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THE HENRY J.
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The Healthcare Experiences of Women with HIV/AIDS

Insights from Focus Groups

FULL REPORT OF FINDINGS

Prepared by Lake Snell Perry & Associates, Inc.
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INTRODUCTION

The Henry J. Kaiser Family Foundation commissioned this focus group study of lower-income women with HIV/AIDS to gain insight into their experiences with the healthcare system. The purpose of the study is to hear directly from women with HIV/AIDS about their lives, their health, and the challenges they face in obtaining the services they need to remain healthy and active. The study offers a vivid picture of the range of obstacles that women with HIV/AIDS may face when seeking medical care and support services and identifies areas where improvement can be made to enhance their access to quality care and information.

The specific issues explored in the focus group discussions include the following:

- Barriers to receiving care,
- Interactions with the healthcare systems,
- Relationships with their providers,
- Unique challenges that women face in handling their illness and seeking care,
- Knowledge level about their illness,
- Effects of HIV/AIDS on the other aspects of their lives, and
- Information needs and the sources they trust.

Lake Snell Perry & Associates (LSPA) conducted six focus groups with women with HIV/AIDS in Philadelphia, Los Angeles, Miami and Savannah, between January and February 2002. Focus groups were held with African American, Hispanic, and non-Hispanic white women of lower-incomes (at or below 300% of the Federal Poverty Level). The focus groups with Latinas were conducted in Spanish.

Background

The motivation for this study is that women account for a growing proportion of new AIDS cases and new HIV infections in the U.S. Women now account for one-quarter (26%) of new AIDS cases and an almost one-third (30%) of estimated new HIV infections, with most new infections occurring among women of color. Heterosexual contact and injection drug use are the major modes of transmission among women.[1]

Women living with HIV/AIDS contend with a number of factors that complicate the management of their illness. Many women living with HIV/AIDS are low-income and one-fifth do not have health insurance.[2] Among those with health insurance, Medicaid, the federal-state health insurance program for low-income families, is a particularly important source of coverage. Studies show that women with HIV/AIDS may face additional barriers to obtaining needed care and services than their male counterparts.

In addition, many women living with HIV/AIDS have significant family responsibilities, including caring for dependent children or other family members who are ill. Many of these women face considerable challenges balancing their daily responsibilities with their own health care needs.

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[1] Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, Year End Edition, 2001, Vol. 13, No. 2.

[2] Analysis of HCSUS data, January 2002.

Research Methods

Fifty-three women who are HIV-positive, ages 21-50, participated in the focus groups, conducted between January and February 2002. The length of time since their diagnosis varied – a few women only learned recently of their HIV-positive status while many of the women have known their status for more than ten years, some since the 1980s. More than half of the women have health coverage through Medicaid. There were also several women in each group who were uninsured and one or two who were privately insured. Table 1 shows the schedule of the focus groups and a profile of the participants.

Table 1

	Group Description	Number of Participants	Date	Site
1 (Pilot)	African-American women w/HIV/AIDS	8	1.23.02	Philadelphia
2[3]	Mixed Race/Ethnicity women w/HIV/AIDS	8	1.24.02	
3	White women w/HIV/AIDS	7	2.19.02	Los Angeles
4	Latinas w/HIV/AIDS (in Spanish)	11	2.20.02	
5	Latinas w/HIV/AIDS (in Spanish)	9	2.25.02	Miami
6[4]	African-American women w/HIV/AIDS	10	2.28.02	Savannah

To be included in the focus groups, the women had to be HIV-positive and have moderate or low incomes (defined as at or below 300% of the federal poverty level). Lower-income women often face more barriers to accessing health services due to their limited financial means and the high cost of health coverage – we wanted to learn about these additional barriers to services and how they affect women with HIV/AIDS. The women were recruited with the help of community-based organizations in Philadelphia, Los Angeles, Miami and Savannah that serve low-income women.

The focus groups were organized to allow us to hear insights into issues of race, culture, and language and to understand if these factors play a role in terms of access to quality healthcare services for women with HIV/AIDS.

It is important to note that focus groups are a qualitative research tool and therefore these results cannot be statistically projected to the larger population of women with HIV/AIDS. The experiences and attitudes detailed in this report should not be considered representative of the kind of care most women with HIV/AIDS receive. Rather, this type of research provides more subtle insight into individuals' experiences, attitudes, and opinions. By giving women with HIV/AIDS the opportunity to share their feelings and experiences in their own words, the focus groups allow more textured findings than quantitative research methods can achieve.

[3] This focus group included five African American women with HIV/AIDS, two non-Hispanic white women with HIV/AIDS, and one Hispanic woman with HIV/AIDS.

[4] Seven (7) follow-up telephone interviews were conducted with participants from the Savannah focus group to learn more about their individual situations.

DETAILED FINDINGS

I. Learning One's Status, Getting Tested, and Starting Treatment

Women in the Focus Groups Became Infected With HIV in Different Ways.

"I didn't know anything about [HIV]. I didn't know anyone that had it. I kept getting sick and I kept going back and forth to the hospital. There was a sign in the lobby one day that says we'll pay you $20 if you take the HIV test…so I [took] it. [It] never, ever crossed my mind that this test would come back positive."

African-American woman from Philadelphia

Women in the focus groups explain that they became infected with HIV in a number of different ways. About two-thirds of the women say they contracted HIV through heterosexual sex. Many of these women know who infected them – most often it was a husband or partner. Some women believe they were infected by sexual transmission but do not know who had infected them or when. There were a few women who say they contracted HIV through prostitution and at least one woman says she became infected through rape. Between six and ten of the women state or intimate that they became infected with HIV through injection drug use. Lastly, one woman reports she was infected through a blood transfusion and one says a tattoo needle infected her.

Of note, a substantial minority of women in the focus groups did not consider themselves to be at risk for HIV infection. These are women who were married or in ostensibly monogamous relationships for years, and had never used drugs. One such white woman from Los Angeles explains,

> A lot of people today when you say, "I have HIV or AIDS," they think drugs or prostitution… They think you either used drugs or you were sleeping with a lot of men. That's one of the things here in Los Angeles, more than anywhere else, they judge you badly. For instance, I was a married woman with a husband and two daughters from the same husband with a happy, quiet home. I never thought it would come to my house. And it wasn't drugs or prostitution.

How women in the focus groups believe they contracted the virus, and whether they considered themselves to be at risk, appears to influence how they reacted to the news that they were HIV positive. Likewise, whether others, especially health care providers, perceived the women to be at risk seems to affect when they were tested for HIV and how they were treated during and after testing.

[After] my husband advised me that he was positive, I did not take the necessary safe sex precautions to prevent myself from contracting the virus. I felt as it we'd married each other for better, for worse, in sickness and in health and I believed that literally as well as spiritually.

African American woman from Philadelphia

Reasons For Being Tested: They Became Ill, They Learned Their Partner Was HIV-Positive, They Were in Drug Treatment, or They Were Pregnant.

About a third of the women in the focus groups say they discovered their HIV status when they became ill and sought treatment. Most say that they did not suspect they had HIV. For example, one African American woman from Philadelphia explains, "Two weeks before my birthday I just got very sick and I thought I had a cold. Within that two-week timeframe I lost about 40 pounds. I didn't have a clue. Then I went to the doctor and he said I have … bad news." A Miami Latina says, "I got ill. I thought it was a normal illness. I had a cough. Before that – three or four years before – I got tuberculosis and I thought it had come back. I went to the clinic. They sent me to get a regular check-up and that's where I found out."

I've had my husband since '80 something. He's bisexual. He told me, so then we separated. In '84, he told me told me he had been with somebody before [we separated]. I went to the hospital, they wanted [to do] the [HIV] tests and I said "No". Then in '91, I had meningitis. They told me I had tuberculosis … It was a social worker that asked me, "Do you want to do these AIDS tests?"

Latina from Miami

Some found out when being treated for other sexually transmitted diseases or gynecological problems. For example, a Savannah woman explained,

> I kept getting a vaginal infection and it would clear up and after I'd be with this one sex partner, it'd come back. I'd go and get medication and treat it again …The third doctor asked me did I want to take an HIV test and I was like, "Sure." I didn't have a problem with it because I knew I wasn't HIV [positive], you know…I was devastated. I mean, I was devastated.

Similarly, a Miami Latina explains, "I got herpes and [went to see] the doctor… He discovered the disease through the herpes."

Others were tested when they learned their partners or husbands had been unfaithful, engaged in high-risk behaviors, or had themselves been diagnosed with HIV/AIDS. One African American woman from Philadelphia says, "I met a guy and consequently I found out that he was seeing a man besides me." A Los Angeles Latina reveals that she was tested "because a partner that I had died of [AIDS]. I didn't know that he was infected until he was dying and the doctor called his mother and called me. He asked us to come in and told us what was really wrong with him …So I told the doctor to please give me the AIDS test."

Many of the women who had been IV drug users were tested while they were in recovery. An African American woman from Philadelphia says, "I was actually in recovery. When you go into recovery in this city, you are tested for STDs and inadvertently [sic] the clinician might ask you to take your HIV antibody test. I agreed to take it. It came back in two weeks, and it came back positive." A few found out in prison or when they were arrested. A white Los Angeles woman explains, "I got arrested for prostitution. It was a court order. I found out at [the] county jail. The doctor called me in and he told me. I was in shock …California tests you if you get arrested for prostitution."

Several women in the focus groups were tested because they were pregnant. As one African American Savannah woman tells, "They give an HIV test to people that's pregnant… So they told me to come in and I went in and that's when she told me." Others were tested routinely for other reasons. For example, one Miami Latina explains, "I left Miami to study… at the Job Corps, which is for young people, where you study. To enter there… they do all kinds of tests to all the young people and it turned out positive."

I … never thought anything about the disease because I didn't know anything about it. I didn't know anyone that had it. I kept getting sick and I kept going back and forth to the hospital. There was a sign in the lobby one day that says we'll pay you $20 if you take the HIV test. Well, $20 is $20, so I [took] it. [It] never, ever crossed my mind that this test would come back positive.

African American woman from Philadelphia

Many of the women – even those who were engaged in high-risk activities like drug use and prostitution – were surprised when they learned they had the virus. A Savannah woman, for example, explains, "Well I was in treatment one time for drug addiction…I kept getting sick. A cold, a cold, a cold, a cold. So they asked me did I want to take the test – HIV/AIDS test. I said, 'Sure, I know I ain't got that shit…' I took the test. And sure enough, I had it." On the other hand, some were not surprised at all. For example, a white Los Angeles woman says, "I wasn't surprised because I mean, really, everybody that I ever got high with, I've found out, was either dead or had it."

Some Women Say They Were Tested Without Their Knowledge.

Several women in the focus groups assert that they were tested without their permission or prior knowledge. For example, one African American woman from Philadelphia who was diagnosed in 1995 explains, "I found out [I was positive when] because I had a lump on the back of my ear that kept bothering me for a long time. I went to a clinic doctor and he just took a test without my knowledge. I thought he was just giving me an examination…. I didn't sign anything." Another African American Philadelphian from the same group adds, "I also don't recall signing anything. I was hospitalized for pancreatitis, so they were already running several tests on me. That's how I found out." A white Los Angeles woman tells a similar tale: "I was in a hospital … in a drug induced coma. When I woke up they told me they had tested me. And they told me I had the virus when I came out of the coma…"

A Number of the Women Were Told of Their HIV-Positive Results in a Brusque and Uncaring Way, Without Much Helpful Information.

While some women in the focus groups were diagnosed in recent months and years, some were diagnosed many years ago – several in the 1980s. Many of the women who received a positive diagnosis in the 1980s told how they believed they had received a "death sentence." A white Californian diagnosed in the mid-1980's explains, "I've known so many people, when they were diagnosed, the doctor told them they had a certain amount of time to live. They definitely were going to die in a couple of years or whatever…. Doctors were giving out death sentences."

