Sources and Types of Social Support that Influence Engagement in HIV Care among Latinos and African Americans

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Abstract: The change in HIV from acute to chronic disease due to the introduction of HAART in the mid-1990s increased the importance of its successful management and imposed substantial lifestyle adjustments on HIV-positive people and their support networks. Few studies have examined the sources and types of social support and the areas of care relevant for engagement in HIV treatment among HIV-positive Latinos and African Americans. This paper reports the results of 24 semi-structured in-depth interviews that were conducted with HIV-positive African American and Latino women and men who have sex with men. Formal networks were found to be more critical for engagement in HIV-specific medical care; specifically, study participants relied primarily on health care providers for support in accessing and maintaining illness-specific care. In contrast, informal networks (family and friends) were crucial for other general subsistence care, such as emotional, household-related, and financial support.

Key words: HIV, AIDS, social support, African Americans, Latinos, engagement in care.

Disparities persist in access to and engagement in health care for HIV-positive Latinos and African Americans in the U.S.[1-2] Not only are Latinos and African Americans more likely than Whites to test late for HIV infection,[1,2] but they are also more likely to schedule and attend fewer clinic visits and to be more inconsistent in their adherence to health care regimens.[2-4] As HIV spreads among socially and finan-

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cially disadvantaged people of color, such populations are less likely to use ambulatory care and more likely to use emergency room and in-hospital treatment. This results in fragmented and costly care overall.[5] Consequently, it is important to understand better the factors, including social support, that influence engagement in HIV-related health care for these populations.

Studies of several chronic diseases including diabetes, asthma, and heart disease have shown that the nature and characteristics of a patient's social support system can influence the quality and consistency of the health care received.[6–8] The change from an acute to a chronic disease as a result of the introduction of Highly Active Anti-Retroviral Therapy (HAART) in the mid-1990s increased the importance of the successful management of HIV disease requiring regular appointments with medical providers and consistent medication use.[3,9–11] Such changes in treatment and medication adherence imposed substantial lifestyle adjustments on HIV-positive people and their support networks.[12]

There is a growing body of literature that examines the relationship between social support and HIV health processes and outcomes, particularly in such areas as medication adherence,[13,14] clinical outcomes,[15,16] and mental health outcomes.[17–19] For example, previous studies predominantly of White men who have sex with men (MSM) examined social support and HIV disease outcome measures and found that those with stronger social support systems were more likely to have undetectable viral loads[15] and slower CD4 count declines.[16] A study mostly of African American HIV-positive men and women in the southern U.S. found that better mental health status was associated with stronger social support,[17] while another study of African American injection drug users (IDUs) reported that the use of outpatient services was associated with more female members in a social support network and more sources of emotional support.[20] There are fewer studies, however, that examine the relationship between social support and overall engagement in HIV care.

Social support and engagement in HIV care. Engagement in HIV care refers to an overall holistic care of self to manage HIV disease, which includes access to, and active involvement and retention in both health care and general subsistence care. Social support is generally characterized as an enabling factor for engagement in HIV care.[5] It is important to delineate further dimensions of social support, such as the sources and types of support most effective in specific situations and most effective when offered by people in particular types of relationships to the patient.[21,22] Similarly, we must understand better the areas of care where social support is needed, such as illness-specific care and general care and how they affect engagement in HIV care.[6,23]

The literature broadly identifies two categories as sources of social support—formal and informal. The former consists of professional support systems (health care and social service providers) and the latter of family, friends, and other community organizations (such as churches).[24] In managing most chronic diseases (including HIV), informal social support networks, particularly kin, are acknowledged as critical sources of social support.[21,25,26] For some HIV-positive people, availability of support from family members improved odds of entry into medical care, regardless of whether the person was already receiving (or not receiving) support from ancillary HIV services.[24]

However, in the case of HIV, such relationships often become more complex, and

both kin and non-kin may be part of the informal support systems involved in HIV caregiving.[20,27] Historically high levels of stigma regarding HIV disease and homosexuality in African American and Latino communities play a role in shaping relationships to people with HIV within the Latino and African American family structures[28-30] and African American and Latino churches.[31] Perceived and actual stigma present in a person's social and community environment may prevent patients from asking for and/or receiving support (e.g., help getting to a doctor's appointment or receiving encouragement to attend regular clinic visits). Therefore, the stigma felt in minority communities and consequent lack of disclosure from HIV-positive people in family settings[32] may result in greater reliance on non-kin for social support.

Both general and illness-specific care have been identified as important for those with a chronic illness.[6,12] General care is generalized global support in the everyday needs of the sick person, while illness-specific care includes a more medical regimen-specific support and direct assistance with the management of the illness.[6] For minorities with HIV, non-medical general subsistence needs may have a direct impact on the patient's ability to engage in HIV-specific medical care[33] since racial minorities with HIV have been found to have 50% greater odds of reporting unmet needs in the areas of housing, advocacy, and other general support.[34]

In summary, the literature seems to present several gaps in our knowledge about engagement in HIV care for minorities. Because of HIV stigma and non-disclosure in these communities, the extent to which formal rather than informal systems are relied upon for primary support remains unclear. It is important to establish more accurately which people provide support for people with HIV and in which types of situations. Additionally, whereas chronically ill patients tend to need illness-specific care, in the case of disadvantaged minorities, this need can be compounded by more general care issues. Again, it is important to understand how their formal and informal social support systems take part in these different areas of care.

