

Prepared for:
SF EMA Care Council
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Follow-up Needs Assessment: African American Women, Older Adults, Hepatitis C Co-infected, Providers

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Introduction

- + Comprehensive HIV Health Services Needs Assessment conducted in 2008
- + Follow-up study in 2010 focusing on African American women, PLWHA with Hep C co-infection, PLWHA over 50 years old.
- + Conduct further examination of health and social service needs of these subpopulations
- + Focus group with HIV service providers
- + Today, presenting key findings from all focus groups

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Methods

- + Qualitative data collection: Focus Groups
 - African American women, n=1 (7 participants)
 - Older adults ≥ 50 , n=2 (14 participants)
 - Hepatitis C Co-infected, n=1 (9 participants)
 - Providers, n=1 (7 participants)
- + Targeted recruitment intentional
- + Place-based recruitment in SF EMA

Methods

- + Topics covered: Health services, social support, group-specific services, other general services, access (challenges) to care, unmet needs
- + Analysis: Content analysis
- + Not generalizable to all people living with HIV in the targeted populations, but provides in-depth information not captured by quantitative data.

Focus Group: African American Women

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Participant Characteristics

- + 6 female, 1 transgender
- + Average age was 52 years (49 – 55)
- + 4 heterosexual, 3 bisexual
- + Education Level:
 - 2 less than high school
 - 2 high school
 - 1 college graduate
 - 2 decline to state
- + The majority were at or below the Federal Poverty Level
- + Participants reported living with HIV for between 14 to 21 years

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Health and Medical Needs

- + Primary care was the principal health and medical need followed by mental health
- + Most expressed high satisfaction with their health and medical care.

“My doctor is a very sweet doctor. She sits down and takes time for you. If you ask her any questions she answers truthfully. If she can’t she will find someone to come into the room and give you an answer. Sometimes she calls me at home when I’m not feeling well and I like that.”

Other Services

- + Participants depend on the help and guidance provided by social workers and/or case managers: money management, filling out forms due to literacy issues (e.g., medication reimbursement, housing), referrals to services and resources.

“I need different services. I can read, but don’t understand big words and when I have problems they help you and they will break it down to you. They help you fill out paperwork,”

“When I need things like housing, my social worker and case manager got together. One did the application and the other got the funds.”

Challenges and Unmet Needs

- + **Transportation:** limited availability of discounted tokens and passes.

- + **Support groups for straight Black/African American women**

"I think we need more support groups, just for straight women because we do have differences. It's not the same when you are transgendered. When we discuss our problems, female problems it's just for females only."

- + **Reductions in support services due to current economic climate:** food services, transportation vouchers, dental coverage

**Focus Group:
Older Adults \geq 50**

Participant Characteristics

- + 12 males, 1 female, 1 transfemale
- + 7 African American, 6 White
- + Average age: 56 years old (50 – 67 years)
 - Age 50-60 (n=10)
 - Over 60 (n=4)
- + 71% (n=10) identified as gay or homosexual
- + More than half had some college education
- + Average time living with HIV was 17 years; shortest time living with HIV was 4 years; and one participant has been living with HIV for 29 years

Healthcare

- + Participants identified primary care as one of the essential services for staying healthy
- + Overall, participants were very satisfied with their primary care

"I see the same doctor and I like that doctor. He sits there, listens, and asks me what I think...It's not like he has 30 patients [waiting] and he sees [me] for 15 minutes."

"I trust her with my life, she is just that good. When I talk to her, we have eye contact and I know she is listening."

Healthcare

- + Barriers to healthcare included transportation, long wait lists for specialist care (e.g., urologist), and not being able to see a doctor as needed
- + A few participants also mentioned the high turnover among medical providers and attitudes of certain providers as barriers to receiving care

"There are lots of places I won't go to unless I'm dying. I won't go to [medical site] because they're mean to you. I don't want people to be mean to me when I'm feeling shitty."

Healthcare

- + Some participants also expressed frustration with finding information and navigating services

"There is no HIV services coordination at all. If I need to see a specialist, there is no one [to help]. Finding information is difficult. I have to call about 10 people."

"We need a case worker to assess his [needs] and to see what we should be doing and what help we should be seeking for him."

- + Increased need for medical specialists
- + Some participants pointed out the lack of hearing and vision care

"I have developed hearing loss and that is the one thing that has never been addressed with HIV services because there has never been a large senior community. And there is no help available."

Support Services

- + Participants emphasized the need for other services such as stable housing, transportation, and food
- + To stay healthy, participants also mentioned exercise, adequate sleep, proper medications, and complementary care such as herbal medicines
- + Many participants expressed the importance of support groups in their lives and the need for more opportunities for social interaction and daytime activities

"... it's very easy to become isolated. That's for seniors in general. Throw HIV in and what you've done is eliminate children (most of us don't have kids). It's not the same family support system. That's why the social becomes more important. For me, I've not had any support group and that's what I need to find."

