

RECRUITMENT OF HIV POSITIVE AND NEGATIVE WOMEN IN PUERTO RICO: THE EXPERIENCES OF A RESEARCH TEAM

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Background: Women with HIV positive status are considered a hard to reach population by many. We discuss the experiences of a research team while conducting the recruiting process with both Hispanic Puerto Rican HIV positive and HIV negative populations.

Objective: To provide strategies and recommendations for conducting research interventions with HIV+ and HIV- women.

Methods: This study explored the communication skills between HIV+ and HIV- mothers and their adolescent daughters regarding disclosure of their status, and the discussion, or lack of, on topics related to sexuality and prevention of HIV/AIDS. This study explored the recruitment, retention and intervention processes of a qualitative research study that used focus groups to understand the communication skills between HIV+ and HIV- mothers and their adolescent daughters regarding disclosure of their status, and the discussion, or lack of, on topics related to sexuality and prevention of HIV/AIDS. The goal of this team was to describe the diverse factors and dynamics that influence the process of recruitment and retention when conducting research.

Results: The process of recruitment entails not only the action but the planning of the interventions with both the community and the participants. Minority women and the HIV positive population have many difficulties complying with study procedures such as attendance and transportation, among other issues. We describe the importance of constant communication with the centers' coordinators and prospective participants about the process of planning and recruiting.

Conclusions: The significance of flexibility within the research team and recognizing the particular characteristics of conducting research with minorities and women with and without HIV+ status should be emphasized. Researchers should recognize that many of the HIV+ women have been exposed to previous studies. In addition, the general population should be informed about the importance of participating in research studies. (*Ethn Dis.* 2010;20[Suppl 1]:S1-155-S1-157)

Key Words: Recruitment, HIV+/- Women, Minority Research

INTRODUCTION

Historically, recruitment of female minority participants, and especially minority HIV+ women considered to be hard-to-reach, into medical research and social studies has proved to be a challenging task.¹⁻⁶ This may be due to the persistence and pervasiveness of under-inclusion of minority groups in research.⁷ Through our research, we seek to address this exclusion of minority groups and to close the gap between science, researchers, research participants and the community.^{3,8,9}

It is important to consider the historical gaps between researcher and participant and women and minorities in science.^{4,10} As a new vision of community participatory research is embraced, the relevance of cultural diversity and competence is making progress in closing this gap.^{10,11}

This article presents the experiences of a Puerto Rico-based research team during recruitment efforts of female HIV positive and HIV negative populations into research activities. Our goal is to describe the diverse factors and dynamics that influence the process of recruitment and retention and to provide strategies and recommendations for

conducting research interventions with vulnerable and often-stigmatized populations. We emphasize self-evaluation and monitoring as ways to facilitate the recruitment and intervention processes.

METHODS

We explored the recruitment, retention and intervention processes of a qualitative research study that used focus groups to understand the communication skills between HIV negative and HIV positive mothers with their adolescent daughters regarding disclosure of their status, and the discussion, or lack of, on topics related to sexuality, pregnancy, and prevention of HIV/AIDS. The principal investigator and research team developed a well-defined action plan and identified the target population to be enrolled. In addition, the team members knew their roles and had a collaborative approach, which is essential for the planning and application of the study plan. (Figure 1) The centers' directors were contacted informally (via telephone call) and formally (personally visiting the center, clinic or community center and presenting a formal letter). These efforts introduced the research team and the purpose of the study in order to obtain authorization to work collaboratively and to build a network for the future. We identified and introduced the research team to each center's case managers and staff and discussed the goals of the study with them. Communication and incorporation of center staff was essential as they know the inner workings of the clinic and the population they serve. Frequent telephone contact and in-person meetings were the best ways to make ourselves known and included in the

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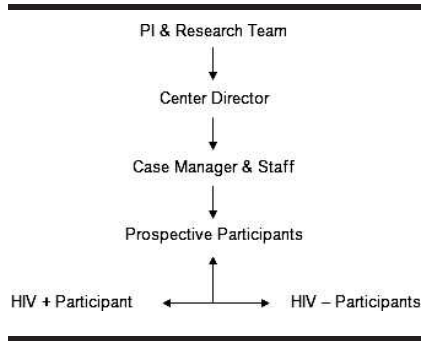


Fig 1. Action plan for communication from researcher to participants

daily dynamics of the research sites. Prospective participants (both HIV+ and HIV – participants) were approached not only through flyers distributed by the case managers and by health providers who could identify prospective participants, but also by the research team who approached prospective participants directly while they waited for their appointments. Many prospective participants contacted the team after reading the flyers, leading us to believe that this was an effective recruitment tool.