This paper presents results from a qualitative study that explored the roles of formal and informal social support systems in engaging in HIV care for socioeconomically disadvantaged HIV-positive Latino and African American women and MSM.

Methods

Study context. The qualitative methods used in this study were based on a grounded theory approach[38,39] where data were analyzed with no preconceived categories, using the method of *constant comparison*.[39,40] A total of 24 people over the age of 18 years were interviewed including six participants each of HIV-positive Latino MSM, Latinas, African American MSM, and African American women. Male participants were limited to MSM as they constitute approximately 75% of people infected with HIV in Los Angeles County.

Participants were also required to be clients at one of two large public HIV clinics and one community-based organization (CBO) that serve indigent populations in Los Angeles, California. We included the latter criteria because we wanted participants who had entered care in order to understand how social support affected their continued engagement in HIV care. The HIV/AIDS clinics and CBO were selected because we

knew that they would have sufficient numbers of members of the target populations of our study. Before interviews commenced, the institutional review boards of Charles Drew University of Medicine and Science, Los Angeles County Department of Public Health, and the University of Southern California Health Science Campus all approved the study.

Procedures. Flyers were displayed at each site, advertising the study and inclusion criteria. Interviews took place either in the participants' home or in the clinic, as determined by the participant, and were conducted in either Spanish or English. Each participant provided informed consent prior to being interviewed and received $50 at its conclusion. All interviews were audio-taped and ranged from 18 minutes to almost two hours, with the average interview lasting 55 minutes. The variation in range may be attributed to the semi-structured, open-ended nature of the interviews and participants who were differently engaged. For example, in the case of the 18-minute interview, the participant appeared to be mostly interested in the monetary compensation, whereas the two-hour interview participant was extremely engaged in the topic. Interviews were conducted by two research associates who were bilingual in Spanish and English and who had graduate-level training in qualitative methods.

Interview instrument description. Interviewers used a script with a variety of themes and specific questions to initiate discussion (see Box 1). The interview began

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Box 1.

INTERVIEW THEMES AND EXAMPLES OF QUESTIONS[a]

Broad Themes	Example questions
HIV health care needed & received	• What are the main ways that you get HIV-related health care? • What types of treatments do you get? • Where do you go?
Types of assistance provided by others	• In what ways do you *need help* from other people to make sure that you get this care?
Obstacles to accessing care	• In what ways do you *get help*?
Sources of help	• Are there any? • What are they? • Who can you turn to for help with getting HIV medical care? • With what types of people do you feel comfortable talking about HIV?

[a]These are examples only of some of the initiating questions used. Other, more probing questions were asked of participants depending on what their responses were, in order to gain more in-depth information.

with general questions and a request for the participant to share a typical day in his/her life. During each interview, the interviewer periodically checked with participants to verify that s/he understood the participant's responses correctly, a crucial technique for establishing credibility.[41] For example, the interviewer would ask, "So when you say that, do you mean [repeats their interpretation back to the participant] . . . ."

Data analysis. Once conducted, interviews were transcribed and all Spanish-language transcripts were translated into English. Atlas.ti (a qualitative software program) was used to store transcripts and manage the data.[42] To protect the privacy of participants, names were not used and each participant was allocated a unique identification number. Open coding was then used where all data were examined line-by-line for the potential for a code, without predetermined categories influencing what would be coded.[38] Coding of one third of the transcripts was conducted independently by the first two authors to develop an initial code book that was refined through subsequent coding of the remaining transcripts and a second recoding of all the transcripts. Ongoing comparison within and across categories and across interviews led to each item being checked against the rest of the data to establish and refine categories that reflected the nuances of the data.[39,40] Consensus-based group discussions among all the authors were used to achieve agreement on the final analysis.

Triangulation is commonly used in qualitative studies to increase understanding of complex phenomena and to confirm validity when there is agreement among different sources.[43] Thus, to increase study validity, we used two forms of triangulation: data source triangulation (across participants) and researcher triangulation (across investigators in the collection and analysis processes).[41,44] The former refers to data obtained from multiple sources (in this case, Latino men and women, and African American men and women). This fostered a more complete understanding of the issues surrounding social support and engagement in HIV care. The latter ensured the validity of analyst interpretations, and involved the use of more than one investigator in the collection and analysis processes.[41,44] The multiple sources of triangulation used in this study increase the credibility of the findings.[41]

Results

Participants clearly delineated between the areas of illness-specific care and general care needs. Thus two main themes emerged from our analysis: sources and types of support for *HIV health care*, and sources and types of support needed for *general care* when living with HIV. Box 2 displays the core categories and subcategories and presents examples of activities identified by participants that were then categorized into different types of social support. Sources of support included individuals with both formal and informal roles (e.g., medical and other care providers, family, and friends) and institutions (e.g., churches and other organizations). We did not differentiate among types of social support nor did we specifically ask about the area of general care at the outset of the interviews. Rather we asked participants questions about their daily lived experiences with engaging in HIV health care (e.g., who helped them and in what circumstances). Three types of social support categories (emotional, instrumental, and informational) emerged and they matched what we found in the literature.[8,45]

Box 2.

