HIV Care Utilization

A Qualitative exploration of HIV Care experiences

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4/9/2009

Instrument Overview:
Interview-delivered instructions are noted within blue text boxes and should be read aloud to participants during the interview. Allow participant to narrate their experiences to open-ended qualitative items, using the follow-up prompts found within the shaded beige boxes to probe for additional information as needed if participant’s original response was terse or needs further exploration to capture enough detail to provide sufficient context to the original response.

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Recommended Citation
Thank you for agreeing to be part of this study. Our main interest is to understand your experience with your HIV medical care, specifically attending doctor appointments and getting your HIV labs done (i.e., blood work to learn your viral load or T-cell/CD4 cell values. We are equally interested in understanding what works to help you get your medical care, and what can make it more challenging. We hope that from your experiences we may learn things that might help others who might be in a similar situation.

Patient Structured Quantitative Interview Tool

Demographic Items

These questions have to do with your background. Your answers will help us to describe the people involved in this project. We are grateful for the information you share with us. First, let’s start with the year you were born and your gender:

1. Year of Birth (YYYY): __________________

2. Gender: (Please check one.)
   - Male
   - Female
   - Transgender
   - Intersexed

3. Which of the following best describe your racial/ethnic background? (Please check all that apply.)
   - African American or Black (not Hispanic)
   - Hispanic American or Latino(a)
   - White (not Hispanic)
   - Asian American
   - American Indian or Alaskan Native
   - Native Hawaiian or Other Pacific Islander
   - Other (specify): _________________________

4. What is your sexual orientation? (Please check one.)
   - Gay or lesbian
   - Straight or heterosexual
   - Bisexual
   - Unsure / don’t know

5. What is the highest level of education you have completed? (please check one)
   - Some high school or less
   - High school diploma or GED
   - Some college
   - College degree (BA, BS)
   - Some graduate school
   - Graduate degree (MA, JD, PhD, MD, etc)
6. **What statement best describes your employment status? (please check one.)**
   - [ ] Currently unemployed
   - [ ] Employed full-time
   - [ ] Employed part-time
   - [ ] On disability or sick leave
   - [ ] Retired

7. **What is your family income per year? (Please check one. If you don’t know, please make your best guess.)**
   - [ ] Under $5,000
   - [ ] $5,000 to $10,000
   - [ ] $10,001 to $20,000
   - [ ] $20,001 to $30,000
   - [ ] $30,001 to $50,000
   - [ ] $50,001 to $75,000
   - [ ] Over $75,000

8. **How many people are supported by this income, including yourself? (Please check one.)**
   - [ ] 1 (myself)
   - [ ] 2
   - [ ] 3
   - [ ] 4
   - [ ] 5
   - [ ] 6
   - [ ] 7
   - [ ] 8
   - [ ] 9
   - [ ] 10 or more

9. **For how many children or older adults are you the primary care-taker? (Please check one.)**
   - [ ] 0
   - [ ] 1
   - [ ] 2
   - [ ] 3
   - [ ] 4
   - [ ] 5
   - [ ] 6
   - [ ] More than 6

10. **What best describes where are you living right now? (Please check one.)**
    - [ ] Living in a house, condominium, apartment or room that you rent or own
    - [ ] Living in a friend’s or family member’s house or apartment
    - [ ] Living in a halfway house, assisted living residence, or rehabilitation program
    - [ ] Living in a homeless shelter
    - [ ] Living in an abandoned building
    - [ ] Living on the street
**HIV Diagnosis and Treatment History**

*Now I’m going to ask some questions about the time you were diagnosed with HIV, and about different types of experiences you may have ever had since you were diagnosed.*

11. **In what year were you first diagnosed with HIV?** *(Please check one.)*

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12. **In what year did you first start going to a medical clinic to get HIV-care?** *(Please check one.)*

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13. **In what year did you first start taking HIV medications, if at all?** *(Please check one.)*

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14. **How do you think you got HIV?** *(Please check all that apply. If you are unsure, please make your best guess.)*