A number of women in this study say their providers told them about their HIV infection in a brusque, uncaring manner. For example, the African American Philadelphian who says she was tested without her knowledge explains, "He told me to come back in four days. When I came back, he took me in a room and said, 'You have HIV,' and just gave me a prescription." While most agree things are better now in terms of how providers reveal test results, some say that even today clinics are not adequately prepared to share the news with newly diagnosed patients. A Los Angeles Latina explains that while her own situation was close to ideal, others' were not:

> The problem here in Los Angeles is that a lot of women go to the clinic, they're pregnant [and they get tested]. Before someone is diagnosed there should be a counselor. A lot of these clinics don't have a counselor. I had a friend who was told, "You know what? You have AIDS. Go get some help." When I was given my diagnosis I saw a counselor. I saw a psychologist and I saw a specialist who talked to me. A lot of clinics here don't have that. People just say, "You know what? This is what's wrong with you," and that's it. [The women] get scared to death.

Well, my reaction [to the news that I was HIV positive] was so bad that I tried to kill myself seven times until they locked me up with the crazy people.

Latina from Miami

Not surprisingly, many women took the news of their positive status very hard. Several say they thought about suicide, and a few say they actually attempted suicide.

Another insight is that few women in the focus groups really understood their test results when they were first told. As one Savannah woman, diagnosed in the late 1990's, says, "I got the letter and I was reading it and couldn't understand what it was talking about. So, I went home and let my mother read it and she didn't understand… The letter only said 'some of my antibodies.' I didn't know all of this stuff. I didn't know what it meant. When I took the test [again, later] at the health department, it showed I was positive."

Not all focus group participants were told of their HIV positive status in a negative or uncaring way. On the contrary, a number of women in this study, especially those diagnosed more recently, say they were told in a compassionate, comprehensive way. For example, one Miami Latina explains,

> I really have nothing to complain about as far as that's concerned because the doctor who took my case said, "I'm the director of the hospital and I'm a specialist in HIV/AIDS. You're not going to die. You have many years ahead of you."

A white Philadelphia woman says, "My doctor was very helpful. He told me as long as I took care of myself and took my medication… I can live a long life."

Many Women in the Study Say They Did Not Seek Treatment Immediately After Their Test Results – Only Later When They Became Ill.

How women are told about their HIV status – and their level of awareness that HIV/AIDS is a treatable disease – can affect their willingness to receive treatment, based on focus group input. That first conversation explaining the test results and their HIV positive status can be a conduit to treatment, as in the case of the Los Angeles Latina quoted earlier who said that her doctor told her she had many years ahead of her still and that she was not going to die. Alternatively, these women's experiences suggest that the diagnosis – particularly if it is presented in a cold and uncaring way – can turn women away from treatment. For example, one white Philadelphia woman who was diagnosed in 1990 while in drug rehab explains that her diagnosis led her back to the streets and drug use. She says,

> I found out in 1990. I was pregnant. I didn't know anything about it either. You didn't hear much about it. I thought that it was a gay disease at that time. I was also in recovery at the time. I just thought I was going to die tomorrow, so I went back out of recovery and went back to using because I was going to die anyway. That's what I thought.

Many of the women in the focus groups say they waited months and even years after their initial diagnosis to seek regular treatment. A white Los Angeles woman explains:

> It was almost a year to the day before I was just kind of forced into a situation where I had to deal with it. But at first I just didn't want to think about it. I didn't feel sick or anything and I just had so much other crap going on in my life at that time. So I was very aware that I had it. I was on my own little pity pot. So I didn't get any medical care. I didn't look up any services or anything like that. It was almost a year to the day that I kind of woke up and thought, "You know what, if I'm not any sicker than I was when I first was diagnosed then maybe I'm not going to die right away. Maybe I better start dealing with this." There were a lot of other circumstances involved there but the most important part was about a year after diagnosis I reached out.

As the quote suggests, some women who originally thought HIV was a death sentence decided it was worth seeking medical care when they realized that it was not. An African American woman from Savannah notes, "I started paying more attention when people were talking about HIV/AIDS on the TV. And they were saying they were coming out with these new medicines and people are living longer. [They were HIV] positive [but] not so much going over to the AIDS. So then I said, 'Well I've got to go to a doctor.'"

Many only seek treatment when they start to become ill, believing there is no need to start treatment if they are symptom free. A Los Angeles Latina explains, "A lot of times you just don't even think of going to the doctor. I didn't do that in my case. I didn't think that I had it. I didn't want to know anything about doctors or anything. You just close yourself up in your own little world and you don't want to know anything. [When] I got sick is when I finally got some help."

Finally, it should be noted that many of the negative experiences of women in the focus groups in regard to hearing their diagnosis may directly relate to when they received their diagnosis. Those diagnosed in the 1980s and 1990s – when there were less-effective treatments and when providers knew less about the disease – were much more likely to reveal negative interactions with their providers at the time of diagnosis.

II. Current Healthcare Situation

Most Women in the Focus Groups Are Enrolled in Medicaid – And Seem Satisfied with This Coverage.

The majority of the women in the focus groups – roughly 30 of the 53 – indicate that they have health coverage through a public program, most often Medicaid. Some have a combination of Medicaid and Medicare. There were also a few in each focus group who were uninsured and one or two in each group who had private insurance.

Based on input from the focus groups, it appears that HIV positive women enrolled in Medicaid are satisfied with the care they receive through this program. According to these women, Medicaid gives them access to most of the health services and providers they need to maintain their health and treat their HIV/AIDS. Most say they receive high quality health care services and they appreciate that their care is free. Many of the Medicaid covered women also praise their health providers and a number are able to see providers who specialize in treating HIV positive patients (which most women in this study feel is critical to obtaining quality care). Most also say they are thankful that their medications, which they rely on, are free or low-cost.

My biggest concern is I've never been sick…. All I've had was just yeast infections. What I'm scared of, since I've never had health insurance and I don't have health insurance now is what's going to happen when I do get sick and I have to go to the hospital?

White woman from Los Angeles

Uninsured Women with HIV/AIDS Appear to Face More Barriers.

The uninsured women in the focus groups appear to fare worse than their Medicaid-enrolled counterparts. They say they face many challenges in obtaining the health services they need. Some are frustrated that they are not eligible for Medicaid – most say they have tried to enroll before but were ineligible because of their incomes. For example a Los Angeles Latina explains,

> The reason I couldn't get Medicaid is they said I made too much money. So I would always be told that I didn't qualify, that emergency Medicaid would only cover me if I was in the hospital. So I was restricted… it didn't even cover my medicine or anything. I had to pay $500 dollars for every visit, even if it was only once a month. …So I couldn't really see the doctor the times that I needed to see him.

The women in the focus groups without health insurance say they feel trapped. On the one hand, many say they have too much income to qualify for government help. A white woman in Los Angeles explains that she does not have Medicaid coverage because, "my husband…pulls in maybe $1,800, $1,900 a month. Because of him, I cannot access a lot of things that I should be able to get. When I go to get help … I can't get the assistance." On the other hand, private insurance is too expensive for many of these women. Says one Miami Latina, "I had paid the insurance for awhile, for like three years. The price went up very high, so I stopped paying it for over a year."

Despite their lack of health coverage, many of the uninsured women in the focus groups say they are still able to receive many of the health services they need. They say they go to public health clinics and receive other kinds of help from free programs for people with HIV/AIDS and charitable organizations. As a Miami Latina explains, "Here [in Miami] there are a lot of opportunities for those of us that are ill and don't have insurance. There are programs that will help people with AIDS." An African American woman from Philadelphia explains,

> Even if you go to the hospitals or the clinics nowadays and you don't have insurance, there are so many other programs that are out there they will refer you… If you get a good doctor, she will really go to bat for you to see that you get what you need…There is a lot of help out there.

One program mentioned frequently in the focus groups is Ryan White (technically known as the Ryan White Comprehensive AIDS Resources Emergency Act). According to comments in the groups, this program plays a vital role in providing access to services (such as case management) and medications not necessarily covered by Medicaid or other insurance programs. Uninsured women in the focus groups seem to rely on Ryan White for the bulk of their care.

One particularly important component of Ryan White is the AIDS Drug Assistance Program (ADAP), which provides HIV/AIDS related prescription drugs to uninsured and underinsured individuals, and other safety net facilities like public health clinics and hospitals, these focus groups indicate uninsured women with HIV/AIDS are able to obtain a basic level of health services as well as their medications. However, a number of the women who rely on these programs feel their care could be better. For example, some say they have a hard time seeing a regular provider who is managing their care and ensuring they receive all the services they need to treat their HIV/AIDS infection.

Of course, to receive help from these programs and organizations women with HIV/AIDS must first know about them, and not everyone does. In the words of one uninsured white Los Angeles woman, "[The other focus group participants] tell me I have access to good stuff, [but] I don't know how to access some of this stuff. I need to know how." Uninsured women not connected to the health system or the HIV/AIDS network of advocates and organizations, therefore, may face many more obstacles to obtaining health services.

Uninsured Latinas May Face Extra Barriers to Coverage and Care and Seem to Rely Heavily on Ryan White Services.

I would have a problem if they eliminate Ryan White.

Latina from Miami

There were more uninsured women in the Latina groups than the African American or white groups (which reflects national data that show that as a group, Latinas are less likely to be insured or enrolled in public health programs). Based on their comments, their uninsured status is due, at least in part, to immigration and citizenship barriers. Uninsured Latinas who are not US citizens say they face extra barriers to obtaining coverage and, therefore, healthcare services. As one Los Angeles Latina explains, "I went and was told that I had to be a resident of the country and to be here legally in order to be able to get Medi-Cal." A Miami Latina explains, "When you don't have a legal status it's very difficult to get insurance." But Latinas do say there are other options. As a Miami Latina says, "Ryan White is the main thing that backs you up, it's one of the federal funds that helps you, whether you have citizenship [or not], if you don't have money." However, a few Latinas in the focus groups are unfamiliar with Ryan White or other programs designed to help low income women with HIV/AIDS, which puts them at risk of not receiving the health services and medications they need to treat their HIV/AIDS.

Women with Private Insurance Indicate There are Some Drawbacks to Their Coverage – Particularly Those in HMOs.

Many of the women in the focus groups who are privately insured say they also face problems in obtaining care. Their biggest challenge appears to be affording the premiums, deductibles and co-payments they must pay as part of their health coverage. A few women give examples of putting off care because they could not afford it – despite having private health insurance. Some women also complain about some of the medications they need not being covered by the plan's formulary, or having to pay for medications out of their own pocket and then have to await reimbursement. For example, one African American Philadelphia woman complains, "Basically, my HMO covers it but since it was something that was new on the market, it didn't get to the HMO. [I paid for it up front,] but they reimbursed me the money."

Women enrolled in HMO plans are the most likely to complain about their coverage. Many say that having to obtain referrals before seeing a specialist is a hassle – especially since many of these women must see an array of specialists frequently. An African American woman from Philadelphia explains: "So you need a referral. Then they want a second opinion and if this second opinion doesn't agree, your HMO is not going to pay for it. So then what was the purpose of going through the hassle of getting a referral and they don't want to pay for what you need it for. I see another specialist, and this is my third specialist. I have to go just to get a hysterectomy."

It is not only women enrolled in privately insured managed care plans who complain about referrals, but also women in Medicaid managed care plans. A Miami Latina says, "Since I have Medicaid and MediPass, I have to choose a [primary care] doctor. So if I want another doctor to see me, I cannot. My doctor has to give permission for another doctor to see me." Since women with HIV/AIDS have a frequent need to see specialists, often are prescribed newer medications that can be missing from HMO drug formularies, and generally use the health system more than other consumers, referrals may be more of a barrier to care than for other populations.

Regardless of Type of Health Coverage, Women Connected to an AIDS Service Provider Seem to Fare Best.