EXAMPLES OF TYPES OF SOCIAL SUPPORT RECEIVED AND SOURCES OF SUPPORT FOR DIFFERENT AREAS OF CARE

Dimensions of Social Support		Areas of Care	
Types of Support	**Sources of Support**	**HIV Health Care**	**General Subsistence Care**
Emotional	Health care providers	Encouragement about health, reminders about appointments & medication adherence, support to try new therapies & "tough love"	————
	HIV-related organizations	Support groups for talking/venting about HIV, encouragement for medication adherence & keeping appointments	Talking, going out & having fun with support group members
	Family and friends	Encouragement with medication adherence, keeping appointments and follow up care	Provision of outlet to talk, distractions from HIV, asking about patient's well-being

Emotional support is understood as non-tangible help from others that leads to a person feeling loved and cared for, with a bolstered sense of self-worth (e.g., talking over a problem, providing encouragement/positive feedback). Instrumental support is understood as various types of tangible help (e.g., help with childcare/housekeeping, provision of transportation or money). Informational support is a third type of social support and is understood as the help that others offered by providing information (e.g., information about medication, treatment options, nutrition, housing, food banks, legal aid).

It is important to note that the main categories of HIV health care and general care, and subcategories associated with types of social support, are not mutually exclusive.

Box 2. *(continued)*

Dimensions of Social Support		Areas of Care	
Types of Support	**Sources of Support**	**HIV Health Care**	**General Subsistence Care**
Instrumental	Health care providers	Provision of medications, advocacy, individualized care, transportation, being available/contactable, help with paperwork for health benefits	————
	HIV-related organizations	Transportation vouchers, translation & mental health services, primary care and referral to specialists	Case management, housing & legal aid, food bank
	Family and friends	Transportation support (rides, loan of car); family members attending appointments	Food, shelter, housework & errands, loans & gifts of money
Informa-tional	Health care providers	Information about medication & other resources	————
	HIV-related organizations	Education about HIV nutrition, medications, treatment options through conferences, workshops and word of mouth	Information about resources (housing, legal aid & food bank)
	Family and friends	Looking for information on the Internet	————

For instance, participants shared examples of family/friends helping with housework and other similar duties so that participants could focus on taking their medication and accessing their HIV treatment. Such examples could have been categorized as social support for HIV *health care*; however, we categorized them under *general care*, because of the emphasis on non-medical general support instead of the secondary outcome, which was how the aid supported them in accessing HIV health care. Selected examples of the viewpoints of participants presented in the insets below illustrate both facilitators and obstacles to the different types of social support from different sources for engaging in HIV health care and general care.

HIV health care: sources. Medical and mental health care staff (including doctors, nurses, psychologists, psychiatrists, social workers, drug counselors, case managers, and other general health care professionals) and HIV-related organizations (including support groups and temporary half-way houses) were identified as the primary sources of support in accessing HIV health care. Typically, there was a small number of family and/or friends who provided support for accessing HIV health care for each study participant.

HIV health care: types of support. The types of support that people received are presented below in categories according to sources of support, enabling easier identification of who provided what type of support.

Health care providers. Medical and health care staff provided emotional support by providing general encouragement to participants to stay the course, which provided hope for the future. Examples of encouragement included a spectrum of different types of interactions with the medical staff, from counseling and help in the assessment of life goals to the provision of so-called tough love. Whereas most examples of encouragement were explicitly supportive behavior or statements received from health care providers, one Latino male participant described a less explicitly encouraging interaction with his doctor (Box 3, Quotation 1). Patients also experienced support in maintaining their antiretroviral medication regimens and reported being encouraged to try new therapies (such as yoga). Some patients perceived that staff members were genuinely concerned for them because they felt listened to, and some staff reportedly reminded patients not to miss appointments. These factors combined made the clinical visit therapeutic, and for some patients, developed a sense of accountability (Box 3, Quotation 2).

Instrumental support from health providers included the provision of medications and assistance with transportation. Extending themselves to facilitate patient access involved some staff being reachable at any time, being readily available for patients in general and providing individual care and advocacy (e.g., helping a participant with the processes and paperwork involved in applying for Medicare). One example from a Latina participant demonstrates how she felt cared for, particularly in the ways that her care provider was available to her beyond her formal medical responsibilities (Box 3, Quotation 3).

Informational support provided by health care providers included the provision of information and advice about medications and other resources available to patients. This included any new information about HIV/AIDS obtained from recent conferences, as well as staff encouraging adherence to medical regimens by explaining the importance of when to take medications (Box 3, Quotation 4).

Box 3.

HIV HEALTH CARE (HEALTH CARE PROVIDERS)

Emotional support

Quotation 1: "So the doctor told me too, she made me an ultimatum. She said, 'If you don't want to do anything for yourself, I can't do anything either.' She said, 'You have to decide whether to live or die. If you want to live, come see me, but don't come in here acting like a pessimist, don't come with a negative attitude. If you want to die, stay at home and don't come waste your time here.' So that helped me a lot. That helped me a lot." (LM)

Quotation 2: "I believe, you know, the doctor's office should be like a family, part of the family . . . . You know, 'Call us! Okay, you are late, why you didn't come? . . . What is going on?' . . . You know 'get up', that type of thing . . . . So yeah, I believe that if it wasn't for some of the staff at the doctor's office, you know, I'd probably still be on that pot, you know. She called, you know, 'Get up' . . . . 'You need to get in; I haven't seen you in, you know.' So they remember . . . . They see you, they remember. You are not just the client. You are not just somebody going there . . . . They care. 'We care, you know!' . . . And you can feel it from their conversation." (AAM)

