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“Understanding Barriers and Facilitators to HIV Prevention, Care, and Treatment”

2m. HIV-discordant Partners In-Depth Interview Guide English

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Understanding Barriers to HIV Treatment, Care and Prevention

Interviewer's Protocol Partner's Instrument

Date _____

Interviewer ID _____

Interviewer Confirm You Have:

__ two consent forms

__ token of appreciation

__ receipt for token

__ two tested and working audio recorders

INTRODUCTION FOR RESPONDENT:

My name is _[Interviewer name]_ and I'm going to be your interviewer for the next hour or so. Thanks in advance for agreeing to do this study. I'm really looking forward to our conversation. Let's start out by telling you more about your participation in this research study and your privacy.

[HAND CONSENT FORM TO RESPONDENT]

This is a **consent form** that gives you details about your rights as a respondent in our study, and the steps that we will go through to make sure that your private information is protected.

[READ CONSENT FORM WITH RESPONDENT, DETERMINE IF HE HAS ANY QUESTIONS. ANSWER QUESTIONS HONESTLY, THEN ASK AGAIN UNTIL RESPONDENT HAS ALL QUESTIONS ANSWERED. IF RESPONDENT AGREES TO INTERVIEW HAVE RESPONDENT SIGN AND DATE FORM. PROVIDE A SECOND COPY TO THE RESPONDENT.



[TURN ON AUDIO]

[READ] As you know, this interview is being audio recorded. Thank you again for being in our research study, which will help us understand why people living with HIV do or do not engage in medical care and treatment for their HIV. Funding for this study is provided by the Centers for Disease Control and Prevention (CDC). Please answer the questions honestly and to the best of your ability. **There are no right or wrong answers.** Remember that you can stop at any time you like or skip any question you prefer not to answer. We take your privacy very seriously. Your answers are completely private, and all personal identifying information – e.g. names of family members or partners – will be removed from the transcript. We encourage you to use nicknames or descriptors such as ‘my daughter’ when talking about other people or places, particularly if this makes you feel more comfortable. Please try not to use your own or other people’s full names or identifying details.

SECTION A: BRIEF RESPONSE

INTERVIEWER READ INTRODUCTION: I am now going to ask you several quick questions to get a better background understanding of you and your situation. Please answer openly and to the best of your abilities. Remember that you can refuse or skip any question you don't wish to answer.

- A1. How old are you?
- Under 18 years old → STOP INTERVIEW
 - 18 – 25 years old
 - 26 – 35 years old
 - 36 years and over
- A2. Do you think of yourself as:
- Gay
 - Straight, that is, not gay
 - Bisexual
 - Something else
 - Don't know/Questioning
- A3. Do you consider yourself to be of Hispanic, Latino, or Spanish origin?
- YES
 - NO
 - REFUSED
 - DON'T KNOW
- A2. Which racial group or groups do you consider yourself to be in? You may choose more than one option.
- American Indian or Alaska Native
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White
 - REFUSED
 - DON'T KNOW
- A3. In what country or territory were you born? [Don't read choices. Circle one.]
- UNITED STATES
 - OTHER (SPECIFY: _____)
 - REFUSED
 - DON'T KNOW

- A4. What is the highest level of education you completed?
- a. Never attended school
 - b. Grades 1 through 8
 - c. Grades 9 through 11
 - d. H.S. Diploma or GED
 - e. Some college, associate's degree, or technical degree
 - f. Bachelor's Degree
 - g. Any post-graduate studies
 - h. REFUSED
 - i. DON'T KNOW
- A5. During the past 12 months, have you had any kind of health insurance or health coverage? This includes Medicaid and Medicare.
- a. Yes
 - b. No SKIP TO A7.
 - c. REFUSED
 - d. DON'T KNOW
- A6. During the past 12 months, was there a time that you didn't have any health insurance or health coverage?
- a. Yes
 - b. No
 - c. REFUSED
 - d. DON'T KNOW
- A7. Are you currently...?
- a. Employed for wages
 - b. Self-employed
 - c. Out of work for more than 1 year
 - d. Out of work for less than 1 year
 - e. A Homemaker
 - f. A Student
 - g. Retired
 - h. Unable to work
 - i. Something else (SPECIFY)
 - j. REFUSED