More than half of the women in the focus groups say they receive medical care through an AIDS service provider or AIDS clinic, and most praise these providers. What they seem to like most is the comprehensive services available to them through these providers, and their expertise in treating women with HIV. They appreciate that they can access a wide range of health services – routine care, gynecological exam and lab tests – usually available in one location. As an African American Philadelphian explains: "I get all my care at [name of service provider] under one umbrella. One doctor… and her associates, the nurse practitioners." A white Philadelphia woman says, "We have a pharmacist, a nutritionist, everything is right there." Women who use these providers say that if a service is not provided on site, they are referred to a provider who is willing and able to treat HIV positive patients.

> Anyone who's HIV positive, the first thing they tell them is, "Get hooked up with a service organization."
>
> *White woman from Los Angeles*

It is this "one stop shopping" element of the local AIDS service providers that the women in the focus groups seem to value most. They remember what it was like seeking care prior to finding their current AIDS service provider, and how overwhelming it can be to find the right providers who understand HIV and who will accept their coverage. To many of the women in the focus groups, being part of a system of care through their local AIDS service provider has been a vital part of their learning about their illness and becoming informed about their treatment options.

While it is important to note that some AIDS service organizations do not provide healthcare services on site, many of these providers are connected to a network of HIV-friendly providers, saving women the task of finding doctors themselves. Women in the focus groups explain that these organizations can also provide case management and treatment education, help people enroll in public programs like Medicaid, and that they accept many different kinds of health coverage. As a white Los Angeles woman explains, "Health insurance will come your way if you are hooked up with a service organization. If [you] have a decent case manager [you are] set." It is this mix of healthcare and social services that prompt many women in the focus groups to praise their AIDS service organization. As one Savannah woman said in explaining why she chose her clinic, "I was interested in being a part of their clinic. Besides, they had different [services] that they offer. You know, like they had counseling and group therapy and stuff like that."

"I've got private insurance [and could go to a private doctor] but I go a clinic that I think is excellent."

White woman from Los Angeles

Most of the women who use these providers feel they are essential to obtaining good care and services. As one Los Angeles white woman explains, "[If you were newly diagnosed with HIV and came to me for advice] I would hook you up with an AIDS service organization, depending on where you lived and what your ethnic [group. It depends] on where you're comfortable." Many women also appreciate the friendly atmosphere and personal attention they receive at these facilities. A Savannah woman reveals, "I went into the Health Department program and I was one of those skeptical people. But I will tell you they have treated me like I was a queen…. I'm in and out. They do what they have to do to me and tell me what's the next step." An African American Philadelphian explains, "I can call there and say it's [name]. They've got to have 6,000 people but they know who I am."

The women in the focus groups covered by Medicaid and those who are uninsured seem more likely to be receiving care at an AIDS service provider than those with private insurance. This may be in part because these providers are likely supported by Ryan White funds, which specifically aim to help uninsured and low-income families. Many of these women cannot afford or do not have access to private doctors, making these services critical for their health. These clinics are so good relative to what else is available, according to focus group participants, that even some women who have private insurance prefer to use them. As one white Los Angeles woman explains, "I've got private insurance [and could go to a private doctor], but I go to a clinic that I think is excellent."

Many Women Point Out That Access to AIDS Service Providers May Be Limited in Smaller Cities.

Focus groups for this study were held in large urban centers as well as smaller cities like Savannah. Insights from the focus groups suggest women with HIV in larger cities have more opportunities to connect with an AIDS service organization than those in smaller cities. For example, in the Los Angeles focus groups, women say there are many options for someone seeking care who has HIV/AIDS and these participants list the names of many clinics and other local organizations nearby.

In smaller cities there may be fewer options. In Savannah, for example, women in the focus groups say their choices are limited. Says one Savannah woman, "Thank God we've got the Health Department because us infected women that don't have anything, at least there is a place for us to go." Some participants in Miami feel Latinas did not have enough options there – i.e., AIDS service providers that specifically served the Latino population.

Some women in the focus groups also say that you have to know where to look for help, even in a city like Los Angeles. A white Los Angeles woman explains, "Once I really started getting involved and connected I found that we have a lot here in Los Angeles. We have a lot of AIDS specific organizations. We're very lucky."

III. Relationship with Providers

Seeing a Primary Care Provider Who Is Familiar with HIV Is Best, Say Women in the Focus Groups.

Most focus group participants report that they have a primary care provider (PCP) and most say they see this provider regularly for check-ups and other preventive services. Those who are currently having health problems say they have doctor's appointments several times a month – some with their PCP, some with other providers. Those who are not currently experiencing health problems see their PCP less often; some say every few months and others say a couple of times a year. In the words of a Miami Latina, "If I don't have anything [wrong], four or five months can go by and I don't have to go."

The first doctor I got was a man, Doctor___. He gave me an ulcer. He was more of [the] "I want to get paid" [type]. He was more HMO… no caring. So I asked for somebody else and they gave me a nurse practitioner. She is excellent. I told her if she was to leave, I was going to follow her.

African American woman from Philadelphia

Most women say their provider treats many other patients with HIV and they like this fact. Many acknowledge that their provider's experience with HIV increases their comfort level and makes them feel they are receiving better care. Indeed, most of the women say they are satisfied with their primary care provider; quite a few are very enthusiastic. Several women who have not been happy in the past have been able to switch to a provider they now like.

For Some, the Main Point of Contact Is a Nurse Practitioner – and That Is Fine.

About a third of the women in the focus groups say their primary care provider – or at least their main point of contact – is a nurse practitioner rather than a physician. This is the case in both clinic/AIDS service provider settings and in private doctors' offices, but seems more common in clinic settings. In Savannah, for example, almost all the women who go to the Health Department clinic say they primarily see a nurse practitioner.

Those who have this arrangement explain that they are usually seen by their nurse practitioner but if problems arise or things seem unusual, a doctor will become involved. As one Savannah woman explains, "We at the Health Department see a nurse practitioner but there is a doctor if you need to see her. But most of the time, when you go in for your check-ups it's a nurse practitioner." A Philadelphia African American woman explains, "I go to [name of service provider] . My doctor [is there and] … under her is a nurse practitioner. I see [the nurse practitioner] monthly. But if I have to go do anything else, that is bothering me besides HIV, they refer me to someone else in the hospital."

Most of these women seem happy seeing a nurse practitioner on a regular basis. They feel comfortable with their nurse practitioners and say they spend more time with them than a doctor would. As a Savannah woman explains, "[The nurse practitioner] was the first person that I got to see when I was first diagnosed with it. And I'd rather just stay with her and listen. I don't want to be having all those different people telling me all those different things because I'd be crazy."

Important Qualities in a Provider: Competence, Caring, Good Communication, and Accessible

In assessing their primary care provider, women in the focus groups talk about four different elements: competence, caring, communication skills and accessibility. In terms of competence, many women say that it is important to them that their provider is very informed about treating HIV/AIDS. An African American woman from Philadelphia says, "[My doctor] really knows her medicine, that's what counts." A white woman from the same group says of her providers, "Everything is done right there. They are very informed; they know everything that is going on." A white Los Angeles woman says, "I have a good doctor. She's a specialist at [name of service provider]."

Having caring and compassionate providers who listen to them is also important to women with HIV/AIDS. A Miami Latina comments,

> [My doctor is] a very human person. He's excellent. When you go he doesn't treat as if he were a doctor…. For me he's not a doctor. He's my friend, my confidant. He dedicates a lot of time to me when I go there. He gives me all the time I need.

A Savannah woman told about her former doctor, "He was a private doctor. He was a great doctor. He was so sweet. He would come talk to me. If I needed him to sign papers, he'd be delighted…he treated me [well and] made me feel so comfortable. He retired last year..."

The most frequent complaints about providers – made more often about doctors than nurse practitioners – is that they do not spend enough time with patients. Says one Los Angeles Latina, "The only thing that I don't like about my doctor is that she gives us very little time. Most of it she leaves to the nurse so sometimes if you have important things to say to the doctor, she doesn't give us the time that we need." Women in the focus groups appreciate providers who are accessible and who answer their questions. For example, a Los Angeles Latina explains, "I think that she helps me a lot because when I get there … sometimes I don't have an appointment and I say "I want to go in." They'll let me have my appointment. They'll ask me how I'm doing and I'll tell them what I'm concerned about. I would not trade her because she's very good for me."

Most Women in the Focus Groups Want a Female Provider.

While some women in the focus groups say they do not care whether their provider is male or female, most say that it matters. They want a female provider, particularly for gynecological care. One African American woman from Philadelphia explains, "To me it would matter. In the beginning I think if it was a man it may not have mattered, but because I've gotten a lot of opportunistic infections in those [genital] areas, it is no way in heck I want to go tell a man, "Take a look at this." A Los Angeles Latina explains, "I've had both, a man and a woman. I think that she pays more attention to me… I trust my [female] doctor more."

Some Latinas Have Faced Language Barriers when Seeing Providers.

"[I had a problem] just once and I left. It was like a doctor's visit. You didn't get a chance to say anything and I didn't speak a lot of English either. So I thought, "They're going to kill me here."

Latina from Los Angeles

Most Latinas in the Los Angeles and Miami focus groups say they are able to see providers who speak Spanish, and this is important to them. They assert that they receive better care, and have a better relationship with their provider, if they can speak freely with him/her about their health. However, a few women in both cities told of incidents where they faced a language barrier with their providers. For example, a Miami Latina tells about a doctor she dealt with soon after her diagnosis years ago, "I [had a problem] because the doctor only spoke English and they had to always be getting someone to translate for me." A Los Angeles Latina explains that she sometime had a longer wait before appointments: "They would leave me for last at the clinic where I was because they were looking for an interpreter."

Most Women in the Focus Groups Say They Also Have Access to the Specialists They Need to See.

Many of the women in the focus groups have multiple health problems, some closely related to HIV, others not. As a result, they see a variety of specialists including Gynecologists, Dermatologists, Oncologists, Neurologists, Ophthalmologists, Cardiologists, Gastroenterologists, and Ear Nose and Throat (ENT) specialists to name a few. One Savannah woman with multiple health problems explains, "Besides [my] HIV [provider], I go to a doctor for polyps in the throat that came from being HIV positive…And then the internal doctor at [name of provider] . Then I have a back surgery specialist..."

Most say they have access to and coverage for their visits with specialists. According to many women in this study, Medicaid almost always pays for specialty care and they are usually able to receive services with little problem. Women who are in the care of an AIDS service provider and/or of PCPs who see many HIV patients also say that they have good access to specialty care and usually can see a specialist who is used to treating HIV patients. As one African American woman from Philadelphia explains, "If I have to see a specialist, my doctor makes sure he can deal with me because I have HIV."

Those Women Not Covered by Medicaid or Not Attached to an AIDS Service Provider – and in Managed Care Plans – Appear to Have More Problems Accessing Specialists.

Some of the women who are not attached to an AIDS service organization and those not covered by Medicaid may face more restrictions accessing and paying for specialists. For example, some women who are in a private HMO say they have a limited choice of specialists they can see, and that their choices may not include a specialist who knows much about HIV. Some of these women also mention a high co-payment they must pay when seeking specialty care.

Some women also complain about long waits to see their specialists, which they say is problematic because of their HIV status. One Miami Latina explained, "They give you an appointment [weeks away even through they know] you're an AIDS patient. Like me now, I was ill with vomiting, nausea, and they gave me an appointment with a gastroenterologist on the 11th of March. I had to go the emergency room after I had been vomiting for a month."

Managed care also seems to play a role in access to specialty care for some women with HIV/AIDS. This includes women in private health plans as well as those in Medicaid HMOs. The issue, which has already been mentioned, is the need for referrals from their PCPs before they can access a specialist. According to some women enrolled in managed care plans, this adds delays and is frustrating especially if there is an urgent need for care although few report being denied access to their specialist.

IV. Drug Therapy, Medications, and Lab Work

Most of the Women Currently Receive Drug Therapy and Understand Its Importance.

About two-thirds of the women in each group are currently on an antiretroviral drug regimen. Many have been on different therapy regimens over time. Several know the names of all their antiretroviral medications. However, some – especially those who are taking multiple drugs or have recently or frequently switched regimens – have trouble with the specific names. In the words of one African American woman from Philadelphia, "I don't remember the ones that I'm taking. Viracept and…then I'm taking some yellow ones. I can't think of what that one starts with."