Quotation 3: "I have my doctor . . . . Since I arrived to Los Angeles and began seeing her, she has never denied me anything, help, everything. She has always assisted me; even if I do not have an appointment, I go and she sees me. Anything that I need—a paper, she fills it out for me—I do not have to come another day; I give them to her and she fills them out for me." (LF)

Informational support

Quotation 4: "Each time we didn't know about something, we asked the nurses here. . . . But in conferences here at _____ [she names a clinic], and here—we find papers from _____ [she names a AIDS service organization] and from any other institution helping us to learn more about the disease. Then they always ask how they can help." (LF)

Obstacles to engaging in HIV care

Quotation 5: "I did not feel comfortable with the psychiatrist. I didn't feel comfortable with him because I felt . . . I know he wasn't doing it, but I felt like he was looking down at me, like he wasn't acknowledging me as a person but he was looking at me more as another case. So I didn't feel comfortable with that. So I said that I'm not gonna see him no more." (LF)

Box 3. (continued)

Quotation 6:

Interviewer: Have you missed any visits to the HIV clinic, visits in the last six
               months?

Participant: Yeah, I missed my psychiatric . . . I missed my GYN visits

Interviewer: You didn't feel like going, why?

Participant: Hell, I didn't want to meet this guy with two of my phone visits didn't
               go well. I only jumped up for the meeting because that's what I need
               to do mentally. I used to go. But I called the day before that I was
               waiting and I didn't feel too well and I told him I was canceling the
               appointment. You know, then I realized it was the next day, you know!
               I 'ave to call back and make another appointment. But I just started
               back accusing him, you know. He had accused me. I was real upset.
               (AAF)

It is noteworthy that while the patient-health care provider relationship was largely identified as a positive influence on a patient's engagement in HIV health care, it sometimes became an obstacle. Some study participants experienced distrust and perceived negativity from their doctor or health care worker, which led to some participants avoiding appointments (Box 3, Quotations 5 and 6). Language was another obstacle for some Latino participants who preferred Spanish-speaking providers. Some Latino men perceived that translators slightly distorted the information they were communicating to the provider. Having to use a translator was also perceived as intrusive, particularly during mental health visits. One participant highlighted the privacy implications when using interpreters as he overheard his psychiatrist and interpreter talking about him, so he disengaged in care: "I've been seeing the psychiatrist here. I didn't like it. He and the interpreter were commenting on what I had told them afterwards . . . . That's why I'm not coming here anymore to see the psychiatrist."

HIV-related organizations. In addition to health care providers, participants also reported getting support from HIV-related support organizations, including social service organizations, support groups and half-way houses. The services provided by these organizations included treatment education and psychosocial services ranging from case management to housing assistance, legal and translational services, food banks, and mental health care at the other support organizations.

Emotional support from HIV-related organizations, particularly support groups, included encouragement and an outlet where participants could talk, air their frustrations, and ask questions about their medical care processes (Box 4, Quotation 1). Specifically, participants were encouraged to adhere to their medication regimens and to attend medical appointments, which they felt directly supported their engagement in HIV treatment. Support groups also provided opportunities for participants to talk about their problems and listen to others in an unpressured setting. Some participants,

Box 4

HIV HEALTH CARE (HIV-RELATED ORGANIZATIONS)

Emotional support

Quotation 1: ". . . in terms of the groups I always go to, the people who go know there are people who are HIV-positive and people who are not. So sometimes you find support there too, albeit moral support. I think that this is really important to help you feel better, like you said, it makes you feel good when someone comes over and says, 'How are you today?' That's really nice and it helps you keep going." (LM)

Quotation 2: "I just never really did want to sit around the group and really just, you know, put my business or tell on people or air my laundry in public, you know, I never really like to do that. And I still don't, I'm still—I'm not very comfortable with it but, you know, depending on the circumstances I may or may not do it." (AAM)

Instrumental support

Quotation 3: "But if I call them and tell them that I'm not feeling good, they'll either change my appointment or they'll send a cab for me. [A little later on] . . . the clinic, they have a pharmacy that delivers, so I just go to the doctor and they call them in, and they deliver them to my house or I can pick them up there, but, usually, I just go home, and then they deliver them to us, so it's good. [A little later on] . . . they can help you with everything; social services, SS, everything. They have social workers and everything, so mostly, I just go there, psychiatry; you know, everything." (AAF)

Informational support

Quotation 4:

Participant:	. . . if I take them [medications] at 9 o' clock in the morning today, I should take them at 9 o' clock in the morning tomorrow . . . . I was takin' them like at 9 today, maybe 12 the next day. But, then I started taking them the right way.
Interviewer:	What made you start taking the right way?
Participant:	Because I went to this—there was a seminar or something. Those are medical updates—the Medical Adherence Group. They tell you how to take your medicines and you think you are taking them right, by taking them at different times every day just as long as you are getting them in that day but, not so. You have to take them at the same time every day. And as it says 'no food', no food; and it says 'eat with food', you have to use food. (AAF)

Quotation 5: ". . . sometimes those services are in English which is another barrier. . . . It's different because when the information is translated from English to Spanish the information is distorted." (LM)

however, preferred to remain reserved in such venues (Box 4, Quotation 2). More men than women reported receiving emotional support from HIV support groups.