- ☐ Having sex with a man who had HIV
- ☐ Having sex with a woman who had HIV
- ☐ Sharing needles or works
- ☐ Blood transfusion
- ☐ Got it at birth
15. In the last year, how often do you come to clinic to get HIV-care, if at all? (Please check one.)
   - I haven’t come in for my HIV-care in the last year
   - Less than once every 6 months
   - About once every 6 months
   - About once every 4-5 months
   - About once every 2-3 months
   - At least once a month

16. Have you ever experienced a gap in HIV care of 6 months or more? (Please check one.)
   - Yes, within the past year
   - Yes, within the past 2 years
   - Yes, within the past 5 years
   - Yes, but it was more than 5 years ago
   - No, I have never had a gap in care of 6 months or more

17. Have you ever had a past or current history of unstable housing since your HIV diagnosis? (Please check one.)
   - Yes, within the past year
   - Yes, within the past 2 years
   - Yes, within the past 5 years
   - Yes, but it was more than 5 years ago
   - Yes, but it was before my HIV diagnosis
   - No, I have never had a history of unstable housing

18. Have you ever had a past or current diagnosis or treatment for any psychological or emotional problems (e.g., anxiety, depression, etc.) since your HIV diagnosis? (Please check one.)
   - Yes, within the past year
   - Yes, within the past 2 years
   - Yes, within the past 5 years
   - Yes, but it was more than 5 years ago
   - Yes, but it was before my HIV diagnosis
   - No, I have never been diagnosed or treated for any psychological or emotional problems

19. Have you ever had a past or current history of substance abuse since your HIV diagnosis, with drugs you did not inject? (Please check one.)
   - Yes, within the past year
   - Yes, within the past 2 years
   - Yes, within the past 5 years
   - Yes, but it was more than 5 years ago
   - Yes, but it was before my HIV diagnosis
   - No, I have never had a history of drug abuse with drugs that I did not inject
20. Have you ever had a past or current history of substance abuse since your HIV diagnosis with drugs you did inject? (Please check one.)
   - Yes, within the past year
   - Yes, within the past 2 years
   - Yes, within the past 5 years
   - Yes, but it was more than 5 years ago
   - Yes, but it was before my HIV diagnosis
   - No, I have never had a history of drug abuse with drugs that I did inject

21. Have you ever had a past or current history of incarceration since your HIV diagnosis? (Please check one.)
   - Yes, within the past year
   - Yes, within the past 2 years
   - Yes, within the past 5 years
   - Yes, but it was more than 5 years ago
   - Yes, but it was before my HIV diagnosis
   - No, I have never had a history of incarceration

22. How long does it take you to travel to clinic (one way)? ____________________

These next few questions are about different types of things some people have said make going to their HIV care appointments more difficult. For these questions, please let me know how difficult these things have been for you using a scale from 1 to 7, where 1 means it is personally very difficult for you and 7 means that it is personally not at all difficult. [Please circle only one number for each item.]

23. How difficult is it for you to travel to clinic for your HIV appointments?

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24. How difficult is it for you to pay to travel to clinic (e.g., transportation)?

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25. How difficult is it for you to afford your HIV clinic visits (e.g., insurance co-pay, having to take time off work)?

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26. How difficult is it for you to get an appointment with your HIV doctor that fits your schedule?

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27. How difficult is it for you to arrange for child or adult care when you come to clinic for your HIV care?

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- I do not have to arrange for child or adult care to come to clinic
INTRODUCTION & HIV CARE UTILIZATION HISTORY

Remember we will be audio taping this part of the interview, and using a pseudonym or “fake name” to help ensure everything you say will remain confidential. If there are questions you don’t want to answer, we can skip them. I may also enter some of your answers into the computer or take notes as we are talking, this is just to help me remember your answers later, and to be sure your experiences are clearly understood and represented.

Do you have any questions before we begin?

To start with, I’d like to ask you a few background questions about your HIV and experiences getting medical care for your HIV.

1. After you were first diagnosed as having HIV, how long was it before you were able to see a doctor about your HIV?

2. How long have you been receiving your HIV-care at this clinic (or through the outreach workers)?

3. When was the last time you saw a doctor for your HIV?

4. Have you been diagnosed with other conditions that require regular medical care, like Hepatitis C, diabetes, anxiety, or depression?