Most women in the focus groups seem to understand that certain drugs – or combinations of drugs – fight HIV, the virus. All seem to know that drug therapy does not cure HIV but keeps the virus in check. Moreover, many understand that these drugs differ from those they might take to treat or prevent HIV-related opportunistic infections (OIs). However, some women do seem confused about the distinction between antiretrovirals and drugs used to treat or prevent OIs.
In contrast, there is a small group of women in this study who appear to be especially savvy about antiretrovirals. For example, one Miami Latina explains, "I never take protease [inhibitors], I just take nucleosides." Some are proactive about investigating drugs and drug therapies. For example, one white Los Angeles woman says, "I…ask [my nurse practitioner] about any med they are going to put me on. Before [I take a new drug] I'm going to say to the doctor, 'Let me see the PDR.'"

Although drug resistance was not specifically discussed in all the focus groups, many women appear to understand the importance of monitoring their drug regimen and know that over time, people may develop immunities to certain medications. As one Philadelphia African American woman explains:

> What I've learned is that within seven years of taking any medicines it becomes resistant, [no matter] if you are taking it right or if you are taking it not right. My viral load is still between 450 to 500. They're only really now letting people go on medicines when their viral load is 350. So, I'm not really playing with the medicines until I start getting sick because I don't know how long the medicines will last in my system.…There are so many different scenarios, so I don't want to play with the medicine.

Staying on a Drug Regimen Is Hard, According to Many Women in the Focus Groups.

Most of the women who are on drug therapy say they take it seriously and are aware that staying on a schedule is critical to the therapy's success. In the words of one African American Philadelphian, "It's a matter of discipline with regards to following the medication regimen. You have a choice. You can adhere or … suffer the consequences from the fall. I just try to remain in compliance. I don't like it, but I know that it is necessary." Another African American woman from Philadelphia explains that she stopped taking her medication even though she knew how important it was to keep to the schedule. She explains:

> I was taken off of medicine about a year ago. Actually, I had stopped taking medicine because I kept forgetting it, and I was told once I started taking medicine that you had to make it a habit like you eat. I kept forgetting to take it, so I just stopped. When I went to my doctor she told me my viral load was 1141. I wasn't taking medicine but I lied to her and I told her I was. [But then] before I left I couldn't stick with that lie. Before I left I had to tell her that I wasn't taking it. I was afraid something could happen to me so I let her know.

[Taking my pills] is harder for me [than all the blood work]. To get up every morning and having to take all those damn pills! It's a lot harder than them sticking me [to draw blood] because I know that is going to be over. But the pills are like every single solitary day.

African American woman from Philadelphia

A third Philadelphia woman expresses similar feelings but has not gone so far as to stop taking her drugs. She says, "I take so many [pills] and I said if it gets any bigger than this, you might as well just forget it. I won't be taking no more medication." Other women agree that taking so many pills can be overwhelming. A Savannah woman quips, "I'm supposed to take one [pill] a minute"

Some women in the focus groups admit that they occasionally forget to take their medications. For example, one Miami Latina explains, "Sometimes I forget…because I'm so busy doing other things. Next thing I know, oh my gosh, I have to wait for the next dosage." One Savannah woman says that her daughter helps her keep on schedule, "At one time it was hard for me to keep up. But now… my little girl, she gets my medicine for me."

Most participants say they know other HIV positive women who have lapsed in their regimen. A few reveal that they too have lapsed at times. Perhaps the best example is the woman from Philadelphia quoted above who stopped medications completely since she was unable to keep to the routine. Another woman from the same group admits, "[Last month] when I was depressed…I didn't take my medicine for a whole week." A white Los Angeles woman says that there was a time when she stopped taking her medicine because she was in denial. She explains, "I thought I could live a normal life like everybody else because I hated getting up and taking pills."

Many Women Say They Experience Side Effects – Some Mild, but Some Severe.

Among the side effects mentioned most often are dizziness, fatigue, weight gain, skin rashes, nausea, diarrhea, and lack of appetite. In the words of one African American woman from Philadelphia, "I'm going through the gamut taking the different medications. The nausea, the vomiting, the sleep, you can't sleep, you are not hungry, you are hungry. It's crazy."

A lot of the women appear to take the side effects in stride, just as they do the strict dosage schedule. For example, a Savannah woman explains how sometimes you just need to get used to the effects of a new medication, saying, "[I had side effects] at first. The first side effect I had was that I broke out all over…. After that, it was a nauseous feeling from taking it. You would feel bad. [But], as the days went on – you had to make sure that you eat properly, got your proper rest and took your vitamins – it was more bearable."

I cannot take not one of the protease inhibitors. Either it feels like I swallowed glass, or I'm calling [my nurse practitioner] saying I can't feel my tongue. I can't take none of them, not one PI. I've tried them all and I had serious adverse reactions.

African American woman from Philadelphia

Some women have switched regimens when the side effects were too extreme. An African American Savannah woman explains, "[My doctor] did cease [the medications] for awhile because the side effects were terrible, they were too devastating for me. After I got straightened out, I started back on them again." Another Savannah woman explains, "I broke out all over. I'm talking everywhere – all down in my private parts. They took me off [that drug]."

While most participants who have stopped medications as a result of side effects appear to have done so in consultation with their provider, a few participants admit having stopped on their own. For example, a Miami Latina says,

> I stopped because the medicine that I was given lately was going to give me a heart attack and I had these really strong chest pains. So I was telling my doctor that the medicine made me feel this way. She wouldn't stop so I just stopped it myself and I felt better. It's been five months and I haven't taken any medicine. But I do want to take some medicine because I know it's been good for me before.

A white woman from Los Angeles explains, "I'm not on medications. I haven't been on medications for three and a half years now, because I was just tired of the side effects, the fatigue and the diarrhea. I could not do anything but go to the bathroom and go to bed."

Most of Those Who Are Not on Drug Therapy Say They Do Not Need It.

Most of the women in the focus groups not currently on drug therapy explain that their "counts look good" and they are being carefully monitored. A white woman from Philadelphia explains, "I have never took meds yet because my count is 519. My viral load is only 100. I take Interferon for my Hepatitis. They keep a close eye on me to make sure that doesn't affect my HIV count and all that stuff." A Los Angeles Latina explains,

> I'm not taking any. I just stopped three weeks ago because I went to the clinic last month and the doctor tested me and it turned out that I have 996 cells. The viral count is undetectable so I can stop taking the medicine for awhile because it also makes the liquid in your bones waste away. So I stopped taking that …

Many of those who are not currently on antiretrovirals are less clear about the details of what their counts are, but do insist that they are under their healthcare provider's supervision and are receiving lab tests regularly.

Many Take Other Medications to Prevent Opportunistic Infections or for Other Conditions.

My doctor says that I am doing very well, that my system is going really well and it's not necessary to take medicine.

Latina from Los Angeles

Most of the women in the focus groups, whether they are currently on an antiretroviral regimen or not, say they take other medications regularly or periodically. Many of these drugs fight or prevent HIV-related OIs. For example, some use nasal spray to prevent pneumonia. Several mention having recently finished a course of antibiotics for pneumonia or other infections. Several of the women have other serious illnesses like diabetes or hepatitis for which they also take regular medications. Among the non-HIV drugs most often mentioned are anti-depressants.

Women Enrolled in Medicaid or Receiving Help from Ryan White and Other Drug Subsidy Programs Seem Able to Obtain and Afford the Medications They Need. Privately Insured Women, However, Struggle with Their Co-Payments for Medications.

Based on focus group comments, women's experiences obtaining and paying for medication differ depending on their insurance status, healthcare provider and site of care, as well as whether the medications in questions are HIV drugs or not.

In terms of insurance status, women enrolled in Medicaid say they have little or no trouble obtaining the medications they need. Most say all their prescription needs are covered completely. Many of the uninsured women in the focus groups say they also have access to medication thanks to Ryan White and other drug subsidy programs. As one Savannah woman explains, "If we can't pay for our medicine, then you just get in touch with your case manager or someone who has to do with the Health Department and they'll pay for it." Another Savannah woman explains, "Patient advocate, Patient Care Assistance …They go by income. And if you have a low income it covers your medicine."

Women with private insurance in the focus groups, however, report more difficulty obtaining and paying for their medications. The main problem is affordability – many say they have to pay high co-payments. As one privately insured Savannah woman explains, "It depends on what the co-pay is [and] the price of my medication. A price on my medication could be $500. My co-pay on $500 still may be $100. I got eight different pills that I'm taking. So imagine what my co-pay is on some of my medications." Another privately insured Savannah woman explains,

> [The price I have to pay] ranges. I have asthma and most of my asthma medications run me about $20 a prescription. My Glucose control is $20, my Dilantin is $5…It can range as low as $5 a prescription or as high as $20 or $25 a prescription.

None of it is affordable. [But] I'm on a special pharmaceutical program, so it is affordable [for me].

African American woman from Philadelphia

Another problem for some is that their private insurance sometimes will not cover medications they need. For example, one African American from Philadelphia explains, "One of the medicines I'm taking is a new medicine. The HMO didn't cover it. It cost me $340 [a month]…That is how much it costs just for 30 pills." It should be noted that a few of the privately-insured women in the focus groups receive medications through the Ryan White AIDS Drug Assistance Program.

Many Women Say Access to Antiretrovirals Is Better than for Other Medications.

A number of women in the focus groups say that coverage and access depend on the kind of drug in question. Simply put, the more directly linked to HIV a drug is, the easier it is for women to obtain and afford. Antiretrovirals are the easiest to obtain through their coverage programs, according to many women in the focus groups. Drugs commonly used for prophylaxis and treatment of OIs are also generally accessible and affordable. Other prescription medications can be more difficult to procure, especially for those who are uninsured. An African American from Philadelphia says,

> [The] Special Pharmaceutical [Program] is only for HIV medicines. But there might be something that is going on with you that [you need a medicine that] is not an HIV medicine. It only covers the cocktails and that is when an insurance problem comes in. But you need it because of the virus. I don't understand that. If it has to do with the virus, just give it to me.

Likewise, a Miami Latina explains, "The immediate medicines, I don't have a problem with them. [But] let's say I get bacterial sinusitis, they have to give me a prescription and to get that medicine it's so difficult. So then I have to pay out of my pocket." As the focus group participant points out, obtaining medications for other health conditions (such as sinusitis) can be harder to obtain.

Another issue for some women is where they must go to actually pick up their prescriptions. It seems some women with comprehensive AIDS service providers are able to pick up their medications – or at least their antiretroviral and perhaps more common OI treatment and prophylaxis drugs – on site. Women agree this is the ideal situation. As a Miami Latina explains,

> I can tell you one of [the problems with getting prescription medications]. For example, I go to [a clinic] to be seen and my specialist gives me the [prescription for my] medicine, but the pharmacy where I have to go pick up my medicine is a totally different place. So sometimes a person just got out of the hospital and you're too ill to be traveling in a bus or wherever, to that pharmacy to pick up the medicine. We are fighting to have a pharmacy right there at [the clinic] because that would be the logical thing instead of going up and down.

Most Women in the Focus Groups Know that Regular Lab Work Is Important to Monitoring Their HIV.

Most of the women in the focus groups say they have regular lab work done and recognize the importance of blood tests as a way to monitor their HIV and inform their drug therapy. The majority know they are given a CD4 test as part of their blood work and that the higher their CD4 count, the better. Likewise, most know that they are given a viral load test, and that a high viral load is a bad sign indicating a high level of virus in their body. Perhaps because they recognize the importance of regular blood testing, most women appear to accept the "hassle" involved with regular lab work – i.e., some women cite the frequent visits to the labs, the discomfort of having blood drawn, and waiting for test results. However, some do complain about the amount of blood drawn. An African American woman from Philadelphia complains, "I hate [getting blood tests]. That's a lot of blood."