Instrumental support provided by HIV support organizations included transportation vouchers/cards and transportation (by taxi or other services) to and from medical appointments, the provision and delivery of medications and vitamins, and the provision of access to health care (including primary care, referral to specialists and other health care). One participant explained that the clinic she attends is a centralized resource for her HIV health care needs; not only are the staff flexible, but the clinic offers referrals for specialty care and a range of medical, allied health, and Social Security assistance (Box 4, Quotation 3). This was not the case for everyone as some participants experienced disconnected services (e.g., no central point for information and inconsistencies among organizations). Other obstacles encountered when trying to access instrumental support included navigating the bureaucracy—particularly problematic was the complexity of the system (e.g., lack of continuity, with some doctors and having to complete paperwork every six to 12 months in order to maintain access to services and/or medications), lack of flexibility (e.g., strict requirements to receive care) and length of wait (e.g., for services).

Informational support provided by HIV support organizations included the provision of information and education about medications, HIV/AIDS, and other illnesses subsidiary to HIV/AIDS. The information was provided in both structured and unstructured formats. Structured information came through events (conferences, workshops, seminars) that provided medical updates, information on health, nutrition, and diseases, as well as an opportunity for people to share their experiences to help others. Such structured information can be important for adherence to the medication regimen, as noted by one participant (Box 4, Quotation 4). However, some Latino participants noted a lack of material in Spanish, which became an obstacle to obtaining the full benefits of that support (Box 4, Quotation 5). Unstructured information was described as word-of-mouth (which facilitated knowing where to go for services). For example, one participant received advice from an acquaintance about a place to attend for more efficient care.

Family and friends. Whereas health care providers and HIV support organizations provided extensive social support to help participants engage in HIV treatment and care, family and friends seemed to play a more peripheral role in their support.

Participants mostly highlighted the instrumental nature of help they received from family members. Transportation was the main form of instrumental support provided by a family member or friend. This included transportation to appointments (e.g., a partner loaning a car to enable one study participant to get to appointments). In addition, some family members attended appointments with the patients, and others were available to help if needed. Most participants reported that transportation to appointments was not needed on a regular basis, as most of them were able to get to appointments independently by using public transportation and the transportation vouchers they received from HIV support organizations. Nevertheless, some participants relied completely on transportation from a family member to get to appointments (Box 5, Quotation 1).

Some participants mentioned emotional support from family and friends (Box 5,

Quotations 2 and 3) that consisted of providing encouragement to take medications, to attend appointments, and to follow up on medical care. Informational support appeared to be less frequent from family members; however one study participant reported receiving informational support from her sister, who searched for HIV-related information on the Internet and passed it on to the participant (Box 5, Quotation 4).

Box 5

HIV HEALTH CARE (FAMILY & FRIENDS)

Instrumental support

Quotation 1:

Participant:	Well the only help they (the family) give me is by bringing me over here, making sure that I come over here. When they don't come over, that's because they either have engine problems or they have other appointments they have to go to. So I understand that. So I am not basically depending on them all the time. So if I can't come over here, I won't come over here but other than that, they bring me every week.
Interviewer:	Okay. So that's your only way of getting here?
Participant:	By them bringing me over here because I am afraid of the bus.
Interviewer:	So you will not take the bus . . .
Participant:	No
Interviewer:	So you need to be driven to all your appointments.
Participant:	Yeah and driven by somebody I know because I feel more comfortable with them. (AAF)

Emotional support

Quotation 2: "By me being on dialysis, sometimes the energy level might not be there to get up and go. Okay, it's time to go to the doctor but yet it's raining and I'm tired and don't feel like doing it. But again my dad (says), 'Now, you know, you got to go. Come on!'" (AAF)

Quotation 3:

Participant:	My nurse and my friend also help me and remind me to take my medications.
Interviewer:	They insist that you should take your meds, keep your appointments and maintain your treatment routine.
Participant:	Right. Every time they see me they encourage me to keep taking my meds because they're working, because my viral load is undetectable and my T-cell count is rising gradually. (LM12)

Informational support

Quotation 4: "As she has a computer, she looks for information on the Net and tells me. Yes, because when I was pregnant, she always told me to take my medication for the girl to be born healthy. She looks for information for me on the Internet." (LF)

Obstacles to receiving instrumental, emotional, or informational support from family and/or friends included having non-accessible family members (estranged, interstate, or deceased) and non-disclosure of HIV status. While some obstacles to engaging in HIV health care were related to sources and types of support from others, a number of personal issues were also identified as obstacles. These included health condition making it difficult to attend appointments (e.g., fatigue); missing appointments (e.g., forgetting, mixing up appointment time, not caring, not having babysitter); addiction problems (e.g., being refused HIV medication by doctor while still on illicit drugs; fear of not taking HIV medication appropriately due to past drug addiction); adherence to medication (e.g., side effects of medications making it difficult to follow treatment); and lack of money or insurance to see a doctor.

In addition to assistance with HIV treatment, it emerged from our interviews that participants also received general care not related to direct engagement in HIV treatment, but still relevant to the person's HIV status. Below are outlined first the sources of general subsistence care, and then the types of general subsistence care identified by the participants.

