

Health Care Utilization: The Experiences of Rural HIV-positive African American Women

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Abstract: This qualitative study explored perceptions and experiences of HIV-positive rural African American women regarding availability, accessibility, and quality of health care and social services. Twenty-two women residing in rural areas of South Carolina were recruited to participate in one of three focus groups. A conceptual model of health services utilization was used to guide the study and served as a framework for coding data. Verbatim transcripts of group discussions were analyzed using content analysis to code and identify data categories. Data revealed common perceptions of lack of services and inferior quality of available services to meet some of their most important needs. Overall, findings provide a picture of women whom the health care/social services system fails to serve. The findings have significant implications for increasing resources and designing interventions that empower these women and enhance their quality of life.

Key words: Health care utilization, HIV/AIDS, women, rural.

Changing trends in HIV infection rates demonstrate that the epidemic is now advancing most rapidly among women, racial and ethnic minorities, and those living in rural areas. Although African American (African American) women represent only 12% of all U.S. women, they account for 67% of all female AIDS cases in the country. Nearly 30% of new AIDS diagnoses in 2005 were women.

In the southeastern U.S., the epidemic is distinguished by a disproportionate impact on African Americans, women, and rural residents.^{3,4,5} Sixty-eight percent of all rural AIDS cases are in the southeastern US.⁵ Nearly 44% of all the reported cases of AIDS in South Carolina (SC) are from rural areas and small cities.⁶ Women accounted for over 25% of cumulative adult AIDS cases in SC through 2005 with the adult AIDS case rate of 9.8 per 100,000 population.⁷ It is estimated that as many as 3.5% of rural women in SC are infected with HIV, more than 21 times the national estimates for women based on Centers for Disease Control and Prevention (CDC) case reports.⁸

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Despite the growing numbers of HIV-positive women in rural areas, many primary care physicians lack training in the diagnosis and treatment of HIV infection.9 The majority of HIV-positive individuals are of lower socio-economic status and have difficulties accessing much-needed health care, 10 and this is particularly true for women in the rural Southeast.11 African American women are at particular risk as they tend to be financially and socially disadvantaged and have difficulties in accessing health care services, factors that contribute to episodic and fragmented utilization patterns. 12,13 The unique characteristics of rural communities (including geographic distance and lack of transportation) isolate rural women from supportive resources and services. 9,14 In addition, conservative values and norms support stigmatization of HIV-positive individuals such that they are often reluctant to use HIV/AIDS services for fear of discrimination. 15,16,17,18 According to the National Rural Health Association, the most common barriers for accessing HIV care in rural areas are spatial (distance), health care system gaps (limited infrastructure with few providers and facilities), and issues with stigma and confidentiality.¹⁹ There is evidence that even minimal barriers suffice to discourage an individual from seeking treatment.²⁰

Currently, very little is known about rural HIV-positive African American women and their experiences in accessing and utilizing health resources and services. Such information is crucial to the development of interventions that are effective in improving health and reducing health disparities. The purpose of this study was to explore the experiences of HIV-positive African American women residing in rural SC to identify their perceptions of the availability, accessibility, and quality of health care and social services. The findings have implications for increasing services and the development of supportive interventions.

Background on methods. Focus groups, carefully planned discussions designed to obtain perceptions of a defined area of interest in a permissive, non-threatening environment, are among the most widely used qualitative tools in the social sciences. Qualitative data from focus groups about the feelings, perceptions, and opinions of participants can improve our understanding and provide insights for planning, developing, and evaluating new programs.

The key to effective focus groups is the development of a comprehensive discussion guide based on the research purpose. A conceptual model of service utilization (Figure 1) was used as an aid in the development of discussion questions. Rost, Fortney, Fischer and Smith used a similar model to study the mental health care within a rural context.²⁰ According to the model, a person's entry into a particular service depends on his/her perceptions about need, access, and barriers. Social networks and social support influence these perceptions. In addition, previous experiences with caregivers moderate entry into a particular service. According to Bowlby's attachment theory, individuals internalize early experiences with caregivers and form cognitive models that determine whether they are worthy of care (the individual's *view of self*) and whether others can be trusted to provide care (the individual's *view of others*).²⁴ Quality of care and ultimate outcomes are determined by both patient and provider factors, with patient-provider communication being a critical factor.