But Some Women Have Questions about Their Lab Results and Do Not Always Understand Them.

While many women are confident that they understand their CD4 and viral load counts, some acknowledge being confused. For example, an African American woman in Savannah admits,

> I didn't get [information] about the CD blood counts and the viral rules for a long time. And what I really don't still understand to this day is what's the difference from AIDS and HIV? Because [its] been diagnosed [that I] went from HIV to full blown AIDS. My count was less than 20. I'm like, "What does this mean?" They called my family in for family counseling but they're still not telling me nothing. Now, it's back up to 308. So I'm still not understanding that. They say you're doing good. That's all they're telling me.

Others explain that it took a while for them to understand all the terminology associated with their lab work. One white woman from Philadelphia says, "I didn't know what the hell they were talking about…It used to be just your T-cells, then all of a sudden they came out with your viral load and wait a minute. They tell me I'm supposed to know about my CD4 and now it is your viral load. At first you don't know...It's very scary and you don't really know and they could be telling you anything."

While most women in this study feel that their questions about their lab work are answered by their doctors, nurses, and other medical providers, some say they are able to get answers only if they are aggressive about asking. For example, a Los Angeles Latina explains, "I'm demanding with my doctor. I say, 'What is my CD4 like?' 'What is my viral load like?' … I always ask what's going on with my tests."

Others report that they rely on other sources of information when interpreting their lab results. For example, a Miami Latina explains where she has learned about the tests: "At [name of provider] there's a special group to educate people on HIV. So people have the opportunity when they are waiting for the appointment to not be there wasting time, they take these classes and they inform you of everything there." A Savannah African American woman explains that her clinic gives out booklets to help explain what the test results mean.

Many women report that they are receiving additional blood tests other than their CD4 and viral load. For example, a Latina in Los Angeles explains, "They say [the blood test are for] the liver and T cells. Anemia. Diabetes. Viral load. CD4." Another adds, "They look at your pancreas, your liver, your viral load, your anemia, to see if you have any brain disease." A white woman from Philadelphia says, "I get checked more often because I also have Hepatitis C."

V. Two Important Services: Gynecological and Dental Care

Most Women in the Focus Groups Say They Know that Gynecological Care Is Important for Women with HIV.

The majority of the women in the groups appear to recognize that regular gynecological exams and pap tests are especially important for women with HIV/AIDS. A Miami Latina explains, "It's very important, especially when we have the counts low and the virus is high. You have to check the pap smear very, very closely because it comes back abnormal and that becomes cancer." In the words of a Los Angeles Latina, "It is important because of the condition that you're in…Even if it's nothing serious, it's still important. It's necessary."

Most women also appreciate the need to obtain gynecological care from a provider who specializes, or at least has experience, in treating women with HIV. As a white Los Angeles woman says, "When you're speaking about OB/GYN, for women it's just like you need a doctor who has experience treating people with HIV and stays up on the latest things. As much as I read, I know that HIV manifests itself there quite frequently in women." Another white Los Angeles woman switched from her regular gynecologist to one who had experience treating HIV positive women. She explains the reasons for her switch:

> Now that I know I have HIV, now that I know that it's manifesting itself in me gynecologically, I have no faith that [my regular gynecologist] could treat me from that point. If he didn't even know what the symptom was, how was he going to treat me day to day, … I asked my HIV specialist for a gynecologist that had numerous [HIV] patients. She didn't have to be a specialist, but she had to be so familiar with HIV through her practice so that I felt she would catch on to anything that might happen to me.

Most Say They Receive Regular Gynecological Exams.

Most women in the focus groups also seem to know they should have a gynecological exam – or at least a pap test – on a regular basis.. About half of the women say they see a gynecologist for their ob-gyn care. Others have their pap test and exams done by their regular provider, often a nurse practitioner. Some say they use a regular provider for routine exams but have access to a gynecological specialist if needed. As one African American woman from Philadelphia explains, "The nurse practitioner specializes in [treating women with] HIV and she gives us our pap tests and stuff and if there is a problem, she will send us somewhere."

When I go, [the nurse practitioner] will look on the chart and [say,] "No, you don't need a Pap smear." [Then I wonder] How do you know? I want you to check me down there today.

African American woman from Philadelphia

There were some women in the focus groups, however, who admit they are not so rigorous in receiving pap smears or seeing their gynecologist. A few admit being lax in this area; they know they should go more often but do not.. There were also a few women who seem unaware of the particular need for women with HIV to receive frequent gynecological exams.

Most Women Say They Have Access to Gynecologists. Once Again, Those Enrolled in Medicaid and/or Under the Care of an AIDS Service Provider Seem to Have the Best Access.

For the most part, women in this study say that they have access to gynecologists and that their gynecological exams and pap tests are covered by insurance. Those women enrolled in Medicaid and those who are with an AIDS service provider are especially likely to say they have coverage for and easy access to these services. Many of the women involved with an AIDS service provider receive gynecological care on-site, while others indicate that their organization has relationships with gynecologists who specialize in treating HIV positive women

Those without Medicaid, and those without a connection to an AIDS service provider, appear to have more trouble obtaining quality gynecological care. Some of these women say they have had the experience of seeing providers who were uncomfortable treating HIV positive women. A privately insured Savannah woman tells of her experience: "The gynecologist that I went to see, he really hurt my feelings. No matter what, I'm still a person and I feel that I should be treated equal. I don't mind them putting on your gloves, but don't treat me as if I'm nobody."

Others, especially the uninsured, have problems because of a lack of coverage. For example, one Los Angeles Latina explains, "It's been about two years [since I have seen a gynecologist]…Because I've had appointments and I haven't been referred … There are no funds to pay. I don't have Medi-Cal. I don't have insurance so I have to pay [if I go]."

When It Comes to Dental Care, Most of the Women Say that Improvement Is Needed for Women with HIV. Their Biggest Complaint Is a Lack of Providers Who Will See Them.

Many of the women in the focus groups claim they are not receiving adequate dental care. In each focus group, there were several women who had not seen a dentist in over a year. A substantial minority of woman admitted they have not been to a dentist in several years; some have not been since their HIV diagnosis.

One of the main reasons the women give for why they do not see a dentist is that there are too few who are qualified and willing to see HIV positive patients and/or people enrolled in Medicaid. In Savannah, for example, most participants see a dentist who works with the health department. While they appreciate that this dentist is available to them, there is often a long wait for appointments. As one woman explains:

> I'm not going to a regular dentist. I'm going to the Health Department dental provider. We have a dentist that works solely with us ….Him being basically the one that you want to deal with because he knows your HIV status puts it in a bind because your appointments are three and four months before you can get in to see him. I booked this appointment in January to see this doctor in April because that was the earliest opening that he had… There are so many people that he has to work with.

Another Savannah woman explains: "I haven't had a dental appointment in about a year because the facility where I went was not up to date to treat HIV patients… Then the appointment I had at [the Health Department], was like a six month wait for August. I didn't even let her make an appointment because I knew I probably would have forgotten it."

Women in other cities also complain about difficulty finding dentists who will treat HIV patients. A privately insured Los Angeles woman explains,

> I had a problem and I went to a dentist using my dental insurance. I checked the box with HIV and the dentist said, "Oh, we're full. You know, USC has a dentist. They can better help people like you." So I went home and I thought, "Well, that's just the way it is. I need special care." Then I just happened to talk to a friend of mine who also happened to go to that same dentist and got that same thing.

In both Philadelphia and Los Angeles, some of the women say they are treated by dental students because they are more available and willing to see them.

I had [a dentist] appointment and I said, "Oh excuse me, but this is confidential, I have AIDS" and he said, "Oh, no no." And I said, "Hey what happened?" And he said, "No it's impossible, no." He said, "Get out of my chair!" He sprayed the chair. He sprayed the frickin chair.

Latina from Miami

Many Women Can Tell of Unpleasant Experiences Seeing a Dentist.

A white woman from Los Angeles, in listing the biggest healthcare challenges facing women with HIV, said, "What's bad is dental care. If you go to a private dentist and you let them know [you have HIV] they don't even want to touch you. When they do go to touch you, they're scared." Other women say they have been poorly treated by dentists or even turned away once they shared their HIV status. A few even say this happened with a dentist they had been seeing for a long time. A white Los Angeles woman explained,

> I had to have a root canal because my tooth fell out. You talk about precautions….I'm thinking, "I've been going to you with the same HIV in my blood for four years now, and all of the sudden now that you know I have HIV…" He could barely move his fingers with how many gloves he had on.

Other women reveal that they fear their dentist's reactions to their HIV status and so delay care so they do not have to tell him or her. One Savannah woman says, "I'm afraid to go to my dentist and tell them that I'm HIV positive because I don't know how they are going to react." An African American woman in Philadelphia is hesitant to go to the dentist for similar reasons. She said, "That's why I don't go [to the dentist]. I'm sorry. I know it sounds ignorant. I know it does sound ignorant because I'm saying it and I'm hearing myself. But it's just that with me, this is not the first time I felt discriminated against."

Women with Medicaid Coverage Seem to Have the Least Problem Accessing Dental Care. Uninsured Women and Those with Private Insurance Appear to Face More Challenges.

Those women in the study enrolled in Medicaid say their dental care is covered by the program and they appreciate this since they consider dental care to be important. However, cost and coverage are issues for the uninsured and those who are privately insured and do not have dental coverage. In the words of a Los Angeles Latina, "There are no funds to pay [for dental care]. I don't have Medi-Cal. I don't have insurance so I have to go pay."

My dental care is paid through Ryan White because my [regular, private] insurance does not have dental. It doesn't have a dental plan attached to it.

African American woman from Philadelphia

Some uninsured women say they are able to obtain their dental care through Ryan White. Other women just say they pay out of pocket when they can afford it or admit they just do not see a dentist because of the cost. Those women connected to an AIDS Service Provider, regardless of type of coverage, seem best able to access dentists familiar with treating HIV patients. This is important since a number of women say they have faced discrimination and poor treatment at the hands of dentists unfamiliar with HIV/AIDS.

The Connection between Regular Dental Care and HIV May Not be Fully Understood by Some Women with HIV/AIDS.

Some women in the focus groups appear to have only a vague sense of how their HIV interacts with their oral health. While many seem to know that it is important that they see a dentist regularly, they may not know what to look for or to ask the dentists. An African American woman from Savannah says, "I do know that I need to be seen by a dentist because being HIV, it really decays your teeth real fast and bad." A Miami Latina said she believes that dental care is more important for people with HIV because, "You lose calcium a lot. We have a lot more problems. We get a lot more cavities." Another explains, "When you are HIV positive, things are more serious….You are more affected by any little problem you have and just the blood. Once you get infected you get this white thing in your gums."

[Dental care is important for those with HIV] because our immune system is down. It caused me to have all my uppers out at the infectious disease dental clinic.

African American woman from Philadelphia

However, some women are unaware that dental care is especially important for those with HIV. For example, one Miami Latina explains that she had not been to the dentist for three years because she "did not need to go." Others make similar comments that indicate they do not see a dentist regularly.

Many Women See the Value of Seeing Specialized Dentists Who Treat People with HIV.

The majority of women in the focus groups recognize that it is in their own best interest to see dentists who know how to treat patients with HIV. In the words of a Savannah woman, "[Dentists who are not specialists] are not familiar with what kind of symptoms an HIV positive person might have. They don't know exactly what they're looking for." An African American woman from Philadelphia explains, "It is best to go to an infectious disease dentist because your lab work, they won't touch you until they see it and it has a lot of things to do with your T-cells, your viral load and a couple other [things like] liver function test and stuff that they do if they need to extract a tooth or give you Novocain and that kind of stuff."

They are looking for certain things that a dentist doesn't know to look for, if he doesn't know you are HIV positive…. Sometimes you can have a little pimple in your mouth that could be something else, turning into an ulcer and you wouldn't know. All kinds of things that is HIV related.