General subsistence care: sources. Compared with the support related to accessing HIV health care (where much of the support was provided by formal networks such as clinical staff), the people who provided general care were more commonly in informal social support networks, such as family and friends. HIV-related organizations, support groups, and churches also provided some general care, but less than family and friends.

General subsistence care: types of support. As for the previous theme, the types of support are presented below in categories according to the sources providing that support.

Family and friends. Participants discussed a range of types of emotional support offered by family and friends that contributed to their general sense of feeling supported in dealing with the disease. Types of emotional support were categorized in three main ways: providing an outlet to talk, asking about the patient's well-being, and providing distractions and not being solely focused on the participant's HIV status.

Providing an outlet to talk meant that a friend or family member was available to participants when needed to provide general encouragement, such as by talking on the telephone or in person and being available to listen and receive confidences (Box 6, Quotation 1).

Asking about the patient's well being was a form of emotional support that involved a family member or friend making inquiries about a participants' health status, particularly regarding their HIV treatment (Box 6, Quotation 2). This type of interaction was categorized as part of general care and support because the focus was on the general well being of the participant, even if the specific information being sought was about the participant keeping up with medical appointments.

On the other hand, some participants reported not wanting attention focused on them and their HIV status and, for them, distraction from their HIV status became a form of emotional support. This type of support entailed the preference for family and friends to simply not talk about HIV, not check up on the person's medical updates, and have fun socially without any reference to HIV. This was perceived by some participants

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Box 6

GENERAL SUBSISTENCE CARE (FAMILY & FRIENDS)

Emotional support

Quotation 1: "I can count on [my ex-girlfriend] in some ways, by talking to her about my—about our positivity. I have somebody to confide in . . . support. I went and talked about this to her. She did the same with me . . . just being there." (AAM)

Quotation 2:

Participant:	Well, my brother . . . he helps just by talking to me: 'How are you?' I mean, even though he is withdrawn—distant, he asks me how I am doing, if I have gone to my appointments, how I have been feeling. I mean, it makes me feel good.
Interviewer:	By telephone?
Participant:	Yes, by telephone.
Interviewer:	How many times a week does he call . . .
Participant:	Once or twice . . . If he does not call me, I call him twice a week. (LF)

Instrumental support

Quotation 3: "When I am feeling sick, they (the family) don't make me do anything. I stay in my room resting or I do whatever I can and use the rest of my time to rest. . . . Sometimes they see that I was busy all day at meetings and that when I get back from the meetings, I have to take care of the house and sometimes when I get home at night, they say, 'Don't worry about the house, there's nothing to do. Take your time and rest and take your medicine.' Since they know that I am now doing and having the fusion shots and that the fusion [inhibitors] have caused a lot of problems with my legs, well, the mother tells me, 'You don't have to do anything. Just rest.' She's a nurse." (LM)

Quotation 4: " My dad, he is there just all the time, you know, takes me where I want to go, if funds get low, he is right there for that. And then for whatever I need, he is there." (AAF)

Quotation 5: "My mother has helped us a lot; she has even helped us financially when he (her husband) had no money left." (LF)

Quotation 6: "My friend, who lives here. . . . He tells me not to worry, that I don't have to work if I feel ill, that I can work when I feel better, if I want to. He has this house and a good job . . . . He's very supportive." (LM)

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as receiving respect and privacy. For example, one African American woman said that she does not like to talk to anybody but her social worker about her HIV status. When asked if she talked to her family members about her HIV status, she said, "Talk at home—it's all like nothing's going on. They ask me, 'How did your doctor's visit go?' 'Oh, I am ok.' 'What did he say?' 'Nothing.' I just don't share with them."

Instrumental support provided by family and/or friends included household-related and financial support. Household-related support included food, shelter, exemption from household duties, receiving help around the house (e.g., cleaning) and having a person who could run errands, including grocery shopping. One participant highlighted the many ways that participants needed general care and support as they go through HIV treatment (Box 6, Quotation 3).

Several participants reported receiving financial help where they would receive money from a friend or family member (Box 6, Quotations 4 and 5). Usually, this financial support was not on an ongoing basis; rather, it tended to be on an as-needed basis. In other cases, while money was not directly given to participants, the equivalent of financial support in terms of household expenses or rent was taken care of by friends or family (Box 6, Quotation 6).

As with HIV health care, obstacles to obtaining general support from family and/or friends also included having non-accessible family members and non-disclosure of HIV status. Additionally, social distancing was an obstacle for some (e.g., not engaging in social activities after diagnosis and avoiding people assumed not to understand HIV). Some study participants also felt stigmatized by family and friends, experiencing refusals to help, breaking off relations, not wanting to share a coffee cup, not wanting children around the person, and being shunned by friends.

