



The Healthcare Experiences of Women with HIV/AIDS

Insights from Focus Groups

EXECUTIVE SUMMARY

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For the Henry J. Kaiser Family Foundation

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The full report of findings for The Healthcare Experiences of Women with HIV/AIDS (Pub# 3380), is available online at www.kff.org.

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 system,
- 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 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.

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

² Analysis of data from the HIV Cost and Services Utilization Study, 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.

KEY FINDINGS FROM THE FOCUS GROUPS

The women who participated in this study tell compelling stories about their lives and their struggles. There was much they had in common – most talked freely about their HIV status and its effects on their lives – but it also became clear that each faced individual challenges and struggles in life.

Consider Stacey⁵, a non-Hispanic white woman who participated in the focus groups. She told about the problems she faced getting an accurate diagnosis of her HIV status. As a married woman who lived in a nice neighborhood, neither she nor her doctors considered an HIV test despite the many symptoms she had been experiencing. By the time she was finally tested, Stacey explained, “My fallopian tubes were infected. I had bad gynecology problems, a lot of infection. I had cysts that had abscessed. I was very, very ill. I was so infected inside that I was literally suffocating. My air tube was so coated in yeast infections that it was closing in so I couldn’t breathe. I couldn’t talk. I couldn’t swallow. I couldn’t eat. I was losing weight. I was weak. I was starting to get the first symptoms of dementia.” She was in and out of hospitals during this period and had surgery to remove her fallopian tubes. Only after all this did her healthcare providers decide an HIV test was needed – by that time, Stacey reports that her T-cell count was 50.

There is also Wendy, an African-American woman who has private insurance and has multiple health concerns in addition to HIV, including diabetes and asthma. Although she has access to private providers – and had several regular doctors and specialists whom she saw prior to and just after her HIV diagnosis – she now goes to the Health Department clinic because she thinks she receives better care there. Specifically, at the public clinic, she can see providers who specialize in treating patients with HIV. She was unhappy with the way her private doctors treated her once she told them she was HIV positive and is now afraid to even tell her private dentist about her status. Instead, she prefers to pay out of pocket at the clinic so that she does not have to face the negative attitudes of her private doctors and where she can know that her doctors are familiar with her infection and how to treat her.

These are just two of the women participating in this study and their problems provide a window into the kinds of challenges women with HIV/AIDS may face when seeking healthcare. Following are highlights from the focus groups with these women who discussed their lives with HIV/AIDS and their experiences interacting with the healthcare system.

⁵ Note that all names have been changed to protect the identity of participants.

Learning their HIV Status

Comments made by women in the focus groups reveal that the time of their diagnosis was a critical moment for learning about HIV/AIDS and connecting to experienced providers and the services necessary to care for themselves. However, the stories many women tell suggest this opportunity was lost.

How they learned about their HIV status affected their views about treatment.

Women in the focus groups offered stories of how they learned about their HIV status. In many cases, the women say they became very ill and only were tested because their doctors could find no other reason for their symptoms. Some say that they were tested when they learned their partner was HIV-positive. Some were tested while they were in drug rehabilitation or when they discovered they were pregnant. In addition, some of the women say they received an HIV test without their knowledge – they did not request the test nor were they informed by their providers that they were being tested for HIV. For most, the diagnosis was a surprise despite the fact that some women reveal they were using intravenous drugs or having intercourse without using a condom. Many of the women reveal they became depressed or even suicidal when they received the diagnosis.

How they were told about their HIV status had a considerable effect on many focus group participants. It was a profound moment for all the women in this study and a number say they were told they were HIV-positive in a brusque, technical, and uncaring manner with little information about how to care for themselves. Many of these same women say they resisted treatment and postponed seeing a provider after their diagnosis. Many felt hopeless, that they had received a death sentence, and felt uninformed about treatment options and the potential of medications to control their HIV disease, which may be a function of when they learned their status, since there were fewer treatment options available before the mid-1990s. However, those women who say their providers were helpful and informative at the moment of diagnosis were much more likely to start treatment immediately and to be connected with information and an experienced provider.

Using their Health Insurance Coverage

The majority of women in the focus groups are covered by Medicaid. Each group also included one or two women with private health coverage and one or two women who are uninsured. Based on their discussion, it seems women with HIV/AIDS who have Medicaid have better experiences receiving the care and services they need.

“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

Those women with Medicaid coverage seem most satisfied. The women in private plans or who are uninsured say they face more challenges obtaining the services and care they need for their HIV/AIDS.