Preparing Providers for Geriatric HIV Care

- + Participants shared how their medical needs are changing as they age and providers are not prepared or educated to understand their emerging needs

"I think it gets into a very confusing area for the doctors. They don't know because there are so many side effects to HIV meds and they aren't quite sure if you are dealing with an HIV problem or an aging problem."

- + Some participants noticed doctors having difficulty differentiating which symptoms are tied to aging or HIV.

"They blame everything on my age, but I shake my head. They say, 'you're getting older, that's why you're losing weight.' But it's not."

Changing Needs with Age

- + Several participants expressed worries about the long-term effects of HIV medications on their physical health

"We don't know the [effects] of long-term use of taking HIV drugs for people over 50."

"When people are over 50, everything begins to slow down. Your body functions are not as good. HIV medications have side effects like diabetes. [Doctors] need to be as educated as possible about [HIV medications] that will not add to the aging process."

"Heart disease runs in my family. I don't want my doctor to give me HIV meds that will increase the problem and make it worse."

Changing Needs with Age

- + One participant commented that adherence to a medication regimen becomes more difficult as memory becomes an issue
- + Mobility issues came up as a concern for a few participants as well as how to keep an active and healthy lifestyle
- + Other concerns include depression, hearing loss, and general health problems associated with aging

"I worry about being African American with high blood pressure and diabetes. Mostly just keeping blood pressure at a normal level and not stressing out so much..."

"With aging in particular, if you are a gay man and HIV positive, it's a very ageist society – the gay community. Getting old in itself can become depressing."

Fear of the Unknown

- + Many participants expressed anxiety about the future and not knowing what to expect in regards to their health and well being

"I'm 67 and I've had issues both age and HIV-related...now the only thing I'm not sure of is what will happen as I turn 70, 75...What is it I can expect healthwise? Where do you get that information?"

- + There were also worries about housing and limited incomes

"In San Francisco, there is fear you won't find housing you can afford. There needs to be some place for people approaching age 65 [and older] who have AIDS."

"That's one of the problems we might have is to live in an assisted living [facility]."

Focus Group: Hepatitis C Co-infected

Participant Characteristics

- + 4 males, 4 females and 1 transgender
- + Average age was 49.6 years old (32 – 62 years)
- + 7 African-American and 2 White
- + 6 Gay/Homosexual, 2 Heterosexual, 1 Bisexual
- + 5 high school education or less, 4 more than high school
- + 7 of 9 reported a household income of less than \$15,000/year
- + Participants have been living with HIV for between 5 to 23 years.
- + Participants have been living with Hepatitis C for 2 to 16 years.

Health and Medical Needs

- + **Quality primary care physician:** trustworthy, good communication skills, knowledgeable about HIV and Hep C, good reputation, empathetic

“A good primary care physician asks certain questions of patients – if I am taking my meds, if I’m doing unprotected sex, etc. They should ask those questions. I look for my physician to ask those questions.”

- + **More information and education about Hepatitis C treatment, care, transmission/prevention, medications**
 - Majority reported that they did not receive good information or education about Hep C, particularly on how to avoid transmitting. Or were not satisfied with the info received.

Hepatitis C Testing: Shock, Fear and Confusion

- + **Various testing routes:** found out unexpectedly as part of routine primary care visit, part of a study advertised in a newsletter, doctor suggested the test, asked to be tested
- + **Most reported feeling shocked by test results**

"When he came back with the news I was traumatized. It felt like Nightmare on Elm Street. I had one [HIV], then found out I got another [Hep C]. When you are living with this your mind is not really there because everyday you are walking like a dead man walking; you don't know when you will drop and die."

"It scared me at first because I thought I would die – I'm already HIV positive, then I find out I have Hep C? What is that?!"

Hepatitis C Testing: Shock, Fear and Confusion (cont.)

- + **Confusion and frustration by nature of Hepatitis C and its diagnosis**

"I beat Hep C one time (cleared it), but then two years later it was back again."

"When I first got tested for Hep C they told me I was positive, then called back and said it was a false positive. A year later I found out it wasn't a false positive."

"In '94 I wasn't positive, but in '95 I was. They told me that it might have been there all along but hadn't shown up. I found out over the years as I got more educated that it can lie dormant."

Challenges with Hepatitis C Treatment

- + Nearly all participants expressed concerns and apprehension about taking additional medications, i.e. medications for Hepatitis C on top of HIV medication.

"I choose not to do anymore medication because sometimes the meds can make you worse."

"We've talked about treatment but I've decided not to so far. I don't want to do too much more meds on top of my HIV meds."

- + Others also talked about not seeking treatment or medication in hopes that the "body" or "liver will heal itself."

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The Need for Hepatitis C Support and Services

- + Participants pressed on the valuable role mental health services play in maintaining their overall health.