   If Yes, ask:
   - What condition(s) have you been diagnosed with?
   - How long have you had this (these) condition(s)?
   - Where do you receive care for this condition(s), if at all?

Because having HIV is only one part of who you are as a person, many people have different life experiences that may take precedence or need more attention than getting into see your doctor or get lab work done for their HIV.

5. For whatever reason, how many times in the last year have you missed an appointment to see a doctor about your HIV or get labs done?

   If participant has not missed any appointments over the past year, probe:
   - What types of situations can make it really hard to get in to see your HIV doctor?

   If participant has missed any appointments over the past year, probe:
   - In general, about how long does it take you to get back in to see your doctor or get labs done once you’ve missed an appointment?

6. In general, about how long does it take you to get back in to see your doctor or get labs done once you have missed an appointment?
Now I’d like to ask you a little bit more about the times you have experienced gaps in your HIV care, or any time you hadn’t seen a doctor for your HIV for 6 or more months.

7. Since the first time you saw a doctor about your HIV, what is the longest period of time you have gone without seeing a doctor for your HIV or getting your HIV labs done?

8. Thinking about this period of time, tell me a bit more about what else was happening your life:  
   
   As the participant reflects on these times, probe for more information about what was going on in their life in term of:
   - work or housing status, substance use and related issues, mental health (for example, depression) and related issues, any relationship with having been incarcerated around that time, relationships with family, friends, partners during that time
   In exploring these issues, try to elicit the participant’s perceptions about what they feel was the main reason(s) they were not in regular HIV care.

9. At that time (during the gap in HIV care), what was your biggest priority?

10. On a scale from 1 to 10, with 1 being very important and 10 being not at all important, with all that was going on during this gap in care how important it to you to get in to see you’re a doctor for your HIV?

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11. During this time how would you describe your overall health?

12. At that time, how difficult would it have been to get in to see a doctor about your HIV given everything else that was going?

13. How long ago was you’re most recent gap in care, and how long did it last?

14. Thinking about your most recent gap in care, tell me a bit more about what else was happening in your life:  
   
   As the participant reflects on these times, probe for more information about what was going on in their life in term of:
   - work or housing status, substance use and related issues, mental health (for example, depression) and related issues, any relationship with having been incarcerated around that time, relationships with family, friends, partners during that time
   In exploring these issues, try to elicit the participant’s perceptions about what they feel was the main reason(s) they were not in regular HIV care.

15. At that time, what was your biggest priority?

16. On a scale from 1 to 10, with 1 being very important and 10 being not at all important, with all that was going on during this gap in care how important it to you to get in to see you’re a doctor for your HIV?

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17. During this time how would you describe your overall health?
18. At that time, how difficult would it have been to get in to see a doctor about your HIV given everything else that was going?

19. What was it that got you back into regular care, or what do you think would need to happen for you to begin coming to care regularly?

20. In general, what are 3 things that help you to see your HIV doctor and get your HIV labs done when scheduled?

21. In general, what are 3 things that make seeing your HIV doctor and getting your HIV labs done when scheduled more difficult?

**HIV TREATMENT KNOWLEDGE**

22. How often would you say people are recommended to come in for regular care HIV care visits, like viral load checks, in terms of months? Why do you think that is?

23. What is the point of a regularly scheduled HIV care visit, if you are not feeling sick or having trouble with your medications? Do you think such visits matter even when you don’t feel sick?

24. What would be really important for people to know about HIV or their HIV care that would help them to come into care regularly?

25. How often are you supposed to get your labs done? Why do you think that is?

26. What does your CD4 and viral load tell you?

**HIV TREATMENT MOTIVATION**

27. What are the challenges or sacrifices you make to get in to see your HIV care provider or get labs done at least once every 3-4 months?