Based on the comments of women in the focus groups those covered by Medicaid seem most satisfied with their access to providers and medications and with the quality of care they receive. They appreciate that most of their care is free, that most of the medications they need are covered, and that providers who specialize in HIV/AIDS are in their plans. That does not mean that they do not face challenges – those women in Medicaid managed care plans express concern about their ability to see specialists and say that obtaining a referral can be difficult. A few also say that some of the newer medications they need are not covered by their HMO. But for the most part, they seem to face fewer barriers than women with private coverage or who are uninsured.

Women with HIV enrolled in private health plans seem much more likely to say they face problems, particularly in terms of affording the premiums and co-payments required by their plans. Many of these women wonder how long they will be able to afford their private insurance because their costs are increasing. In addition, women in private health plans were more likely to say that medications they need are not covered by their plan and so they must pay out of pocket. Furthermore, some women in private plans say they have difficulty finding doctors who specialize in HIV in their plan's network, and a few say they see doctors out-of-network to access this expertise.

Uninsured women in the focus groups appear to face the most challenges. Many have applied for Medicaid in the past and been turned down because their incomes are slightly above the eligibility limit. They say they want Medicaid coverage because it is free and covers most of the services they need, whereas they have to pay out-of-pocket for much of their health care now. In addition, uninsured women say it is difficult at times to obtain the services and treatments they need from the public health clinics and that they sometimes must put off medical care because they cannot afford it.

The big problem for uninsured women with HIV/AIDS, based on their comments, is the inconsistent care and treatment they receive, and the fact that they have no regular doctor watching out for them. Most patch together a basic level of care through public health clinics, hospital emergency rooms, private doctors when they can afford it, and through free programs for people with HIV/AIDS and charitable organizations. In terms of their medications, most of the uninsured women with HIV in the focus groups rely on AIDS Drug Assistance Programs (ADAPs), which they appreciate and say cover most of the HIV medications they need (although they do not cover other kinds of medications for other conditions). Of course, to receive help from these programs and organizations, women with HIV/AIDS must first know about them, and some women in the focus groups were not aware of these programs (particularly the Latinas in the focus groups).

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

“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

services (such as case management) and medications not necessarily covered by Medicaid or other insurance programs. Uninsured women and Latinas in the focus groups seem to rely on Ryan White for the bulk of their care.

Making Important Connections

The women in the focus groups who seem to be faring best in terms of accessing quality care and information about HIV/AIDS tend to have two things in common – they tend to be connected to a local AIDS organization (many of which receive support through Ryan White) and they see providers who are experienced in treating women with HIV/AIDS.

Those women involved with a local AIDS organization seem better informed and more empowered than others.

Another insight from the focus groups is that women with HIV/AIDS who are connected to a local AIDS organization are more likely to say they have good access to the services and supports they need. According to many women, these organizations can connect them to the providers, services, medications, programs, and information they need to stay healthy regardless of the type of health coverage they have. Since most of the women in these focus groups had this kind of link to a local AIDS organization, it is unclear what sort of challenges women who lack this connection face in terms of receiving the care and information they need. However, based on their experiences prior to connecting with the AIDS organization, women in the focus groups suggest finding a provider who knows about HIV/AIDS and obtaining the information they need to care for themselves is much more difficult without help from a local organization. Also, many say they felt more alone and unsupported prior to connecting to a local AIDS organization.

Most women in the focus groups believe they receive better care from (female) providers who are experienced in treating women with HIV/AIDS.

A core theme in the focus groups is that most women believe they receive better care when their providers – primary care physicians, specialists, dentists – are familiar with HIV/AIDS and treat many patients with this condition. Most say they feel more comfortable when their provider is experienced treating women with HIV, and they feel these providers know better what infections and other symptoms to look for that could be missed by less experienced providers. In fact, many say they prefer to see a female doctor because they will know their body better, and know specifically how HIV affects a woman's body.

For many, the nurse or nurse practitioner is the main point of contact with the doctor's office. In most cases, they say the nurses and nurse practitioners they see are experienced treating patients with HIV/AIDS and these women are quite happy with their care. Indeed, a number of women say their nurse or nurse practitioner spends more time listening to them and asking questions than their doctor. In fact, many women complain in the focus groups that they feel rushed in their doctor visits and would like to have more time to ask questions and talk about other aspects of their life.

"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.'"

African-American Woman from Savannah

"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."