African American woman from Philadelphia

VI. Stigma and Discrimination

Most Women in This Study Say Stigma and Mistreatment Are Still a Problem.

Many women say that the personal treatment of HIV positive women by the healthcare system has improved over the last five to ten years. These women say that the increasing number of HIV-friendly providers and sites make obtaining health services easier and more pleasant for women with the virus than it used to be. Several women point out that these providers are "special" and "dedicated"; they work with HIV positive people because they want to.

Nevertheless, nearly every woman in this study has a story of discrimination or poor treatment at the hands of someone in the healthcare system. Many of those who have been positive for several years still smart from being treated poorly in the past. More troubling still, many women tell recent stories of discrimination and ill treatment from healthcare providers. Such treatment appears to be most prevalent in dentist offices, emergency rooms, and in the offices of physicians, especially specialists, who are not used to treating HIV positive patients. Not surprisingly, mistreatment at the hands of primary care physicians and specialists who routinely treat HIV-infected individuals is far less common according to focus group participants.

It depends where you go for services. If you go to a place that's HIV friendly, it's going to be a hell of a lot different than walking into a county hospital.

White woman from Los Angeles

The following quotes demonstrate the mistreatment participants have experienced in the healthcare arena:

> [Going to] ______Hospital doesn't work… I know that. They don't treat [HIV positive patients] fair. They take them, but they treat them like dirt. They are very rude and they discriminate.
>
> *- African American woman from Savannah*

> When I got to [this] gynecologist's [office] and I had to do a pap smear because I hadn't done it for awhile, he told the nurse to get the things while he talked to me. I told him I was positive and he went like this [gestures surprise and disgust]. He didn't do the pap smear. He said he couldn't take care of me….[So] I left. You know, you get confused because at this point in life you don't expect [that]. At this point of the disease you don't feel you are going to run into someone ignorant like that. It did bother me a lot.
> I got sad.
>
> *- Latina from Miami*

> Once I told [this general practitioner] that I was HIV positive and that there were years that I had not seen a doctor and I [just moved here] from Boston… He handled me like I had a contagious disease or something. He threw me out of his office right away.
>
> *- Latina from Miami*

> I initially found out [I was HIV positive] from ___ Hospital. They sent me to a doctor right there in that facility. I had met with him a couple times before [when we were trying to find out what was wrong with me.]. Once he found out my diagnosis, he acted like I was this horrible germ. [He said,] "I'm going to refer you to somebody else. I don't need to see you anymore." You are just finding this out and then someone treats you like [that]. He sent me subsequently to ___ which turned out to be good because it is a very good department there. But just the way he did it like, "Get your disease ridden self away from me." I really felt angry about the way he treated me.
>
> *- African American woman from Philadelphia*

People see my chart and they see HIV. They treat me bad…. I don't care what they said but don't treat me bad because I treat you bad. You are human just like me. You are a normal person just like me. Only because I have a disease is not mean you treat me like shit.

Latina from Philadelphia

It is unclear that every experience shared in the focus groups was about discrimination – in some cases, it may be that the provider felt unqualified to treat a woman with HIV/AIDS. However, even in those cases, it seems that providers rarely explain this to their patient or handle the situation in a positive way. An exception is provided by a Savannah woman who told how a doctor referred her to someone more qualified without making her feel badly:

> When I was first diagnosed, my son's teacher [referred me to her husband, Dr. ____] He was so good. He was just the sweetest doctor. I recommended [him to] a couple of [HIV positive friends] … He wrote me a letter saying not to refer anybody else to him because he took me on as a favor to his wife but he's not very familiar with the disease and what kinds of medicines to give. And, as a matter of fact he stopped seeing me when my T-cell count dropped. He stopped seeing me because he didn't know what to do if I got real sick.

Concern about Mistreatment Causes Some Women to Hide Their HIV Status.

Several women in the focus groups say they have hesitated in the past to share their HIV status with providers for fear they will be treated poorly. In the words of a Savannah woman, "Sometimes when you go to the doctor – if you have to go to the hospital or the emergency room or something … Sometimes, I don't think that I should tell them that I am HIV positive, because they are going to treat you different." Many women say that they know about other HIV-positive women who do not tell healthcare providers their HIV status. A few women say that they have, on occasion, not told healthcare providers their HIV status. For example, one Savannah woman tells the group,

> I had a thing lanced from under my arm and I had four doctors in there holding me down. But I bet you, if I would have told them that I was HIV positive then one doctor would have said, "You want this thing lanced? Are you going to stand there and take this needle [and do it yourself] or what?" That's just how they would have treated you.

Likewise, some women seem to feel that if a medical problem is not HIV related, or if treatment will not involve needles or blood, there is no need to tell a provider that they have HIV.

The challenge with not informing providers about their HIV status is that they might miss symptoms or other signs that could be important to the overall health of women with HIV/AIDS. By keeping this information private, some of these women many be limiting the ability of the provider to treat them to the best of their ability. Since providers today should follow universal safety precautions with all of their patients whether they have HIV/AIDS or not, unknowingly exposing providers to HIV infection should not be a major problem.

Shame and Privacy Concerns Can Be Barriers to Care.

These focus group results suggest that shame and concerns about privacy and confidentiality can be a barrier to care for some women with HIV/AIDS. A few women appear to have made healthcare choices based on privacy concerns. For example, an African American woman from Philadelphia picked her healthcare facility in part for privacy reasons,

> [The clinic was] was across the street from the hospital at the time. I really liked it because it was like a separate entrance because in the neighborhood where I live, you really didn't want nobody to know you had it. It was like you were going like this [gestures hiding your face] before you even opened the doors to go in. So that really made a difference that I had a lot of privacy.

A Savannah woman opted against going to a certain facility for care because, as she explains, "…I had a lot of kin people and a lot of friends that were employed there. And I didn't want everybody in my business, you know, traveling information."

Another Savannah woman says that she once lost a job because they "did a background check and something came up about me being HIV positive and I lost my job because of that." Moreover, she says that as a result of that experience her husband, who is also HIV positive, will not seek treatment for fear of losing his job, even though (or perhaps because) he has private insurance through his job.

A lot of women when they find out they have the virus, they want to die. They're ashamed. And they don't want to take care of themselves. That is the worst part of this whole thing, the stigma involved and people not knowing what to do.

White woman from Los Angeles

Personal Acceptance, Self-Empowerment, and Connecting to AIDS Organizations Are Vital to Overcoming Barriers, Say Many Women in the Focus Groups.

These focus group results suggest that accepting or identifying as an HIV positive woman can be an important step. According to some women in the focus groups, acceptance of their HIV positive status led to self-empowerment which is important in overcoming barriers to obtaining good healthcare and other goals. In short, those who recognize that the virus does and will always play a major part in their life and those who become active and learn about the disease and treatment options feel better about their care, and about their prognosis. A Miami Latina explains,

> It becomes part of your life. It becomes like your job and it's better to be that way because for ten years I didn't want to know anything about it. I didn't want to go to the doctor. I thought I could solve it all, but now that I'm taking more care of my health, I've done very well.

Similarly, a white Los Angeles woman explains that those who act as partners in their healthcare rather than just patients have a significant advantage over those who do not. She says, "See, when you have the virus, you have a certain responsibility. No one is going to take care of you. You need to learn to be proactive and take care of yourself."

One of the big problems is that the women who really are seeking [help] don't know where to go.

White woman from Los Angeles

For many of these women, part of acceptance and empowerment is becoming connected to AIDS organizations. The information and support these organizations provide is vital, according to women who have benefited from these relationships. As an African American woman from Philadelphia explains,

> Basically, it's networking. Once you start going to the support groups, you meet people. You have to come out. If you come out and come to just one support group, you are going to have learned so much.

The focus groups themselves demonstrate the appeal of networking and mutual support among women with HIV – participants often exchanged information about providers, support groups, sources of information, and medications to each other both during and after the focus groups. Also, those women in the focus groups who were less connected and informed about HIV/AIDS received much attention, support, and advice from the more connected women in the groups.

VII. Mental Health and Emotional Support

Most Women with HIV/AIDS Believe that a Healthy Mental Outlook Is Critical to Maintaining Their Physical Health.

As a Savannah woman explains, "My mental stability has a lot to do with my physical stability." Another Miami Latina says,

> The psychological part is very important. I think that's one of the greatest things that we need help in. The psychological part is very important because we can be very well nourished and have [coverage for our health needs], but we need more psychological help.

In the words of another Miami Latina, "We are very vulnerable to depression. That's the way it is. It's true no matter how strong we are."

[The most important thing is] the psychological help…If you don't get that nothing works for you.

Latina from Los Angeles

A significant number of women in the focus groups say they receive needed emotional support and psychological help from a variety of sources. Many report that they currently see a psychiatrist, psychologist or counselor or have done so in the past. Some women say their AIDS service organization has counselors on staff and relationships with HIV-friendly mental health professionals to whom they refer clients. Some women also say they receive help and emotional support from support groups and case managers.

While coverage for mental health care was not discussed in the focus groups in detail, many women say that Medicaid covers counseling and psychiatric medications. It is less clear whether and to what extent the privately insured and the uninsured have access to mental health care. While many seem happy with the psychological help available to them, a few complain that psychiatrists are too quick to put them on anti-depressant medications. For example, a white Los Angeles woman explains:

> I had a doctor [who was] putting me on all kinds of psychological medications, something for depression and for this. She put me on some BuSpar and she put me on Zoloft. I took all this s**t back and I said, "I don't want this s**t messing with my head and all that." She put me on anything, like she was experimenting with me.

Unfortunately, these experiences may make patients turn away from psychiatric care entirely. For example, a Savannah woman reveals, "I had been seeing a psychiatrist… That ended about four or five months ago, because he was trying to put me on psychotropic medication and I didn't want to get on that."

Women's stories in the focus groups about their reaction to learning about their HIV status suggest that having counseling available immediately after their test results are revealed is vital. As noted previously, many women, especially those who were diagnosed several years ago or told about their status in an abrupt way, tend to react by withdrawing completely. Many say they were depressed. A few attempted suicide. Some waited years to start regular medical treatment.

For Some Women, Becoming Infected with HIV Has Made Their Life and Their Health More Precious.

Some women in this study say their HIV status has made them turn around their life and take better care of themselves.. For example, a white Los Angeles woman explains,

> I spent my whole life trying to kill myself. When I tested positive, it was probably the one defining moment in my life when I realized that I don't have to try to kill myself anymore. As bizarre as that sounds … I realized I don't have to actively try to kill myself anymore. I've got a disease that will do it. It'll do it in its time. I don't have to do that anymore and it was kind of like a big relief for me. You know what I mean? I got off the streets … It just kind of turned my whole life around really. I did literally spend a better part of my life trying to kill myself… I started shooting dope at 14. I was pregnant at 13. I started taking drugs when I was eight. So I had been pretty actively killing myself for years…"

I thank God today for the experience because it has made me such a stronger person.

African American woman from Philadelphia

Others express similar sentiments. For example a Los Angeles Latina says, "I try to live every day better than the last. Before, I didn't care. I thought you've got your whole life ahead of you. You have all this time." An African American woman from Philadelphia explains, "Everything about me has changed. If you saw me five years ago, you would just be shocked… I wanted to be nothing like the way I was… I'm trying my best to live a positive life.… I wanted to be a better person and be real about things that I'm dealing with."

Some women say they have become much more religious as a result of their struggle with HIV. One African America from Philadelphia explained, "With me it made me spiritual… Once I found out it just made me more spiritual. It made me start focusing on church and I didn't have a clue what church was about. Then it made me closer to Jesus."

VIII. Case Management and Support Groups

Many Women in the Focus Groups Have Access to Case Management Services of Some Sort.

A case manager's job is to empower you…You will have them in place for your continuing care, for when you may need housing, when you may need respite care, when you may need transportation.

African American woman from Philadelphia

Over half of the women in the focus groups say they receive case management services in one form or another; many work with an individual case manager. Not surprisingly, those who are attached to an AIDS service provider are more likely than others to say they have a case manager.