RESULTS

Through phone and in-person recruitment efforts, 120 HIV– mothers were initially approached. Of these, many did not meet the inclusion criteria (eg, having no teenage daughter living at home, having teenage daughters who lived outside the home, or having only sons). Some were not able to participate because they had a previous engagement on the day of the focus group. The remaining 20 women were contacted and, through a second phone call, we found several were unable to participate because of work, a previous engagement or lack of transportation. In the end, 10 HIV– women participated in the focus group scheduled for a Saturday (a mutually agreed-upon date to accommodate working schedules and personal responsibilities).

Table 1. Recruitment results

| Group | Interviewed/ Approached | Recruited | Refused to Participate | Confirmed | Attended Focus Group |
|-----------------|----------------------------|-----------|---------------------------|-----------|-------------------------|
| HIV (–) mothers | 120 | 20 | 8 | 12 | 10 |
| HIV+ mothers | 45 | 14 | 21 | 7 | 7 |

For HIV+ mothers, we initially approached 45 women but many were not suitable for participation as they did not meet the study criteria. From the group of 45, 14 were recruited but, through a second phone call, we found some who were unable to participate because of work, previous engagement or lack of transportation. In all, 7 HIV+ women participated in the Saturday focus group. (Table 1)

All participants signed informed consent forms. It is important to note that an internal assessment was conducted to ensure that the focus group site was convenient for all prospective participants.

DISCUSSION

Passive and active strategies for the recruitment of study participants have been proven effective in past research. Passive recruitment involves disseminating information to the target population through various channels (eg, flyers, advertisements, mailings, and public service announcements) and prompting prospective participants to contact project staff. Active recruitment involves bringing the project staff into contact with prospective participants, ie, telephone or in-person appeals. The general engagement strategies for recruitment are similar to those for retention: communicating respect and benefits without coercion, discussing minimal risk, creating convenience, offering compensation for expenses related to participation, obtaining a private space for data collection, communicating appreciation for investment of time and effort, assuring anonymity and confidentiality, obtaining fully in-

formed consent, conducting all research in an ethical manner, providing incentives, and maintaining contact.

Retention is also strongly influenced by recruitment activities.⁷ Distrust, as a barrier to participation, is an aspect that should be addressed with both HIV+ and HIV– participants; the distrust may be due to trust-related barriers that can be eliminated by improved communication.

As part of the research process, the present team will continue to observe, assess, adapt and learn from this experience to expand our strategies for working with women of color with and without HIV.^{1,12} We believe this will facilitate the understanding and development of ethical research interventions for a population that has been historically discriminated due to sex and medical status.^{13–15}

For this reason, we have developed a list of suggestions for research recruitment efforts:

- Consider your mentor as a valuable resource. During the planning and recruitment process, the researcher’s mentor is a guide, model and “sounding board” in the management of the different issues that emerge during the development and active phase of the study.
- Understand the challenges of your target population. The HIV± population has many difficulties complying with study procedures. For this reason, it is important to meet with case managers, community clinic directors, and doctors at the locations where recruitment will be conducted.
- Recognize and learn about the main issues and concerns of the targeted population. Recognize the possible presence of stereotypes and prejudices.

Being self-aware and culturally sensitive will allow you to prevent the “image of an insensitive, aloof researcher.”

- Become culturally sensitive and understand its importance in research, this is a lifelong process that requires self-awareness, study, practice and guidance.

- Learn about the history of HIV/AIDS and the individuals, minorities/diverse groups in research studies. Learn the new vision/approaches to expand and engage participation from these groups in new studies.

- Be knowledgeable of the language and cultural factors of the target population.

- Inquire about previous experience(s) as research participants. Many participants spontaneously will share their experiences; listen carefully and learn from their positive and negative experiences.

- Recognize that individuals with HIV/AIDS may not feel comfortable talking with strangers about their personal experiences. Be sensitive to the stigma that is still attached to the disease.

- Maintain contact with prospective participants; listen to their needs and resources to participate in the study. This information will give you valuable information on the logistics and availability to participate.

- Listen to the issues shared by the prospective participants such as: their time to participate, transportation needs, location of the research activity, and availability of child care, among other issues.

- Contact research teams with previous experience with the population you will study and ask about their achievements and challenges.

- Do not be afraid of taking risks and making mistakes. As a researcher you are in a continuous learning process. Recognize the responsibility of your role but at the same time learn from your experiences both positive and negative.

- Understand the importance of constant communication with the centers’ coordinators and prospective participants about the different stages of the recruiting and planning processes. Be sure to communicate your appreciation for their time and efforts.

IMPLICATIONS FOR IMPROVING HEALTH DISPARITIES FUTURE RESEARCH

This experience serves as a platform to develop qualitative studies based on recruitment processes and the identification of factors that intervene when working with the HIV+/- populations. When research teams recognize these challenges and make adjustments, we will close the research gap by improving and advancing research and services to minority groups.

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