

PETS Qualitative Study

Background

Most peer intervention studies in the HIV literature examine changes in clients' knowledge, risk reduction behaviors, and emotional coping strategies. (Broadhead, 2002, Kalichman, 2001, 2005, Purcell, 2004) These studies examined interventions using peer support groups and one-one interventions usually of a relatively short duration of six months or less. Yet few published studies describe from the client's perspective the role and impact of the peer relationship on client use of HIV services and adherence to appropriate treatment. Furthermore, most published studies of peer-based interventions for HIV care and prevention have not described in detail the peer support provided through these interventions.

The purpose of the PETS qualitative study is to examine in-depth the impact of peer support on client's use of health care services, as well on their HIV knowledge, attitudes & beliefs, self-care, and overall quality of life. The study will also result in a detailed description of HIV peer support provided by a sample of trained HIV peer educators. The results will be used to develop a series of products (publications, instructional materials, etc) for policy makers and program planners to integrate effective peer educator/advocate programs in HIV service delivery.

Multisite questions

1. Does client interaction with peers impact a client's access to care, health care utilization, self-care practices, quality of life, HIV knowledge, attitudes/beliefs, unmet needs, experience of HIV stigma, self-efficacy and empowerment?
2. How do trained peer educators apply their skills and knowledge in their work with clients and in their community?

Study Design

- Longitudinal design for clients—Year 3 baseline interviews; repeat Year 4 (6-9 months);
- Cross-sectional for peers

Methods:

- In-depth interviews: conducted face-to-face or telephone by local staff request tape recording for transcription; study guide to developed by study team
- Purposeful sampling frame-
 - (Region, gender, race/ethnicity, length of time in program)
- 5-8 clients per site;
- 5-8 peers/site

Description of sample

1. HIV-positive Clients.
 - a. Time since living with HIV:
 - Newly diagnosed clients (living with HIV \leq 12 months)
 - Non-newly diagnosed clients (living with HIV more than 12 months)
 - b. Level of retention in care
 - Clients living with HIV with history of inconsistent health care

(having a gap of 6 months or more in the past 2 years)

- Clients at-risk for dropping out of care
- c. Length of time working with a peer
- New clients: minimum of 5 contacts
 - Experienced clients: at least 6-12 contacts

Recruitment:

PETS will work with partner program staff to identify clients of PETS-trained peers who have been working together for a minimum of 5 contacts. A client participant is a person living with HIV who has a relationship with a PETS-trained peer either through the peer's employment, volunteer position, *or* may be associated with the PETS trained peer in the community (i.e. with or without an organization). Client participants may be recruited through community or clinic settings depending on the local PETS partner organizations. There is no requirement for the number of hours that a client works with a peer.

PETS Qualitative Study
1st Interview Guide
Clients

[INTRODUCTORY SCRIPT]

Thank you for agreeing to be interviewed today. We (Name of site) are working with HRSA on a national program to train people living with HIV/AIDS to become peers to work with others in managing their life with HIV. HRSA is interested in understanding how peers impact the lives of people living with HIV. I'm going to ask you questions about your experience living with HIV and then about your experience in working with a peer.

The information you share with us today is completely confidential. You will be assigned (or you can give us one!) a pseudonym and your responses will not have any identifying information. Your responses will only be shared with members of the study team and will be compiled with other participants across the country. The information we gather here today will be used to develop materials for other peer programs across the country.

To ensure that we are able to capture accurate and complete responses, we would like to record this interview. As I mentioned, the recording will be transcribed and all names and places will be removed so as to protect your identity. Recordings will be destroyed after transcription.

Do we have permission to tape record?

- 1) In what year did you test HIV positive?
- 2) Let's go back to the time before you started working with [peer].
What were your feelings about HIV and being HIV positive?
In the long term, what were your expectations about living with HIV?
What kinds of things did you do to take care of yourself?
- 3) Now I'd like to ask you about the HIV-related health care you have used since you have tested positive.
 - a. Think about your experiences in gaining *access to* HIV healthcare services. Tell me about your good experiences in getting HIV healthcare. Tell me about the challenges you have faced in getting HIV healthcare.
 - b. Now think about your experiences with your healthcare treatment providers. What challenges have you had in *sticking to* the HIV treatment and care plan recommended/prescribed to you by your provider(s)? (By HIV treatment and care plan I mean your visits to the doctor, HIV treatment adherence, medication, visits to the dentist for oral related care)

Probes: How has your relationship with your health care provider influenced you in sticking to your HIV treatment and care plan?