HIV-related organizations. Along with family and friends, HIV support organizations and support groups were a source of emotional support as they provided outlets to talk and, in particular, enabled HIV-positive people to meet others going through similar experiences. For example, one African American male participant characterized his HIV support group as "a little resource of networking of outside people who I can discuss this stuff with mainly." Some participants also reported communicating with people

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Box 7

GENERAL SUBSISTENCE CARE (HIV-RELATED ORGANIZATIONS)

Emotional support
Quotation 1: "We plan something, plan to go to the movies or something. Might plan a little something at the park or plan something over (at) somebody's house. 'This time it's at your house, next time it will be at my house,' something like that . . . it's not everybody. It's just among the ones that's friends . . . . Yeah, I talk to them on the phone and stuff." (AAF)

Instrumental support
Quotation 2: "They have those resources, housing, the transportation, you know, food vouchers. So it is really beneficial. That really has helped me a lot too, knowing that I can go to get some food because there have been times. Just because I have the apartment doesn't mean that I can afford everything." (AAM)

from the support group outside of the support group setting, such as talking on the telephone or going out for fun and simply talking and relaxing (Box 7, Quotation 1).

HIV-related organizations also provided <u>instrumental support</u>, in that they offered food and/or food vouchers, housing assistance, and even veterinary assistance for participants' pets. Case managers from the organizations were key conduits for the support as participants described case managers facilitating housing, support with legal issues, and being general advisors. The HIV support organizations were described as centers providing access to an array of instrumental support (Box 7, Quotation 2). African Americans reported more instances of instrumental support from HIV support organizations than Latinos.

Churches. Whereas family members, friends, and HIV-related organizations were sources of support for participants' HIV health care treatment, one institution that was exclusively mentioned in connection with general care needs was the church. Notice-

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Box 8
GENERAL SUBSISTENCE CARE (CHURCHES)

Informational support
Quotation 1: "One church that I was attending actually gave me a booklet on HIV ministry and from that booklet, I mean, they were sharing that information with me to show that they are aware. So I guess I would say yeah (the church was supportive) because that was an experience that I would have never thought my pastor would have given me." (AAF)

Instrumental support
Quotation 2: "Church organizations helped me a lot, you know! Would surprise me often! They offered me assistance, housing, vouchers. They sent me to _____ [She mentions a clinic], you know." (AAF)

Quotation 3: "There are a lot of churches here that are beneficial for doing the food bank and I go for that. You know it's that extra food." (AAM)

Quotation 4: "I was also rejected by a church. The priest told me I could not take communion and I could not be part of a church. Therefore, he made me feel awful because the church is God's house, why was he rejecting me? Me that I was Catholic, that I made my first Holy Communion. I could take the communion and now I can't? This marked me and today I go to another church, which is gay, it welcomes gay men." (LM)

Quotation 5: "But what does surprise me though . . . is that some people in the church are on that just don't know status, you know? And I couldn't believe it, you know. Or that they will shun you off you know . . . . . And . . . it's knowing, knowing that they knew about being HIV." (AAM)

ably, African Americans reported receiving support from churches whereas Latinos did not mention churches as a source of support. Some were surprised at the general support provided by the church (Box 8, Quotations 1 and 2), yet churches were sources of social support for general care needs for some participants, albeit to a lesser extent than the other sources of support. The support for general care needs seemed to be centered on <u>instrumental support</u> such as food banks, housing, and vouchers (Box 8, Quotations 2 and 3).

While churches were generally perceived to be sources of support, some study participants experienced HIV-related stigma in church. This included being unable to take communion, people with HIV being segregated and provided with separate seating, and being shunned by some people (Box 8, Quotations 4 and 5).

Discussion

The relationship between social support and engagement in HIV care is complex and multifaceted. Our data suggest that participants received social support for both HIV health care as well general care from a range of formal and informal sources, and that the support can be categorized as emotional, instrumental, and informational. However, participants identified distinct patterns of the sources of social support for different types of care. Obstacles to engaging in HIV health care were also identified from these formal and informal sources of support, as well as from individuals themselves. To sustain engagement and maintenance in HIV health care, participants were more likely to rely on health care providers and HIV support organizations than their informal networks of family and friends. When needing general support for daily living, they were more likely to turn to family and friends.

This was an interesting finding since informal social support networks tend to play the primary role in providing social support among populations with chronic illnesses.[25,26] That some study participants experienced stigma from family and/or friends (and some chose non-disclosure for fear of this) supports the notion that high levels of stigma in minority communities and consequent lack of disclosure from HIV-positive people in family settings[32] may result in greater reliance on non-kin for social support. However, stigma was not the only reason for greater reliance on non-kin for social support. Some study participants preferred to contain discussions about HIV-related issues with health care providers or HIV support organizations—opting for privacy and, perhaps, a sense of normality where conversations did not bring attention to the individuals HIV status. While medical providers are part of the formal structures of support, our results point to emergent informal caregiving roles that they perform, sometimes outside the scope of formal medical responsibilities. This finding also suggests the importance of examining microsocial environments where support is obtained and where informal caregiving roles may emerge.[46]

Although health care providers are not generally included in the conceptual framework of social support effects on medical care utilization,[20] our findings suggest the extent of support a patient perceives from health care providers at an HIV clinic may affect whether or not that patient continues and maintains engagement in regular HIV care. Communicating rudely, providing a narrow focus of care or projecting lack of

interest through not listening or seeming not to care can equally, and negatively, affect engagement in care. That some participants avoided appointments because of perceived negativity from a doctor or health care worker reinforces this point. The medical practice implications of our findings include the importance of health care providers encouraging patients, which can affect a patient's likelihood of engaging in HIV treatment, and the importance of communication and coordination between health care providers and HIV social support organizations in the support of individual patients. There are also implications for population-specific differences in intervention approaches that take into account the varied social contexts of population groups to enhance effectiveness of social support interventions on engagement in HIV care.[20]

In addition, our data suggest that HIV organizations such as support groups and social service organizations play important roles. Such organizations may be staffed and explicitly utilized to provide connections in the management of both types of care needed by HIV-positive people. Since such organizations are involved in providing both illness-specific care and general subsistence care, they could act as bridges to develop consistency and coordination between the formal and informal social support networks of their HIV-positive clients.