- A8. In 2013, what was your total combined yearly household income from all sources before taxes? "Total combined household income" means the total amount of money from all people living in the household. *(INTERVIEWER: Clarify range if not clear in response)*
- a. \$ 0 to \$25,000
 - b. Over \$25,000 but under \$50,000
 - c. \$50,000 or over but under \$75,000
 - d. \$75,000 or over
 - E. REFUSED
 - F. DON'T KNOW
- A9. Do you currently receive any of form of public assistance?
- a. Yes - What? _____
 - b. No
 - c. DON'T KNOW/ DON'T REMEMBER
- A10. [ASK FOR SPANISH ONLY] The rest of this interview is all in Spanish, but for classification purposes we need to ask: how well you speak English? Would you say....
- a. Very well
 - b. Well
 - c. Not well
 - d. Not at all
 - E. REFUSED
 - F. DON'T KNOW
- A11. In the past 12 months have you stayed on the street, in a shelter, or temporarily in someone's home because you had no regular place to live or stay?
- a. Yes
 - b. No
 - c. REFUSED
 - d. DON'T KNOW

- A12. Who lives in your household? Please tell me by giving their relationship to you rather than their name like 'my grandmother' not her name. *[INTERVIEW: Note descriptors for use in IDI]*

DESCRIPTOR 1 _____

DESCRIPTOR 2 _____

DESCRIPTOR 3 _____

DESCRIPTOR 4 _____

ADDITIONAL DESCRIPTORS _____

COUNT _____

Section B: HIV Experience and History with HIV+ Partner

INTERVIEWER READ:

Thank you. **This rest of the interview will be more like a conversation.** I'd like to talk about your experiences and opinions on HIV treatment, care, and what influences your involvement in your partner's care. Please be as open and honest as possible with your answers. We want to hear everything you have to say.

HIV & Testing History

Goals: Does R get tested, is his HCPs aware

- B1. To start, can you tell me a bit about your current relationship with your partner? *(IF NECESSARY: And what has his HIV status meant for you?)*
GIVE THE RESPONDENT A CHANCE TO START TALKING. LISTEN ACTIVELY. ALLOW R TO CONTINUE FOR TOPICS COVERED IN THE INTERVIEW AND REFER TO IT DURING PROBES AND PROMPTS.
- B2. Were you two sexual partners at the time he first learned he was positive? *(IF NECESSARY Tell me more about when you first learned he was positive.)*

- B3. Let's talk a little bit about your status now. Have you ever been tested for HIV?
- B3a. Why/Why Not?
 - B3b. IF NOT → SKIP TO B4
 - B3c. IF YES → Tell me how about how you get tested, like how often, and where. PROBE AS NECESSARY TO LEARN IF R WAS REGULARLY TESTED BEFORE HIS PARTNER WAS DIAGNOSED.
- B4. Do you have a doctor or nurse or clinic that you go to for your health care?
- B4a. IF YES → Does your doctor/nurse/clinic know that your partner is HIV+?

INTERVIEWER CHECK: You should understand if R gets tested, frequency, if he was tested prior to being in SDP relationship and if his HCPs are aware of his SDP status.

Status Disclosure

Goals: Hx of disclosure and reaction

Interviewer: Verify response if already answered previously

- B5. How did you find out about your partner's status?
- B6. Did you and your partner talk about his status? Tell me about that conversation.
- B7. What did his being HIV positive mean to you? *(Interviewer: determine both what HIV means to him as a definition, and if it impacts behavior or attitude and what it means to the relationship)*

INTERVIEWER CHECK: You should understand if PLWH disclosed information to SDP, how and when, and impact of disclosure on partner and relationship.