Latina from Los Angeles

Using Health Services

Women in the focus groups were asked about their experience using health services. Although they discussed a range of services, everything from doctor visits to transportation services, their focus was on specific services with which they have encountered problems or challenges. These include: antiretroviral medications, gynecology, lab and blood work, mental health, and dental care.

Antiretroviral Medications: Most say they have access to these HIV/AIDS medications. Their bigger problem, they say, is sticking to their strict drug regimen and dealing with side effects.

“[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

Most of the women in this study 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. Most also seem very aware of the importance of these medications for treating their HIV infection. For the majority of the women in this study, obtaining these medications has not been a major problem. Most of the women enrolled in Medicaid say their medications are covered (at no cost) by that program. Uninsured women say they rely on AIDS Drug Assistance Programs (ADAPs) for their HIV/AIDS medications. It is those women with private insurance that seem to struggle the most with obtaining their medications – they say the co-payments are sometimes difficult to pay. Also, a few women who are taking newer medications say they have experienced trouble obtaining this medication through their HMO whether through Medicaid or private insurance.

The bigger problem for most women in this study is staying on their drug therapy schedule, which they say is very hard to do. 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. But they admit to occasionally forgetting to take their medications at the appointed time, and a few even reveal that they stopped the drug therapy at various times because it was just too difficult taking the medication so often. A few women explain that depression and denial often trigger these lapses as well as wanting to avoid the side-effects of the medications and their desire to just live a normal life.

The other problem women in the focus group mention often is side-effects, which can run the gamut from mild to severe. Among the side effects mentioned most often are dizziness, fatigue, weight gain, skin rashes, nausea, diarrhea, and lack of appetite. While many of the women take these side-effects in stride, others struggle with them. Some have switched regimens to avoid these effects while a few simply stopped taking their medications.

Gynecology: Most know that regular gynecological care is important, but some may not be getting it.

Many of the women in the focus groups know that regular gynecological care is important to women with HIV. Many seem aware that they are more susceptible to infection and other gynecological problems due to their HIV status. However, while most say they have access to a gynecologist and receive regular care, some women in the group do not. These women seem inconsistent in their use of gynecological services and do not appear to be aware of some of the consequences of not having regular care. They explain that they miss appointments or do not have regularly scheduled appointments.

Lab Work: Most believe that regular lab work is important to monitor their HIV, but some do not understand how to interpret their results.

Most of the women in the focus group say they have regular lab work done and many seem to 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. Many women know that their CD4 count/T-Cell count has to do with their ability to fight infection. 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 HIV 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.

While many women are confident that they understand their CD4 and viral load counts, some acknowledge being confused. Others explain that it took a while for them to understand all the terminology associated with their lab work.

Mental Health: Most women say that mental health services help address the emotional and mental challenges of HIV/AIDS, particularly at time of diagnosis, yet some women are not receiving this kind of support.

A number of women say that a positive mental outlook is just as important as physical care in dealing with their HIV disease. Many say they see a mental health provider or use support groups as a way to keep balance in their life. Some women even assert that HIV/AIDS has turned their life around in a positive way, but more common is the depression and sadness that many women in the focus groups say they feel at times. Those women enrolled in Medicaid and those connected with an AIDS service organization appear to have the best access to mental health providers such as counselors and to medications to treat their mental health needs. Of note, many women discuss the depression and even suicidal thoughts they had when informed of their HIV status. Many felt they could not turn to family members during this time. Those women who did receive counseling during this time seem to appreciate it and believe it helped them seek treatment earlier.

“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.”

White Woman from Philadelphia

“We are very vulnerable to depression. That’s the way it is. It’s true no matter how strong we are.”

Latina from Miami

Despite the importance they attach to counseling and mental health support, some women in the group say they are not receiving these services right now. In many cases, these are the women least connected to a local AIDS organization and less connected to a network of peers and providers. Others simply do not seem informed about these services, where to find them, and whether or not their health plan covers them.

Dental Care: Many say they cannot find a dentist who will treat them because of their HIV status.

“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 in the focus groups say there are not enough dentists who will see people with HIV/AIDS or who will accept their Medicaid coverage. Of note, many of the stories that women tell regarding discrimination and mistreatment take place in a dentist’s office – i.e., dentists who refuse to treat them. Moreover, while many of these women know that oral health is especially important for people with HIV/AIDS, other women are not aware of their special need for regular dental care and need further information on this topic. In other words, they do not seem to know that they are more susceptible to oral infections due to their HIV.