A total of five questions and discussion prompts relevant to patients' perspectives and experiences were developed in accordance with the conceptual framework (Box 1).

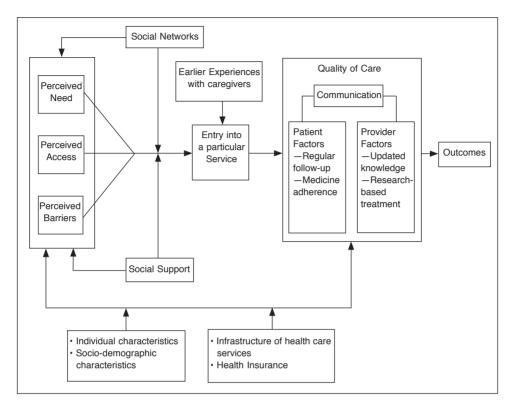


Figure 1. Conceptual model guiding research questions.

Methods

Recruitment. From January through February 2005, participants were recruited through three sources: two community-based organizations (CBOs) and a university-based research study of rural women with HIV disease. The CBOs were selected for participation because they provide preventive, medical, and support services to a large number of HIV-positive clientele living in rural South Carolina. For the purpose of this study, *rural* is defined as areas and small cities/towns with populations less than 50,000.

Sample. In March 2005, a convenience sample of 22 women participated in focus groups conducted at each of the 3 sites, with group sizes ranging from 5 to 10 women. Participation was limited to women who were: 1) African American; 2) age 18 or older; 3) English-speaking; 4) HIV-positive; 5) living in rural areas and small towns with population less than 50,000; and 6) willing to take part in a group discussion.

Procedures. The Institutional Review Board of the University of South Carolina approved the study. The staff of the cooperating organizations provided space for conducting the focus groups and served as intermediaries for recruiting women in the study. Each participant completed a written informed consent and a brief anonymous demographic questionnaire.

Box 1.

FOCUS GROUP DISCUSSION GUIDE QUESTIONS

- 1. What are the services available to HIV-positive people in your local area?
- 2. What are your experiences in locating and accessing the supportive resources and services you need to successfully live with and manage your HIV disease?
- 3. What is the quality of care and services you receive?
- 4. What new services or improvements in existing services are needed?
- 5. What specific types of interventions are needed to help you live with your disease and manage your HIV-related issues and concerns?

Possible Probes

- 1. What do you mean by that?
- 2. Can you explain your point further?
- 3. Can you give an example of what you are referring to?
- 4. Tell me more about it
- 5. Does any one else has something to say about this?

An experienced member of the research team moderated the focus groups, using a semi-structured discussion guide with open-ended questions (Box 1). During the sessions, the moderator used comprehensive probes such as *Would you give me an example of what you mean?* or *Could you explain it further?* to obtain and clarify responses from participants. Each session was audiotape-recorded and lasted approximately 2 hours, at the end of which each participant received \$10 as recognition of her contributions to the study.

Data analysis. The verbatim transcripts, observation notes, and demographic data were the primary data for analysis. Content analysis²⁵ was performed in a systematic manner by utilizing the interview questions as a framework for organizing the data and adopting a *constant comparison method*.^{26,27,28} This method involved the refinement of semantic codes by continually comparing them with new ideas, findings, and relationships both within and across the group data. In the *open-coding* phase,²⁸ two investigators independently identified possible themes, marked the corresponding texts and assigned semantic codes. Next, *axial coding*²⁸ was performed to connect code categories and to look for relationships between them. A theme was deemed to be any thought, idea, or experience noted by two or more participants across all the groups. The investigators then met to review the extracted data segments and to verify the accuracy and meanings of the codes. Additional codes were added as necessary. A third investigator validated the coding.