Care and Treatment

Goals: Awareness of treatment and involvement

- B8. I would like to know what impact your partner's HIV care, pill schedules, doctors visits and so on have in your own life. I'm most interested in **you** and how what he does affects **you**.
- B9. Does your partner go to a doctor or nurse for HIV care? PROBES IF YES AT B9:
- B9a. Do you ever go with him? Tell me about that.
- B9b. IF NECESSARY: Why do you go with him? (e.g. partner social support, ensure provider listens to issues, translation assistance, provide transportation)
- B10. Does your partner take any HIV medicines? IF YES, Tell me more about that..
IF NOT COVERED, PROBE:
- B10a. Does he takes his pills the way he has been told to do? How does he change it?
- B10b. Tell me if you are involved in any way in his taking this meds
- B10c. Does he have any side effects from his pills? Like feeling sick or tired from the pills?
- B11. When it comes to how your partner is managing his HIV, would you prefer to be left out of that or would you like an active role? What would that be? *(Interviewer: Probe to determine level of advocacy R feels he should have)*
- B12. Have you ever tried to find out more about HIV and the medical choices for him? Tell me about that. (Interviewer: Probe long term care/referral assistance)
- B13. Some people in HIV treatment know more and some know less about what the lab tests show about how they are doing, and the same is true for those around them. How about you: do you know your partner's viral load? His CD4 count?
PROBE: And how much do you know about what these things mean? CD4 counts? viral load

INTERVIEWER CHECK: You should understand the extent to which SDP is aware of partner's treatment; if he thinks he should be involved; and if he perceives his partner as aware and engaged in treatment.

R's Treatment

INTERVIEWER REFER TO B4 TO DETERMINE IF R HAS DR/NURSE/AND IF THEY KNOW SDP STATUS

IF NO DR/NP/CLINIC GO TO SECTION C:

IF HCP AND HCP KNOWS GO TO SECTION D:

IF HCP AND HCP DOES NOT KNOW GO TO SECTION E:

GOALS FOR ALL THREE SECTIONS: EXTENT TO WHICH R PROTECTS HIMSELF

Now I'd like to talk with you about your health and anything you might be doing for yourself in terms of your partner's HIV status.

Section C: NO HCP

You said that you did not have a doctor/nurse or clinic of your own where you go for health care? Is that correct?

- C1. IF YES: Tell me more about that, have you had one in the past? Why did you stop going? (e.g., perceived discrimination, uncaring and unsupportive, access challenges – too hard to get to doctor office)
- C2. IF YES: How well did you understand what the doctor had to say?
- C3. IF YES: And how well did the doctor understand what you had to say?
- C4. IF YES: IN SPANISH ONLY: Was language a problem? **SKIP TO**

- C5. IF NO: Does s/he know that your partner is HIV+?
 - a. IF YES GO TO Section E:
 - b. IF NO GO TO Section D:

Section D: HCP UNAWARE OF HIV

- D1. You said before that you have a doctor/nurse or clinic of your own and that s/he does not know about your partner's HIV status? Is that right?
 - a. IF NO: SKIP TO Section E:
- D2. Tell me about why you have not told him/her about your partner's HIV (e.g., stigma, discrimination)?
- D3. How well do you understand what the doctor has to say?
- D4. And how well does the doctor understand what you have to say?
- D5. IN SPANISH ONLY: Is language a problem? **SKIP TO**

SECTION E: HCP AWARE OF STATUS

- E1. You told me before that you have a Dr/Nurse/Clinic where you go, and that they know about your partner's HIV status. Tell me about what things s/he has suggested you do to keep you from getting HIV as well (e.g., condoms, PrEP)?
- E2. Did s/he talk to you about how to avoid getting HIV? What did he say?
- E3. Did s/he mention any medicines you could take to keep from getting HIV?
- E3a. PROBE: Did s/he mention Pre-exposure Prophylaxis, or PrEP
- E3b. PROBE: Do you feel you know enough about that to make a decision to take PrEP pills?
- E4. How well do you understand what the doctor has to say?
- E5. And how well does the doctor understand what you have to say?
- E6. IN SPANISH ONLY : Is language a problem?
- E7. Do you think there are more things out there that can keep you from getting HIV as well that s/he didn't cover with you? Tell me more.

INTERVIEWER CHECK: You should understand SDP relationship with his own HCP if the HCP knows of SDP status and if R has talked to HCP about prevention including PrEP and extent of perceived stigma and discrimination. For Spanish- if language is a barrier.

