRT Program

1999-01 Program Director, Robert Taylor Boys & Girls Club, Chicago, IL

Additional Research Experience
2003 Research Trainee, University of Indonesia, UIC MIRT Program
- Awarded a competitive research travel grant through the NIH-funded Minority International Research Training (MIRT) Program; participated in an intensive 3-month research training internship in Jakarta, Indonesia; planned and implemented a survey study examining Indonesian nursing student’s beliefs, attitudes and behaviors related to caring for hospitalized HIV patients

2000 Intern, Field Museum, Center for Cultural Understanding & Change, Chicago, IL
- Selected as one of eight post-baccalaureate interns to participate in a 3-month internship in urban anthropology; in collaboration with the MacArthur Foundation, planned and conducted a participatory ethnographic research study of loosely structured youth after-school programs in Chicago
Teaching Experience
2009  *Visiting Instructor*, Xian Jiaotong University, People’s Republic of China
- Planned and implemented a 2-week curriculum in community health nursing
2009  *Visiting Instructor*, Shandong Jinan University, People’s Republic of China
- Developed and led three-day workshop on prevention and control of Hepatitis B
2007-08  *Staff Instructor*, PCCTI Information Technology & Healthcare, Chicago, IL
- Instructed students on nursing fundamentals and applied clinical nursing skills

Publications
2012  Interruption of Antiretroviral Therapy among Recently Incarcerated Men: Cultural Factors Influencing Access to Treatment in the U.S. (In preparation for submission)

Invited Presentations
2012  *Mass Incarceration & HIV Infection: The American Syndemic*, UIC
2009  *Primary health care & traditional medicine*. Bamboo Bridge, Nursing Conference
2009  *Nursing care of hemorrhagic stroke*. University of the Philippines, Manila
2008  *Historical standards for conduct of scientific research*. University of Illinois at Chicago
2008  *Silence as evidence of lapse: Public health nursing, social justice and the war*. 4th International Congress on Qualitative Research, Champaign-Urbana, IL.
2007  *Nursing care of hemorrhagic stroke*. University of Riau, Indonesia, University of Indonesia, Jakarta, CIPTO Mangunkusomo Hospital, Jakarta, Indonesia

Awards
2011  First Place, Competitive Research Award ($2500)  
*Sigma Theta Tau Nursing Honor Society*
2010  First Place, Graduate Student Poster – American Correctional Association (ACA)  
*140th Congress of Correction*, Chicago, IL July 30 – August 4, 2010
2009-11  UIC College of Nursing, Van Doren Scholarship

Licensure & Certification
2004-present  Registered Nurse, State of Illinois
2010  ACLS/BLS Certification, CPR Associates, INC., IL
2009  Clinical management of HIV/AIDS, Core training, MATEC, IL
2010  HIV test counseling, MATEC, IL

Professional Affiliations
2005-present  Association of Nurses in AIDS Care (ANAC)
2006-present  American Public Health Association (APHA)
2009-present  Center for AIDS Research (D-CFAR), Behavioral Core Steering Committee

Additional Skills
- **Language**: Spanish (conversational), Indonesian (basic)
- **Computer**: MS Office Suite; Research software: SPSS, Atlas Ti