According to women in the focus groups, their case managers help them access a range of financial, support, and clinical services. They say their case managers help them to enroll in Medicaid and other programs like ADAPs. They also serve as a resource about things like housing and transportation programs. As an African American woman from Philadelphia explains, "I go to my case manager for knowledge, for things that I don't know like different programs that might be out there." A white woman from Los Angeles simply says, "[Case managers] educate and teach [you] how to work the system."

For some women, their case manager is also an important emotional support. As an African American woman from Philadelphia says, "I can talk to [my case manager]. I can say, 'Look, I'm having a bad day or I woke up and I'm having this insane thought.'" A Los Angeles Latina states simply, "When I need to talk to her I talk and she listens, so she really helps me."

A few women in the focus groups also stated that their case managers offer some assistance with medical case management. For example, some women's case managers help patients schedule appointments with specialists or resolve coverage problems. One Savannah woman, for example, explains that her caseworker referred her to a place where she could receive free eyeglasses. A few women, especially Latinas, say they turn to their caseworkers when they have questions about their care and treatment. As one Los Angeles Latina explains,

> Sometimes we don't understand the medical terminology… Sometimes doctors will tell us things in medical terms and we don't understand them. So I write everything down and then I tell my counselor and he explains it or he helps me talk to the doctor so that I'll get rid of my doubts.

Another Latina from the same group adds, "When I need to know about any medicine I call her. 'Is it okay to take it this way and do I take it with food or without food?' So she advises me."

A Few Women Question the Need for Case Management.

A few women in the focus groups – usually those not connected to an AIDS service provider or who admit to having problems accepting their HIV positive status – say they do not want or need a case manager. As a Latina from Philadelphia explains,

> I don't want [to have a case manager] ….Because I can do my own [decisions]. Why do I need a case manager? I can make it. I can do stuff. …I'll be [very sick one day] but now that I'm okay, I don't need no service from nobody. I can do it on my own.

A few women question the benefit of a case manager because they have had bad experiences with case managers in the past. Another reason why a few women do not want case managers may be that they do not understand the breadth of services and supports that a caseworker can access and provide.

Many Say Support Groups Are Important for Fellowship, Education, and Networking.

Many women in the focus groups say that that support groups are important to women with HIV.[5] Women connected to an AIDS service provider and who strongly identify themselves as HIV positive seem the most enthusiastic about support groups and being part of the HIV community more broadly. A fair number of these women belong to multiple support groups or organizations.

Basically, it's networking. Once you start going to the support groups, you meet people. You have to come out. If you come out and come to one support group, you are going to have learned so much.

African American woman from Philadelphia

Among the most important benefits of being in a support group, according to many women, is the chance to be with others who know what you are going through. As one Miami Latina explains, "I want to go to a place [with people] that are infected like me, people that feel what it's like to live with this." A white woman from Los Angeles says, "For me that is the most important part of dealing with this disease was connecting with somebody else that's got it." Being able to share with a group may be especially important for those who are not sharing their status with other people in their lives. As an African American in Philadelphia reveals, "There is only two people besides the [women in my] support groups that I talk with, and that is my mother and my husband ….. Sometimes I feel isolated because I can't share like I want to, or talk about what is going on with me because I'm afraid of what people may think." Support groups provide emotional and spiritual support too. As a Savannah woman explains,

> It's a group of women who sit down and talk about how to better take care of themselves. How to deal with whatever problems or stress that might be going on….The support group tries to keep each other strong. Keep yourself on your medication, keep your head up, don't give up.

In the words of one Miami Latina, "We have a support group through our church. We get together once a month. It's more of a spiritual thing. Sometimes psychologists… or people that specialize in the immune system [come] and give us classes, but it's mainly spiritual because we have like retreats and things like that."

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[5] It should be noted that the women participating in these focus groups may be biased in favor of support groups since many of them were identified and even recruited by local AIDS service providers, where support groups would likely be offered and encouraged.

As the previous quotes suggest, support groups appear to be good places to learn and share information. As one white Los Angeles woman explains, "I think for a lot of women, whether they realize it or not, one of the best resources they have [is] other women. The doctor can tell [a woman] everything he wants to in his office. Regardless of what he or she tells her, she is going to go to a support group and say, 'What are you taking and how are your side effects?' Then she is going to make her decision."

Some Women Do Not Want to Be Involved with Support Groups.

Some women say they are not currently involved in support groups. Some of these women have been involved in the past but feel they no longer benefit from attending. For example one Miami Latina explains,

> Little by little I realized that in these support groups they didn't have [what] I needed…Each of these support groups you go to tell the same story and leave [out] the psychological part that we need so much …. These support groups should be more towards the psychological part on how to mentally help us, how to overcome stress. That type of support is what we need the most.

Another Miami woman says, "I used to like to go to the support groups, but now you go to the support group you have to tell the story again. How you got infected and all this. That's why I don't go, it becomes a routine thing."

Others have never gone to support groups. Some explain that they are just "not the type." For example, one Savannah woman says, "I don't take time to go to support groups because I'm just that kind of stand back person, that's just me."

IX. Logistical Barriers: Transportation and Child Care

A number of women in the focus groups say they face additional barriers to obtaining the care and services they need. As a white Los Angeles woman explains,

> It's not just a matter of whether, for instance, healthcare is available. For women, there always seems to be the question, "How am I going to get there?" Or "Who is going to watch my kids?" Transportation and childcare are big issues and yet, in funding, the county, they put it way low on the priorities list. As if they feel that offering medical care shows that they really care about women. But the fact that there's no funding to get women there and watch their kids is not important. Then they turn around and say, "Well, women aren't accessing these services, so we're cutting the budget."

For women, there always seems to be the question, "How am I going to get there?" Or "Who is going to watch my kids?"

White woman from Los Angeles

As this quote suggests, transportation and child care are issues for many HIV positive women in this study.

A Number of Women Say They Have Faced Transportation Problems When Trying to Access Medical Services.

Several women in the focus groups say they sometimes have problems getting to and from medical appointments. This appears to be due, at least in part, to the limited number of providers and clinics that serve the HIV community. In the words of a white Los Angeles woman, "I live here and the place they want me to go is [far away]. I've got two kids and no car." A Miami Latina explains, "I have found problems to get there because I live very far from ____." Another adds, "I go on the bus; I go two hours before my appointment."

Some women point out that help with low-cost or free transportation services is available in some areas through Medicaid and Ryan White, but it seems many do not take advantage of these services. The problem may be that many women simply do not know these services exist. Others are confused about the details of who is eligible and how the programs work. And still others find the programs to be too complicated to be worthwhile – i.e., they require advance scheduling or the transportation service is not reliable.

Sometimes transportation is difficult because we have to wait for the bus for a long time…I have two children and one I have to leave in school and it's very far from the clinic.

Latina from Los Angeles

Philadelphia provides a good example of the transportation challenge that some women with HIV/AIDS face. More than half of the women in the focus groups had heard of a specific transportation program in that city, but only a few knew how the program actually works and even fewer had used the service. There is substantial confusion about the details of this service. For example, some women in Philadelphia believe you are only eligible for transportation under certain circumstances. One African American woman says,

> You get [transportation help] if it is dealing with disability, like if you can't get around, if you are sick then you get the service. [You are not eligible] just because you have the virus. You have to have like an opportunistic infection or not be able to stand for a long time or walk or something like that.

In Philadelphia, and in other cities, some women complain that arranging for transportation or being reimbursed for travel expenses is too burdensome or inconvenient. For example, one Philadelphia woman says that she can sometimes be reimbursed for travel costs but, "You have to go through too much." In Savannah, one African American woman says she sometimes finds using the Medicaid-provided service difficult because you have "to call three days in advance."

With Medicaid, you've got to call the Medicaid Van. That's what I have to do. Unless it's a last minute appointment. Like you made it a day before. Then the white van, the little happy white van, will be more than glad to pick you up.

African American woman from Savannah

Women who are not Medicaid beneficiaries point out that many of the transportation options are only available to those with Medicaid. In the words of one Savannah woman, "If you're not a Medicaid patient, and you don't have anybody to take you, how are you going to get there? They have these specialized Medicaid vans or whatever to pick you up but if you're not a Medicare or Medicaid patient, you can't get there."

Child Care Can Be a Barrier too.

As one African American Philadelphia woman who is a mother explains, "You miss appointments because you don't have a babysitter." A Los Angeles Latino explains, "Sometimes what we need most is child care because sometimes we don't go to programs or meetings or to discussions because we don't have the child care, which is what we need as mothers."

Some women make due with neighbors and friends. A Miami Latina explains her situation, which she finds less than ideal: "[My daughter] is ten-years-old. I have to leave her at a lady's house. I always have a problem with that."

No, they [the clinic] doesn't have child care. My support group, they have respite care where they have someone who comes to your house while you go to clinic.

African American woman from Philadelphia

There are some facilities and organizations that do provide child care and mothers in the focus groups say they are very appreciative of these services. An African American woman from Philadelphia says, "Where I go, I can take my children and there is someone there to watch my children." Other women's answers suggest their clinics might not have an official caregiver but that they allow and expect that some patients will bring their children with them to appointments.

X. The Unique Challenges of Women with HIV/AIDS

Having Children Adds to the Distinct Challenges and Responsibilities that Women with HIV Face.

A number of focus group participants say that women with HIV, especially those with children, face different issues and have more responsibilities than men. In the words of a Los Angeles white woman, "Women are third class people to begin with and then you take into consideration that we are taught to take care of others first. And that's what we do. We save ourselves for last." An African American woman from Savannah says, "A women prioritizes things in life, so she can see her worth in taking care of herself. A man doesn't feel like that. A woman has responsibilities as long as she has children."

As the previous quote suggests, many women also say they have more responsibility caring for others and more reasons to take care of themselves and keep the disease from progressing. As a Savannah woman who is guardian of two abandoned children explains, "I think God sent me those two children, it got my life straight." A Los Angeles Latina explains, "A man is always out on the street. Women stay home. She thinks of the children more than anything. You [take] your children all over. The man just gets dressed and goes to the doctor by himself."

A number of women cite that their concern and love for their children kept them from committing suicide, especially in the period right after diagnosis. For example, one Miami Latina explains that when she was diagnosed,

> I almost threw myself from the fifth floor because I had just gotten married. It had been three months only. The truth is I was going to jump. God is so great and at that moment I was living with my daughter and I thought of her….I said, whatever life I have, I'm going to live for her.

In each of the focus groups, there were one or two women who discovered their HIV status during pregnancy. As one white woman in Philadelphia explains, "I got tested because I was pregnant. I ended up losing the baby anyway. They just started it back then like it was mandatory – when you are pregnant, they did one." A Miami Latina explains, "I found out when I was pregnant with my son … I went to have my pregnancy test I was asked if I wanted an AIDS test and I said yes."

Many of these women say their pregnancy gave them a reason to take care of themselves. As one woman from Los Angeles, a Latina, explains, "Since I was pregnant, I thought about my baby. I thought my baby was going to die. So that's why I was motivated more than anything."

Having children after being diagnosed with HIV was not directly discussed in the focus groups, although several women in the study who had children after learning of their HIV diagnosis. There were others in the focus groups, however, who clearly felt that having HIV precluded them from having additional children. For example, a Los Angeles Latina explains, "The barrier I feel is having another child. I see other friends who get pregnant and they're happy with their partner. I don't know if they don't care but the way I see it, knowing that I'm HIV positive, I just don't want to get pregnant. I don't dare to get pregnant."

The overall impression from mothers in these focus groups is that they have additional responsibilities – caring for children and other family members – that can affect how they care for themselves. Some women put off their own care because they put everyone else first. Others say having children and others who depend on them makes them take better care of themselves. And as mentioned earlier, having children can make seeing a doctor and receiving medical services difficult because of child care and transportation challenges.

Some Women Assert That Women and Men Deal Differently with HIV/AIDS.