Results

Mean age of participants was 44 years (standard deviation, SD=9.24, range = 26–63), over half of them were single, and approximately 45 percent lived alone or with children. (See Table 1 for descriptive statistics.) Thirty one percent of the participants had not completed high school. More than 72% were unemployed and nearly half had an annual household income of less than \$5,000. The length of time since HIV diagnosis ranged from 1 to 20 years, with a mean of 8.57 years (SD=5.17). Participants were comparable to other rural HIV-positive women in South Carolina with respect to certain demographic characteristics including age, marital status, living situation, employment, and annual household income.¹⁵

The content analysis revealed four major categorical themes: (1) availability of services, (2) barriers to services/programs, (3) quality of services, and (4) services needed/wanted.

Availability of services. When asked about the availability of services for HIV-positive persons in their local areas, many participants indicated lack of services including health care, social services, housing, and childcare. According to some participants, South Carolina compared poorly with states where they had lived before. One said,

It's nothing like the inner city like New York or Baltimore. They have plenty of resources. North Carolina, South Carolina, they have nothing.

Table 1.

DEMOGRAPHICS OF PARTICIPANTS (N=22)

Variable	Mean (SD)	Number	(%)
Age	44 (9.24)		
18–30	(* ' /	2	9.09
31-45		9	40.91
45+		10	45.45
Missing		1	
Residence			
Within limits of towns		11	50.00
Outside limits of towns		8	36.36
Missing		3	
Marital status			
Single		12	54.55
Married		3	13.64
Living with partner		2	9.09
Divorced		2	9.09
Separated		1	4.55
Widowed		2	9.09

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Table 1 (continued).

Variable	Mean (SD)	Number	(%)
Living situation			
Living alone		6	27.27
Living alone with children		4	18.18
Living with friends/family		5	22.73
Living with spouse/partner		3	13.64
Living with spouse/partner			
and children		2	9.09
Other		2	9.09
Education			
High school drop-outs		7	31.82
High school graduates		3	13.64
Some college		7	31.82
College graduates		3	13.64
Attended graduate school		1	4.55
Other		1	4.55
Employment			
Yes		6	27.27
No		16	72.73
Household income (\$)			
0–4,999		10	45.45
5,000-9,999		5	22.73
10,000-19,999		2	9.09
20,000-29,999		3	13.64
Missing		2	
Duration since diagnosis	8.57 (5.17)		
<5 years	0.07 (0.17)	7	31.82
6–10		5	22.73
11–15		8	36.36
16+		1	4.55
Missing		1	

Participants identified discrepancies between what the agencies say they provide in terms of services and what the women were actually able to get. As one noted:

But when you have a need for the services unfortunately they are not there. It all looks good on paper. Even though the title is there, the service is not there. They are dressing up the outside and ain't working inside.

Barriers to services. Participants cited several barriers in locating and accessing resources including lack of transportation, stigma/discrimination, red tape, lack of support/help getting disability, and lack of housing, child care, and affordable dental

services. Although each rural area from which the women were recruited was served by health department clinics, private doctors' offices, and HIV/AIDS social service organizations, most of the women lived a significant distance from such services. Nearly all women identified lack of transportation as a major barrier to accessing much needed services. Even when special transportation services were available, they were limited and difficult to use. For example, one woman noted:

Our van only runs like on clinic days. But if they have appointments elsewhere they don't have transportation. You got to call them [the transportation company] three days in advance; I mean what if something comes up?

HIV-related stigma and discrimination were major concerns and barriers to accessing and using HIV-specific resources/services. One woman described her experience at the clinic this way:

I mean they put on gloves to take my blood pressure after I told them I was HIV-positive. Some of them walk around like we got the plague, you know what I mean? They treat people who are living with HIV like they are in a different class of illness than they treat other people.