"Sometimes it's a mental thing. There can be a lot of depression that comes along with this, especially if you have HIV."

"They asked me if I ever thought about suicide or depression and that scared me because I don't want new meds to make me think about that."

- + Psychological burden of being dually diagnosed and the usefulness of case management and support groups.
 - Useful services received at Ward 86, Black Coalition on AIDS (BCA), AIDS Health Project, Black Brothers Esteem, Shanti

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The Need for Hepatitis C Support and Services (cont.)

- + *Case management and support groups continued*
 - Case managers with knowledge about Hep C resources
 - Hep C services in San Mateo County
 - More information about Hep C-specific support groups
- + Participants expressed concern about how difficult financial times may affect the availability of important resources such as food, housing and transportation.

“Having stable housing. It is important to stay healthy. If you have housing you are more likely to take care of yourself, eat right, and take your medications. There is less stress.”

Focus Group: HIV Service Providers

Participant Characteristics

- + Representation from all three counties: San Francisco, San Mateo, Marin
- + Services areas represented: medical, housing, food, neighborhood health center, program directors

Needs of Clients/Consumers

- + Case management!

"...they have case managers who look at the medical component and also the social services piece too. The case managers that begin a referral, they also follow-up on that referral for the client."

"I think what's helpful is not the amount or intensity of case management, but the coordination of it."

"One thing that has been difficult, given decreasing resources, is having to eliminate social workers so you have a population of 600 clients seeking out 2 ½ case managers, so the impossibility of doing intensive case management, keeping patients engaged in care, making phone calls to remind clients' of their appointments. With fewer and fewer resources, it becomes this surface-y case management."

Challenges

- + **Accessing services on an emergency, urgent or as needed basis – rather than on a regular, continuous basis**

“I wish that they would access a primary medical care provider, rather than a drop-in medical setting so we can give more continuity in care rather than episodic fragmented care, even though they are in the same setting.”

“I will reiterate that it would be great if people came in regularly for their appointments rather than dropping in for episodic care.”

- + **Re-emphasizes the need for case managers or social workers to help coordinate care**

Challenges

- + **Limitations and parameters on funding: restrictions, eligibility requirements, targeted funding**

“We almost have to build our programs based on the funding instead of build the programs you need and find the funding for the programs that you need. It’s as if the services follow the funding rather than the opposite. So, we can have this really great program for a small segment of our population that can’t be accessed by the 90% rest of the population that can benefit from it because of the targeted, super specialized funding.”

“When you’re dealing with housing what you’re dealing with is a very long-term problem. It takes a long time for the client to get into the situation they’re in, and it takes a long time to get out. You’re talking about something that is not so time-limited that funders like. Most funders like a special program where there is a beginning, middle, end, and then a report, and that’s really hard.”

Challenges

- + **Smaller number of clients who are sicker and have multiple needs.**

"The hardest folks for us to work with are the folks who are seriously ill in some way with transportation and housing problems. They need someone to manage their money, meds, and be a mom. It's nearly impossible to find board & care; mental health services are being cut; clients are reticent; their situation has become very scary."

"there's always that smaller # of clients that are difficult to engage in care and they are the individuals with multiple needs and have the most medical issues."

"The severest needs clients need a lot of intensive work and when resource shortage happens, it becomes more about how I can impact the greater numbers instead of the individual."

Awareness of Issues

- + **Providers were well aware of issues facing the three groups, including their challenges.**
- + **However, they were mostly unaware of resources specific to those subgroups**
- + **Overwhelmed or frustrated with trying to meet some of these needs with limited resources, accountability and equity among social services.**

Recommendations

Recommendations

- + Increase opportunities for support groups geared towards straight African American Women.
- + Continue case management services that provide assistance with accessing vital services such as continuous primary care, housing, and transportation.
- + Expand comprehensive medical services for HIV and Hepatitis C co-infected individuals.
- + Increase awareness and education about Hepatitis C prevention, transmission, care and treatment.

Recommendations

- + Provide accurate information about Hepatitis C and HIV medications to reduce apprehension and uncertainty.
- + Increase awareness among providers regarding mental health issues that are specific to patients with Hepatitis C.
- + Provide a centralized information source & service coordination for seniors, specifically.
- + Train and prepare providers for a growing elderly population living with HIV.

Recommendations

- + Increase opportunities for social interaction and connection:
 - Support groups geared for seniors and their unique issues, including daytime social activities.
- + Provide and expand resources related to housing and finances for aging PLWHA
- + Expand research on geriatric HIV including long term effects of HIV medication

Recommendations

- + Discuss and share strategies to overcome funding challenges.
- + Widely distribute and “market” resources specific to African American women, older adults and Hepatitis C co-infected to providers.
- + Conduct similar focus groups with newly diagnosed individuals.

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