Gender and Stigma

According to many of the women in the focus groups, their sex means they face distinct challenges when it comes to dealing with HIV/AIDS – everything from motherhood to specific gynecological needs. What is more, they are unsure that the medical community pays enough attention to these gender-related facets of HIV/AIDS. Another challenge women face is the stigma and discrimination that can affect anyone with HIV/AIDS, male or female, when they seek medical care.

Women with HIV/AIDS face unique challenges.

“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.”

White Woman from Los Angeles

Many women with HIV/AIDS in this study are mothers and they say the challenges they face are unique. Some women tell poignant stories of learning their HIV status when seeking a pregnancy test. Also, when they received their diagnosis many say their children and desire to have children in the future figured prominently in their decision to seek treatment. For some, their children are a motivation to stay healthy but for others there is the added worry of succumbing to AIDS and leaving them motherless. Mothers in this study also say they face practical barriers to receiving treatment due to child care and transportation challenges.

Other participants also point out that women tend to put everyone else first – their children, their spouse, their parents – and look after themselves last. This means that some women are not as vigilant about their health as they need to be because they resist putting a high priority on their own needs. A few women also believe that women have a greater need than men to express their feelings and talk about

the effect of HIV/AIDS on their lives – which may explain the priority they place on counseling and receiving support services to cope with their HIV/AIDS. Finally, some women still think the medical community treats HIV/AIDS as a gay man's disease and that the resources and information flow follows this emphasis.

Stigma and discrimination still exist for women with HIV/AIDS.

Virtually every woman in this study can tell of an experience where they were turned away by a provider or treated in a cold and insensitive way because of their HIV infection. Those diagnosed many years ago tell particularly gripping stories of discrimination by providers. In fact, many women in this study say they know other HIV-positive women who keep their status secret from their providers because they are afraid they will not receive treatment otherwise. This seems most often the case with dentists. Even a few women in this study imply that they have kept their own status hidden when receiving medical services because they were afraid of how the provider might react.

Information Needs

Most of the women in this study say they are hungry for information about HIV/AIDS. Even those who feel they already know a lot want more. Most seem aware of multiple sources for this kind of information, but tend to rely on just two or three main sources.

Providers and other women who have HIV/AIDS are considered the best sources of information, although most use other sources as well.

Those women involved with a local AIDS organization appear to know a lot about HIV/AIDS and their treatment options. They say they actively network and talk to peers to learn about HIV/AIDS. However, some of their comments in the focus groups show that they still hold misperceptions and have knowledge gaps. For example, some are unsure how to understand their lab results, others are not aware of all of their treatment options, and some are unclear how to receive additional services they would like to receive such as transportation assistance to and from their medical appointments. Those who are not involved with a local organization seem to know much less about available services, treatment options, lab results, how to find a provider who knows about HIV/AIDS, accessing a specialist, and more. Both groups – the informed and less informed – say they would like more information about these topics.

Their preferred sources of information currently are their peers – other women with HIV/AIDS – and their healthcare providers. Beyond that, many women mention a local AIDS organization as a good source of information – for example, they mention that these organizations sponsor seminars on specific topics related to HIV/AIDS. 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.

Connecting women with HIV/AIDS to experienced HIV/AIDS providers (including dentists) may lead to better care.

The women in this study who have an experienced provider say that it makes all the difference in their care and in their own personal knowledge about how to care for themselves. Another advantage they cite is that providers who are experts in HIV/AIDS tend to know other providers in the field, particularly specialists, and so can refer patients to other experienced providers when necessary. It is those women in the study who see providers who are less informed about HIV/AIDS who seem to face more challenges – even subtle discrimination at times. A few even reveal they keep their HIV status secret to avoid negative reactions from these providers. Encouraging women with HIV/AIDS to seek out experienced providers is key, as is easing access to these providers.

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 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), thus 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. TV 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.

Make efforts to address challenges that particularly affect women with HIV/AIDS.

These include childcare and transportation problems (solutions might include childcare services at provider offices or travel vouchers for women with HIV/AIDS). Also, many women in this study say they put their own health needs last behind all other family members. This suggests that women with HIV/AIDS need special communications efforts to place greater priority on their own health.

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. 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.

For more detailed findings, please refer to the full report of findings (Pub# 3380), available on the Kaiser Family Foundation's website at www.kff.org.



Additional copies of this report (#3379) are available on the Kaiser Family Foundation's website at www.kff.org.

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