Churches, while seen as important actors in caring for people with HIV,[33] did not appear to play as important a role as other social support systems for participants in our study. Notably, the participants who described receiving support from a church were all African American. Despite the prevalence of homophobia and negative views of MSM and by extension, HIV/AIDS in African American churches, research shows that some Black churches have taken a more active role in HIV prevention efforts. For example, there is the annual Black Church Week of Prayer for the Healing of AIDS, which encourages churches to set up HIV/AIDS ministries in the church and community.[47-48]

The differences in church-related social support found between African Americans and Latinos are complex and may be a result of both individual, cultural, and institutional factors. Nationally, 44% of Latinos, compared with 51% of African Americans, report attending church services on a weekly basis.[49] It is possible that Latinos are less likely than African Americans to consider churches as constituting part of their social support network. Institutional factors may also play a role in these differences. Although 68% of Latinos are Catholics,[49] Latino Catholic churches have been found to be involved in fewer HIV/AIDS-related activities than Latino mainline Protestant churches.[50,51] It is possible, then, that if the Latino participants in our study were primarily Catholic, they did not see their churches as sources of support.

With regard to *types* of support, participants reported the provision of emotional, instrumental, and informational support in both general and illness-specific areas of care. However, there were some variations in the patterns of support provided. Most noteworthy was that when family and friends supported participants' access to HIV health care, they tended to do so mostly by providing transportation. They were least likely to provide informational support about the illness. The only informational support provided by family was obtained from the Internet, and this was only reported by one participant. That there were no other examples of such support from family members suggests the influence of the so-called digital divide separating these com-

munities from others with widespread use of the Internet.[52] Furthermore, increasing family members' access to information and level of knowledge about the disease and its particular medication and treatment regimen may increase their ability to help their HIV-positive relatives better engage in HIV care.[24]

Limitations. A primary limitation of this study is that our sample was made up exclusively of HIV-positive participants who were already engaged in HIV care, who may have been more likely than those not engaged in medical care to report positive interactions with care providers. Furthermore, the small size of the sample affected our ability to delineate many differences in the sources and types of social support used by African Americans versus Latinos and by MSM versus women. For example, in addition to African Americans reporting receiving support from churches, unlike Latinos, they also reported receiving more instances of instrumental support from HIV support organizations. This may be due to Latinos running into a linguistic barrier, which may have impeded their ability to communicate their needs to such organizations. With regard to gendered differences, our finding that more men than women reported receiving emotional support from HIV support groups may be due to limitations inherent in our data collection process. Since the interviews were semi-structured to provide participants more flexibility to discuss their experiences in detail, rather than highly structured (which would have allowed less scope for discovering new and relevant information), not all participants were asked about, and not all talked about, HIV support groups. Thus, while more men than women reported receiving emotional support from HIV support groups, this does not mean that women received less emotional support, as they may not have thought to mention it in their interview. In addition, this finding could be explained by the greater availability of support groups for men than for women in Los Angeles, where approximately 75% of HIV infections are among men.[53]

Because social support is a broad and complex area, we were not able to cover all sides of social support in this study. For example, we were not able to assess the size, density, or quality of the social support networks described by participants. Consequently, we were not able to consider the structural aspects of their social support networks and the variability of support over time. Furthermore, there were several additional characteristics of social support in the literature (such as perceived versus actual support, and negative social support, stemming from family responsibilities taking precedence over self care or behaviors of family or friends that were perceived as unsupportive) that are not delved into here.[6,19] While these areas are important characteristics of social support, they were beyond the scope of this study.

Conclusion. In summary, through interviews with HIV-positive women and MSM who were African American and Latino, we were able to ascertain areas relevant to social support and engagement in HIV treatment. Our findings helped identify the people who provide support and the types of support offered for the different types of care needs. We found that members of formal social support networks (such as health care providers and HIV organizations) appear to be more critical to facilitating engagement in medical and mental health care for HIV treatment, and that informal networks (such as family, friends, and churches) appear to be more critical for other general subsistence care needs. Importantly, it was when health care providers showed genuine interest and concern that patients were more likely to engage in HIV health

care, and conversely, a lack of sensitivity or compassion from health care providers was more likely to yield disengagement. This points toward the critical role of health care providers and HIV organizations in encouraging engagement in HIV health care.

Information from this study can be useful for HIV service providers and organizations working to increase social support and in developing interventions and policy initiatives to enhance facilitation of HIV care retention among HIV-positive African American and Latino MSM and women. For example, we may need to understand better and to improve ways to link and coordinate the assistance offered by HIV organizations with those of health services, given that the participants in our study seemed to rely on these entities for HIV-related support. It may be important for health care providers and HIV organizations to understand how HIV-positive African Americans and Latinos interact with these respective sources of support and to have clear means of communicating the needs of clients up and down the chains of support, including to family and friends who tend to provide support for general subsistence.

Acknowledgments

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