28. What encourages you to come in to see your doctor or get labs done regularly, say at least once every 3-4 months?

29. What kinds of beliefs or feelings do you have about what it means to see a doctor or receive medical care in general on a regular basis? What kinds of beliefs or feelings do you think those close to you or similar to you have?
30. **What kinds of beliefs or feelings do you have about what it means to receive HIV medical care on an ongoing basis? What kinds of beliefs or feelings do you think those close to you or similar to you have?**

31. **What do you think makes it seem like regular HIV care is not important to people?**

32. **Are there other people with HIV who are important to you that stay involved in their regular HIV medical care?**

33. **Are other people who are important to you supportive of your HIV care?**

   **Probe for ways that important others provide emotional/instrumental support:**
   - Do they help by giving you rides
   - Do they help by supporting or pressuring you to get to your appointments?
   - Who are these people and how do they support you?

34. **How much pressure do you put on yourself to get into HIV care regularly, like every 3-4 months or so?**

35. **How much pressure do other people put on you to get into HIV care regularly?**

   **Probe for ways that other people pressure them:**
   - Who puts that pressure on you?
   - What does that pressure look like?
   - What do they say or do?

36. **Please tell me a bit about your relationship with your HIV doctor?**

   **Probe for information on the patient-provider interaction:**
   - How well does your doctor explain information related to your HIV treatment?
   - How easy is it to ask your doctor questions regarding your treatment

37. **Please describe anytime(s) you ever felt that you were disrespected or discriminated against or did not receive the same level of HIV care as you deserve for any reason?**

   **If needed, share with participant the follow up prompt (below) but try to allow them to freely recall these experiences without it if possible.**

   These reasons could be related to how you got HIV, your race/ethnicity, gender, because your substance use or mental health history, or because of your sexual orientation.

   a. **Please describe this experience(s).**

   b. **How does this experience make you feel about coming in to an appointment?**
      (e.g., anxious, nervous, worried, not want to come back?)

   c. **How likely do you think it is that this would happen again?**

   d. **Have any of these experiences changed how you view your HIV providers? If so, how?**
HIV TREATMENT BEHAVIOR SKILLS & STRUCTURAL BARRIERS

Now I’d like to ask you some questions about different skills or strategies that may help some people to see their HIV doctors or get their labs done more regularly.

38. What kinds of things do people need to be able to do to keep coming in for regular HIV care visits? 

If needed prompt participants about different types of reminders, support, or other things like transportation might affect someone attending their regular HIV care visits.

39. What is the most common reason you are unable to make it to our medical care appointments?

40. Are there certain skills or strategies you’ve developed that help you to make it to your care visits?

41. Do you use any non-medical services help you meet your regular medical care appointments?

If needed, prompt participants by suggesting different types of services, and inquire if there are any particular services they think would be helpful for themselves or others.
- (e.g. financial assistance, transportation services, substance abuse support or harm reduction services, mental health services)

42. How does clinic staff influence you meeting your medical care appointments?
   (e.g., Courteous helpful staff, Difficult staff)

43. Given everything else going on in your life, what kinds of other priorities make getting to a HIV care appointment impossible sometimes?
   (e.g., child care, housing status, recent history of incarceration)

We are thinking of developing a program or resource list that could help people meet their regular HIV care appointments. I am very interested in your thoughts on what you think such a program might look like to be most helpful to people.

44. What might such a program need to offer?

45. Where would be a good place to locate the program?

46. What would make people want to come to the program or recommend it to others?

47. Is there anything else related to your HIV medical care that I didn’t ask you that you feel is important for either the doctors, staff, or other people living with HIV to know?

Those are all of my questions. I’d like to thank you for taking the time to talk with me. Do you have any questions for me?
Interviewer Assessment (to be completed immediately after the interview)

1. Was the interview completed? If not, why not?

__________________________________________________________________________________________
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2. Did you feel the interviewee was reliable (i.e. trying to give honest, accurate answers, able to think and remember clearly)?

__________________________________________________________________________________________
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3. Were there particular questions or portions of the interview that you felt the interviewee did not respond to honestly? If so, which ones?

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4. Were there particular questions that the interviewee did not want to respond to? If so which ones?

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5. Were there noticeable inconsistencies in responses? If so, please describe?

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6. Describe the interviewee’s emotional & mental state (if s/he seemed high, got agitated, got upset, etc.)

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7. Other comments:

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