- 4) How is your health affecting your daily life right now?

Probe: Have you had to change your routines?

Probe: Have you stopped doing things you used to do?

5) Who do you turn to for support (for example, emotional, moral or practical support) during difficult times?

Have there been any recent changes in your support system?

When and how often do you turn to [peer] for any type of support?

Now I would like to ask you a few questions about your relationship with [peer].

6) When did you start working with [Name of peer]? Did you ask to work with a peer advocate/worker, or were you referred/assigned to work with [peer]? Who referred/assigned you? Why did you decide to start working with the [peer]?

What are your goals for working with [peer]? *Probe:* What do you expect to get out of the relationship with [peer]?

7) How often do you see [peer]? What is working with [peer] like?

Probe: Where do you usually see or talk to [peer]?

Probe: What are your meetings/talks like?

Probe: How does meeting with [peer] compare to meeting with your other providers (i.e., doctor, social worker)?

Probe: How does your cultural identity (your gender, race/ethnicity) influence your relationship?

8) What is your relationship with [peer] like now, as compared to when you first met?

9) Please provide examples of skills or knowledge about HIV that you have learned from working with [peer]?

(Interviewer note: use suggestions from list of peer core competencies, modified as appropriate for clients receiving peer support. Suggestions include the following: coping with HIV; HIV lifecycle; sticking or adhering to HIV treatment plans; self-care, etc.)

What else have you learned from working with [peer]?

Probe: Life skills like getting other services? Finding a job? Getting an education, etc. Connecting to support groups?

10) Please provide examples of how [peer] has influenced you with the following:

- Your use of HIV health care services, your HIV treatment and taking medications
- Relationship with providers such as doctors, case managers and dentist
- Self-worth (how you feel about yourself)
- Your ability to act in helping yourself and others
- Finally, in what way has the relationship with [peer] influenced you the most?

11) What future treatment and healthcare goals do you have?

Probe: Could you imagine working with [peer] to reach these goals? What might be helpful?

The most helpful?

Interviewer note: Thank participant and notify that he/she will be contacted in approximately 6 months (give an approximate month e.g. June) to get an update on his/her experience with the program.

**PETS Qualitative Study
Follow-up Interview Guide
Clients**

[INTRODUCTORY SCRIPT]

Thank you for agreeing to be interviewed today. We (Name of site) are working with HRSA on a national program to train people living with HIV/AIDS to become peers to work with others in managing their life with HIV. HRSA is interested in understanding how peers impact the lives of people living with HIV. My questions today will focus on your experience with the peer program since our last visit.

The information you share with us today is completely confidential. You will be assigned a pseudonym and your responses will not have any identifying information. Your responses will only be shared with members of the study team and will be compiled with other participants across the country. The information we gather here today will be used to develop materials for other peer programs across the country.

To ensure that we are able to capture accurate and complete responses, we would like to tape record this interview. As I mentioned, the tape recording will be transcribed and all names and places will be removed so as to protect your identity. Tape recordings will be destroyed after transcription.

Do we have permission to tape record?

-
1. How has your health been since the last time we talked?

Probes: Have you been seeing a doctor for your HIV? Taking medications? Experienced any challenges with your health as it relates to HIV? How has [peer] helped you to meet your HIV health care needs?

2. In terms of support, who do you turn to now during difficult times? *Probe:* Can you give me an example of how [peer] has given support to you since we last talked?
 - a. How often do you see [peer]? What is your relationship like now, as compared to when you first met? Is your relationship what you hoped for or imagined it would be? To what extent does your cultural background (race/ethnicity, gender, age) affect your relationship with [peer]?
3. Since we last talked, can you give examples of skills or knowledge about HIV that you have learned from working with your [peer]? (*Interviewer note:* use suggestions from list of peer core competencies, modified as appropriate for clients receiving peer support. Suggestions include the following: coping with HIV; HIV lifecycle; sticking or adhering to HIV treatment plans; self-care, etc.)

4. What else have you learned from working with [peer]?

Probes: Life skills like getting other services? Finding a job? Getting an education, etc.
Connecting to support groups?

5. Please provide examples of how [peer] has influenced you with:

- Your use of HIV health care services, your HIV treatment and taking medications
- Relationship with providers such as doctors, case managers, and dentist
- Self-worth (how you feel about yourself)
- Your ability to act in helping yourself and others
- Finally, in what way has the relationship with [peer] influenced you the most?

6. Since we last talked, can you give me an example of a goal or something that you wanted to get done that [peer] helped you to do?

7. Is there anything you want to say that I haven't asked about?