Another barrier identified by women can best be categorized as red tape or cumbersome bureaucracy and included being made to "run around" and being put through great hardships to get services. One woman described a particularly frustrating experience in trying to obtain her required medications this way:

So the lady told me there was nothing she could do. Oh well, go to Social Services. [It] sends you to Health Department; and Health Department sends you back to Social Services. It's the run around. So here I was two months without meds.

One woman described the extreme measures she had to take to get assistance from a food bank and a helping agency:

You asked about food bank and all. [It] is a joke. [I] went there 2:30 yesterday morning, just to be number one to get my bill paid. I was number eight. When they got to me all the money was spent. That's ridiculous.

Some women perceived that there are funds allocated for them but the corresponding agencies do not want to give them the money. The women also expressed frustration in trying to get such entitlements as disability benefits and Medicaid. For example:

Then you talk about Social Service providers, oh my Jesus, that's a whole another ball game. I called them to see if maybe they had special services for people who have chronic illness. But [the response that I got was] I'm not sick enough to get disability.

Another woman shared her sentiment by saying:

You got to have one foot in the grave and one up here and they ready to shove you in. Yeah, they told me that I couldn't get it [disability] until I get pneumonia. I got pneumonia this year, now they tell me I still can't get it. I have to go down to 200 [T cells].

Many participants mentioned that they could not get affordable dental and eye care services in rural areas.

Quality of services. Also of interest were the women's perceptions of the quality of services received. Participants were asked to share their evaluation of these services. There were a few examples of isolated instances of feeling satisfied about a particular service or the care received from a specific provider. For example:

Well, in my area, services have been real good about making sure that all my friends get to all their appointments, no matter what it is. I think the best care of all is right there in my area.

However, these examples were very limited and did not reflect the experiences of the majority of participants. The discussion revealed inadequacies, poor quality, and gaps in the services. The major issues that emerged were: 1) unsatisfactory medical services including mental health care; 2) poor attitudes and behaviors of caregivers; 3) lack of patient-provider communication; and 4) lack of coordination and collaboration between different providers, services and programs. One woman noted,

They [service providers] make [us] believe it sounds good. I'm going to put this up here [and] say this is available to you, then I'm going to give you something from the bottom of a list that a dog wouldn't take. No, don't do that to me and that's throughout South Carolina now.

Many participants were unsatisfied with the medical services, especially mental health care. Most of them stated that the mental health services were either lacking or, if present, depended more on drugs than counseling and other techniques. For example:

Drugs are their main thing. I'm going to drug you up and this is going to help; help everything. Mental health goes more on drugs, less counseling, and that's more bills.

Many women experienced lack of caring, concern, and support from their caregivers. Some women felt that they are not trusted and have been doubted all the time when they go to the clinics or service providers to get help. The women described many instances of experiencing poor attitudes and behaviors of caregivers. Some were even refused care because of their HIV status. One woman described her experience this way:

You were talking about [XXX] Hospital. I went in there 3 times. I was passing blood clots. The doctor came, gave me 18 hormone pills and sent me home. He did not

examine me. He would not even put his hand on me. Doctors don't want to touch you.

Another woman had a similar experience to share:

I was having real bad pains when I had bad cysts in my ovaries. I had an appointment with a special cyst doctor, gynecologist doctor. I went in there and he looked at my chart and said "Oh you've got HIV." I said, "Yes I do." He said, "I can't check those cysts."

Lack of patient-provider communication was another important factor that compromised the quality of care. For example:

The realism is that there are things that we need to know but we're not being told because they [doctors] think we cannot understand it. They give you pamphlets that are good if you can read them. They don't ask whether or not you can read and comprehend them. What the heck is that?

When asked to rate the quality of care they receive on a scale from 1 to 10, with 1 being the worst and 10 being the best care, one participant said: "I give them one minus." Another said: "0 and a ½." One woman supported these ratings by saying:

Those doctors in the hospital don't know a thing about HIV. They'll be guessing. If you stay in there long enough, you will be dead and they still be guessing.