Section F: Transmission Risk

- F1. We've talked already about how your partner's HIV status affects you. Now let's talk about how it affects your relationship with him and other people. Do your friends know that he is HIV positive? (IF YES: Do you feel they are supportive of you? Both?)
- F2. What about your family, do they know he is HIV positive? Tell me more?
- F3. What are some of the hardest things for YOU to deal with in terms of his HIV status? (e.g., stigma, discrimination, lack of social support) Anything else?

Interviewer check: Does R have social support for dealing with partner's HIV? Is this an issue for R?

- F4. And what about your sexual behavior? In what ways does his HIV status affect that?
- F5. Has your sexual behavior changed at all to protect you from getting HIV? (e.g., changing from bottom to top)
- F6. Do you think you should be doing more? Like what?
- F7. How worried or not worried are you about getting HIV as well?

Interviewer check: You should understand how being an SDP affects relationship and if R is worried about transmission and actively avoiding transmission.

- F8. And what about other sexual partners? In the time you have been with PARTNER, have you ever had sexual relations with others?
- F9. Do/Did you know the HIV status of that/these partner(s)? How?

F10. IF OTHER PARTNERS: And what kinds of things have you done to keep from getting HIV with him/them?

F10a. What about condoms? Do you always use them?

F10b. Anything else?

Interviewer check: You should understand if R has had additional sexual relationships since becoming an SDP and is he taking transmission prevention measures.

F11. Sometimes partners of people living with HIV are referred to services to help them find ways to keep from getting HIV as well. Have you ever been referred to services for other ways to stay HIV negative?

F11a. IF YES: What services? Who referred you

F11b. IF YES: Did you use the services? Tell me about that? Were they helpful?

F11c. IF YES: What could have made them better? (e.g., location, fee schedule, hours and availability, staff attitude)

F12. Are there any resources or services you wish you had to help keep you from getting HIV? (e.g, partner counseling or support groups)

Interviewer check: You should know if services have been offered services. If R perceives need for more services.

Section F: PrEP

Goals: Awareness of PrEP and compliance

- G1. Have you ever tried to find out more about HIV and the medical choices for yourself? Tell me about that.
- G2. What do you know about Pre-exposure Prophylaxis, sometimes people call it PrEP?
 INTERVIEWER CHECK: CONFIRM R IS DISCUSSING PrEP not PEP (Post exposure prophylaxis) IF NECESSARY: There is also something called PEP, post exposure prophylaxis that is taken after you have had unprotected sex with someone whose status is positive or unknown or a needle stick, were you thinking of that or of something else?
- G3. IF NEVER HEARD: PrEP is a combination of a daily pill and other prevention such as condoms that can reduce the chances of getting HIV. Have you heard of such a pill?
- G4. What are your thoughts on this type of pill/PrEP? PROBE IF NECESSARY: Do you think that it can keep people from getting HIV?
 THOSE WHO NEVER HEARD AT G3, SKIP TO SECTION H.
- G5. Are you on PrEP? Tell me more about that decision?

YES, on PrEP	NO, not on PrEP
G6. What are some of the things that make it hard to be on PrEP? What else?	G9. What is keeping you from being on PrEP?
G7. Do you have side effects from taking PrEP, what are they? Do you worry about any long term side effects?	G10. Is cost a factor?
G8. What would you advise someone who wants to stay on PrEP, what should they know or do? SKIP TO	G11. What about getting to the clinic, is transportation an issue?
	G12. And what about getting in to seeing a doctor or nurse you trust
	G13. Have you been on PrEP treatment in the past? Tell me about that? (e.g., side effects experienced, insurance/cost challenges of staying on PrEP, attitude toward partner and HIV vulnerability)
	G14. Are you doing anything else that we haven't talked about as prevention instead of PrEP?
	G15. NOT ON: If you wanted to start PrEP, what would help you do that? (provider recommendation, partner encouragement, social support, insurance coverage) ?

INTERVIEWER CHECK: You should understand if knows what PrEP is, if he is on PrEP or not, why or why not, what makes being on PrEP difficult.

Section H: Closing

H1. That is almost all the questions I have. Thinking about all the things we just discussed. What else do you think is important for me to know?

H2. Are there any questions that I should have asked and didn't? What?

I want to thank you so much for your time and help today! That is all the questions I have.



TURN OFF TAPE RECORDERS AND PROVIDE TOKEN OF APPRECIATION