Some women feel HIV positive men have a harder time than women dealing with their illness. They note that women are used to sharing their feelings and leaning on each other. A Latina from Miami explains, "Perhaps because [women] are more expressive than men. Men keep things inside more. We talk more." An African American woman from Savannah made a similar point,

> Women are more open about their needs. Men are more stand back, they are not as expressive as women. A lot of men don't deal with it like a woman does…You know how a women prioritizes things in life, so she can see her worth in taking care of herself. A man doesn't feel like that.

Women's answers about how women and men deal with HIV may differ depending on the group of men with whom they are comparing themselves. Many women perceive that HIV positive gay men have greater access to certain support services and some medical care. At the same time, some women seem to feel that heterosexual men (or at least outwardly-identified heterosexual men) face problems, at least in terms of finding support and medical care. These perceptions may influence women's attitudes about differences between the sexes in living with HIV.

Help and Support for HIV Positive Women Is Slowly Improving, According to Women in This Study.

Women in the focus groups diagnosed early in the epidemic note that HIV originally was – and to some extent still is – seen as "a gay man's disease." In the early days, these women say there were few places for HIV positive women to turn for help, support and information. One African American woman from Philadelphia who has been HIV positive for over a decade explains,

> The agencies that existed were the only ones that … was able to carry us through this thing. However, [their focus was not] women's issues… To learn about [HIV], we just had to learn about all men's issues. You had to hear about rimming and this and that in order to get an understanding …If you go to one of their forums and you had to hear time and time again that [the] agency specialized in men that have sex with men.

On this same point, an African American woman from Savannah says, "For the longest time there wasn't even any help for women that were HIV positive. It was only a gay thing. And then they switched it from a gay thing to men, but they never did anything for women and also for women with children."

Most women in this study assert that things have improved since the early days and that they continue to improve. As the Philadelphia woman quoted above also notes, "[Now there are] more activities that consist of them wanting to survey us about how we feel about what is going on." A white Los Angeles woman says,

> I won't say it's enough, but I think one good thing is that there are more and more services or things geared to women now. At [name of service provider] which was primarily gay men, there is now a women's services department, a women's lunch, and a women's section in their magazine… You can write articles and read about women's problems. It's slowly starting. There are some more women's support groups.

My biggest pet peeve in the entire world, is to have a doctor come in, look at me, and try to explain to me how the virus works in my body. And I'm sitting here knowing that he doesn't have a clue how this virus works in a female body.

White woman from Los Angeles

Other women also give evidence that their AIDS service providers have become more women-oriented. For example, in Savannah, many participants spoke warmly of a local service provider's attention to women's issues. And in all the sites, many women say that they see doctors and social workers who specialize in treating HIV positive women. As a white woman from Los Angeles says, "Even in the support groups and everything, the gender stuff is a big factor."

Despite the Positive Changes, Many Women Still Say HIV/AIDS Treatment, Research, and Services Are More Geared to Men.

Even with recent advances, many women in the focus groups still feel that much of the HIV community and structure is geared to men. In particular, many perceive that treatment and research are still male-oriented . Indeed, many women in the groups feel that the medical treatment that women with HIV receive is inferior to the treatment men receive. Medical science, they feel, has not totally come to terms with treating HIV in women. White women in Los Angeles were especially vocal on this point. In the words of one white Los Angeles woman, "Unfortunately, it's still this statistic: That most women's 'AIDS defining' illness is death." Another notes, "Why is the 230 pound man taking the same dose as me, and I weigh 130 pounds? That's the big question that's been asked for years now and nobody seems to be interested in looking for the answer." An African American woman from Philadelphia explains, "I think with that there is not a lot of research towards women's health…Even if the medications, if they work differently based on body weight or gender or whatever."

Some women do note that there have been improvements in this area. In the words of one Los Angeles woman, "If we compare where we're at now to five years ago, ten years ago maybe, we've made great strides. Women have access to clinical trials, where as in the '80s you couldn't even get in. Because of your ability to have a child, you were excluded." Another Los Angeles white woman explains how things were:

> When they diagnosed me with an AIDS related cancer, I was told that I did not have this cancer because it wasn't on their guidelines. Here are these people looking at guidelines. They turned me down for my social security because I was not - and they were looking at guidelines for 1981 for gay men. And gee, there are no cervical cancers out there? What do you mean there are no cervical cancers out there?

She goes on to say that at least this would not happen today. A few women also complain that some of the non-health related services and programs – like housing – are easier to obtain if you are a man. They say that women can only receive such help if they have children. As a Savannah woman explains, "Mostly what I see here with the Medicaid and stuff, women have to have children. That's why I work, because I was never able to get any kind of assistance from the city. They do assist men, I know that." When asked to elaborate she mentions that childless men can get help with housing and other kinds of non-medical help but women cannot.

XI. Informational Needs and Sources

Many Women with HIV/AIDS Are Hungry for Information.

Many of the women in the focus groups feel they know a good deal about HIV and how best to care for themselves. Those who are connected to the HIV community or are strongly identified as HIV positive are especially likely to believe they are well-informed. Indeed, their comments in the focus groups suggest they are fairly knowledgeable about the virus, treatment options, and about how to obtain services. However, even these connected women have gaps in their information – such as how to understand their lab results, how to obtain transportation services, how to keep up with their drug therapy regimen, and where to find dentists who will see HIV patients. The unconnected women in the focus groups – those who are not seeing an AIDS service provider and who do not feel comfortable identifying as an HIV positive woman – seem to have many more holes in their knowledge.

I have enough [information] to get by, but I could never have enough.

African American woman from Savannah

Regardless of their perceived or real knowledge about HIV/AIDS, many women say there is always more to learn. As one African American Philadelphian explains, "You never have all you need because there is new stuff every day." A Los Angeles Latina explained, "There are so many things that you need to know." There are also some women who admit outright to having many questions about their condition. For example, a Savannah woman, when asked what questions she has about HIV/AIDS, replies,

> What I really don't still understand to this day is what's the difference from AIDS and HIV? 'Cause I've been diagnosed, went from HIV to full blown AIDS. My count was less than 20. I'm like what does this mean? They called my family in for family counseling but they're still not telling me nothing. Now, it's back up to 308. So I'm still not understanding that. They say you're doing good. That's all they're telling me.

Another Savannah woman says, "I didn't know that HIV was going to bring on everything else that I got…That's why I wish they had told me that I was going to get diabetes or Hep C, high blood pressure. I didn't know all of that come along. And the question is, 'What's next?'"

It appears some women remain in the dark purposely. For example, when one privately-insured Savannah woman was asked if she had all the information she needed she answered, "I really don't know anything about it and it's not because it hasn't been provided, let me state that." She went on to explain:

> It's just because I didn't go out and seek it … because I'm just that kind of stand back person, that's just me. All that I want to know [my AIDS service provider tells me]. We can learn it, it's just not that we can't. It's definitely available if you want it.

Providers, AIDS Organizations and Other HIV Positive Women Are the Main Information Sources, Although Many Use Other Sources such as Television and the Internet, as Well.

When asked where they obtain their information about HIV/AIDS, many women say their primary care provider is their main source. As noted earlier, some of the characteristics women value most in providers are good communication skills and accessibility. Though many women feel their healthcare provider – whether a primary care physician or a nurse practitioner – is the ideal source for information, they also recognize that providers, especially doctors, are often rushed and short on time. For this reason, even those women who have a good relationship with their provider look to other information sources as well.

Another source that many women say they turn to is other HIV positive women in formal or informal support groups. For example, an African American from Savannah explains, "Mostly I get [information] from talking to other people. I get my best information from people who are living with it." Another woman from Savannah says, "My support group helps me a lot too. They have any kind of information you want on HIV. When any kind of information comes out, they share it with us."

You come out of your home and go to different support groups or women's seminars and stuff so you can educated.

African American woman from Savannah

Some women also rely on treatment education programs such as seminars or talks given at different AIDS organizations. For example, a Miami Latina explains, "[Name of health provider] has a talk every month where they update you on the latest medicines and the reactions that you could have to the medicines and all that. I like to attend those."

Some women feel these alternative sources are just as important as the information and advice they receive from their providers. For example, a white Los Angeles woman says "The doctor can tell [her] everything he wants to in his office. Regardless of what [the doctor] tells her, she is going to go to a support group and ask, 'What are you taking and how are your side effects?' Then she is going to make her decision based on all that."

Some women also say they rely on written information. Some say they read the pamphlets and brochures available to them at medical offices and elsewhere. Others read magazines and books, often borrowing them from AIDS organizations' libraries. Many also turn to the internet to look up issues related to their HIV (particularly medications) and some say that TV has been an important source of information.

IMPLICATIONS

Many ideas emerged in the focus groups for improving access to quality healthcare and information for women with HIV/AIDS. Many of these ideas come directly from the women in the focus groups, some are implied by their comments, and others are strategies for responding to the barriers and challenges they identified during the focus groups.

Time of diagnosis is a critical moment to inform, support, and connect women with HIV/AIDS with services.

Some women say that how their provider told them about their HIV status affected when and if they sought treatment. Others talked about their need for support during this time, and how they could not turn to family members for fear of rejection. Others who were directed to an experienced provider during this time are thankful they were immediately put under the care of someone who knew about HIV/AIDS and who could inform them about it. These insights suggest that effort should be made to connect women – at the point of diagnosis – to the providers, organizations, and mental health services that can care best for them.

Women with HIV/AIDS face unique challenges that should be addressed.

Women in this study say they face distinct issues because of their gender – everything from motherhood to the various infections they incur to how they express their feelings about being HIV positive. They are interested in specific kinds of services – mental health support, child care assistance, and help with transportation so they can make doctor appointments. They also want to see female providers because they feel they will know their bodies better. Yet some feel that the medical community as a whole is more focused on men with HIV/AIDS and not on women.

Women with HIV/AIDS have a range of needs that extend beyond traditional medical care.

Needs discussed in the focus groups include transportation assistance, counseling, better information about HIV/AIDS, child care, access to new and low cost medications, and more. It is for this reason that women in the study involved with local AIDS organizations tend to fare better than those who are not – they could access a variety of services and networks of information through their contact with the organization. Those women who are largely dealing with their HIV/AIDS on their own, or who see a provider not experienced with HIV/AIDS, may be missing out on useful connections that would enhance their care.

Address the important role that mental health services can play for women with HIV/AIDS.

Many women in this study say they have used or want to use mental health services to help them cope with the emotional strains of HIV/AIDS. Many say they need to express their feelings and fears and want someone to talk to, particularly soon after learning their HIV status. If made more available, particularly at critical times such as the time of diagnosis, more women say they would use these services.

Making Medicaid available to more women with HIV/AIDS and continuing to support ADAPs may help connect women to the care and services they need.

Focus group participants with Medicaid coverage appear to have better access to the providers and services than women with private coverage or no coverage at all. Making this program available to more women may lead to better care for those women not currently enrolled. Also, ADAPs are an important source of affordable medications for women in this study (particularly the uninsured), and continuing and enhancing these programs will help to ensure their access to medications.

Continue to use providers, peers, and Internet, TV/radio, as well as other sources, to inform women with HIV/AIDS.

Most women say they are hungry for more information and they look to their providers, other women with HIV/AIDS and the Internet as primary sources of this information. They also find local AIDS organizations to be helpful in accessing information. Television also appears to be an important source of information for some women with HIV/AIDS and should continue to be used to relay new and breaking information on this issue.

Reach out to Latinas with HIV/AIDS.

Comments made throughout the focus groups by Latinas with HIV/AIDS suggest they may have gaps in their knowledge of available programs and supports available to them. In addition, language barriers and concerns about immigration may keep them from applying for Medicaid or seeking assistance from AIDS service providers. This suggests that special outreach may be needed to inform Latinas with HIV/AIDS about coverage opportunities and to connect them with local AIDS organizations.

An executive summary of these findings (Pub# 3379) is available on the Kaiser Family Foundation's website at www.kff.org.

Additional copies of this report (#3380) are available on the Kaiser Family Foundation's website at www.kff.org.

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