Lack of collaboration between different agencies and services and among health care providers was of major concern. One woman described it in this way:

When I was going to the HIV doctor and another doctor, it caused a lot of confusion 'cause I say this doctor put me on this medicine, and the other one says you don't need all that. It was a lot of confusion

Some women emphasized the need of a better communication between multiple service providers and expressed that service agencies can reduce burden of completing virtually the same paperwork through networking and communicating with each other.

Services needed. When asked about the services they would need or would be interested in having in their areas, the women identified a list of services including transportation, housing, day care, counseling and mental health services, specialized medical care programs, peer support programs, emergency services, financial support, job/work, nutrition, education, medicines, and childcare services. Some suggested that they should have day care facilities where they can meet others, talk about issues or problems, educate themselves about HIV/AIDS, and have social interactions with their peers. Another suggested more help on getting transportation and finding employment, and assistance with social services.

Participants identified education as key to addressing the majority of issues associated with HIV disease. Nearly all of them agreed that they should have peer support programs. One participant noted:

Everybody who's tested positive should be given some sort of intervention. From the time you test positive, that person should know that there's somebody that they can speak to who is also positive.

Discussion

Evolving HIV/AIDS data in the U.S. reflect changing epidemiological profiles increasingly affecting women, minorities, and rural populations. To reduce health disparities, there must be adequate data concerning health status, patterns of health care utilization, and financing and health outcomes. Our study aimed to explore the perceptions and experiences of HIV-positive women living in rural South Carolina about health care and social services.

Although a few participants reported positive experiences, these did not reflect the experiences of the majority of participants. Much more common were experiences of services being unavailable, inaccessible, and of poor quality. Many of the women had to travel long distances to obtain services. Women who previously lived in other states perceived that services in South Carolina were inadequate in comparison with those available in other states.

The major factor affecting the women's ability to access care was lack of transportation, which has been well documented in literature spanning over a decade. 9,14,15,17,29,30 It not only impaired their ability to access health care, but also kept them from other resources. Lack of adequate housing was another issue that many of these women faced. While lack of childcare was identified as a concern by some participants, it was less important than their other problems.

Many women expressed difficulties in getting disability benefits and Medicaid. A common refrain was that they were "not sick enough" to become eligible for getting such benefits. In general, women did not have confidence in the medical care they received. There was a lack of patient-provider communication in many instances. Low levels of health literacy among these women may have been a critical factor compromising patient-provider communication, affecting various health outcomes. Many women reported biased, negative, or even refusal of treatment by personnel in clinics, emergency rooms, and social service agencies.

The findings suggest that HIV-positive rural African American women are falling through the cracks of resources and services. When lack of services and difficulties in accessing the available resources are coupled with negative experiences with service providers (circumstances noted by many participants), a sense of alienation and lack of support emerges that could easily thwart any motivation people may have to seek and access proper treatment. Feeling alienated and burdened hardships of living in a rural environment, the women expressed feelings of anger, frustration, helplessness, and hopelessness.

The findings reported here are limited in several ways. In addition to a small sample size, women who participated in focus groups may not be representative of the population as a whole. It is possible that women who were satisfied with the services may not have participated in the focus groups. It is also possible that women who feel most alienated and unwilling to use available services were not represented in the sample.

Therefore, the results cannot be generalized to other populations. Further, since group discussions are influenced by group dynamics, it is possible that some participants may have been inhibited by more vocal participants and did not share their opinions.

Despite such limitations, the findings provide a snapshot of experiences of HIV-positive rural African American women. The findings suggest the need for research aimed at developing and testing interventions that address issues arising from the context in which rural HIV-positive African American women live to improve their access to and use of health care and social services and the quality of such services. Further, there is a need to address the issues of HIV-related stigma and discrimination, not only in the general population but also among the service providers. Additionally, peer support programs may prove effective in supporting and empowering these women in their efforts to access care, navigate the system, and develop social support networks. Some of the issues, such as difficulty in getting disability benefits, Medicaid or insurance, demand policy changes at state or federal level.

Further research is needed to improve our understanding of the complexity of the health care and social services delivery in rural areas.

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